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PROMIS® Pediatric Self Report Scales Distinguish Subgroups of Children Within and Across Six Common Pediatric Chronic Health Conditions

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Abstract

Purpose—To conduct a comparative analysis of eight pediatric self-report scales for ages 8-17 years from the National Institutes of Health (NIH) Patient Reported Outcomes Measurement Information System (PROMIS®) in six pediatric chronic health conditions, using indicators of disease severity.

Methods—Pediatric patients (N = 1,454) with asthma, cancer, chronic kidney disease, obesity, rheumatic disease, and sickle cell disease completed items from the PROMIS pediatric mobility, upper extremity functioning, depressive symptoms, anxiety, anger, peer relationships, pain

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interference, and fatigue self-report scales. Comparisons within the six pediatric chronic health conditions were conducted by examining differences in groups based on disease severity using markers of severity that were specific to characteristics of each disease. A comparison was also made across diseases between children who had been recently hospitalized and those who had not.

Results—In general, there were differences in self-reported health outcomes within each chronic health condition, with patients who had higher disease severity showing worse outcomes. Across health conditions, when children with recent hospitalizations were compared with those who had not been hospitalized in the past six months, we found significant differences in the expected directions for all PROMIS domains, except anger.

Conclusions—PROMIS measures discriminate between different clinically meaningful subgroups within several chronic illnesses. Further research is needed to determine the responsiveness of the PROMIS pediatric scales to change over time.

Keywords

PROMIS; pediatrics; self-report; patient reported outcomes; item response theory

Introduction

The Patient Reported Outcomes Measurement Information System (PROMIS®) is a National Institutes of Health (NIH) initiative, created to advance the assessment of patient-reported outcomes (PRO) in patients with chronic diseases. Over the past ten years, PROMIS has developed several pediatric self-report item banks for ages 8-17 years across five general health domains (physical function, pain, fatigue, emotional health, social health) consistent with the larger PROMIS network, and additional health domains will be released soon [1]. We anticipated that measures of these five general health domains would be applicable across pediatric chronic health conditions, and hence they were developed as general or nondisease-specific scales [2-8]. The PROMIS pediatric measures were developed using qualitative and quantitative methods, including focus groups, expert item review, cognitive interviewing, and item administration to a large population of children and adolescents to create banks of items specific to selected domains [2; 9; 10].

The majority of extant pediatric self-report scales, consistent with other clinical assessment instruments [11], have utilized Classical Test Theory (CTT) and have rarely taken advantage of item response theory (IRT) analysis in the scale development process [12]. By utilizing IRT analysis, the resulting item bank can be the basis of a more customizable measure for meeting a researcher's or clinician's needs. Depending on the desired level of precision, the user can select the number of items to administer and obtain scores on the same metric as all other users of the item bank [12].

The validity of a measurement instrument includes its ability to differentiate patients who are known to have different experiences. Studies have documented this known-group validity for other pediatric PRO instruments, such as the Peds QL, that were both general and disease-specific measures of HRQOL [13-18]. Performing these tests across several chronic illnesses supports the notion that PROMIS is a versatile measure applicable in many

different clinical situations. Each illness group and severity of illness within groups can have varied effects across different PRO domains. Documenting the different patters of PRO profiles can lead to a more nuanced understanding of chronic illnesses.

The objective of the present study is to describe the use of selected PROMIS pediatric self-report scales in six common pediatric chronic health conditions: asthma, cancer, chronic kidney disease, obesity, rheumatic disease, and sickle cell disease. Within each group, we identified a marker of disease severity based on our available data and examined differences in patients' health outcomes between these groups. We hypothesized that PROMIS measures would be sensitive to differences in health status for all of the chronic health conditions. Moreover, we hypothesized that across disease groups, children with recent hospitalizations would show worse outcomes than those who had not been hospitalized in the past six months. The primary aim of this study is a test of the PROMIS instruments. Secondarily, we are able to get estimates of the latent traits and magnitudes of difference across the comparison groups. This adds comparative information for future PROMIS users.

Methods

Selection of Patient Samples

Data collection across the samples took place from 2009 to 2010. Participants were recruited from hospital-based general pediatric clinics, subspecialty clinics, and hospital inpatient units. Participants were identified through a review of medical records, clinic appointment rosters, or while in the clinic waiting rooms according to protocols approved by the institutional review boards (IRBs) at each of the participating institutions. The data in the present study include previously published data on three individual disease groups: cancer [19], incident nephrotic syndrome [20], and obesity [21]. However, comparisons for the other chronic illness groups and across health conditions have not been previously reported.

All participants were required to meet the following inclusion criteria: able to speak and read English; able to interact with a computer screen, keyboard, and mouse; and aged 8 through 17 years. The exclusion criteria were children having any concurrent medical or psychiatric condition that might preclude participation in this study or cognitive or other impairment (e.g., visual) that would interfere with completing a self-administered computer-based questionnaire. Parents signed an informed consent document and children signed an informed assent document. Table 1 presents the sociodemographic characteristics for each patient sample.

Asthma sample

Pediatric patients were recruited from outpatient general pediatrics and subspecialty clinics at the University of North Carolina at Chapel Hill and Children's Hospital at Scott and White in Texas. In addition to the general inclusion and exclusion criteria cited above, eligible patients had a physician diagnosis of asthma and were currently using asthma medication. In addition to the short forms of the general PROMIS pediatric measures of depressive symptoms, anxiety, anger, pain interference, peer relationships, fatigue, upper extremity functioning, and mobility (see Appendix Table 1), children with asthma

completed the Asthma Control Test (ACT) [22]. The ACT is commonly used clinically to distinguish different levels of asthma control. For the within-group comparison, children with asthma were classified as “good control” status or “poor control” status based on the scoring guidelines of the ACT [22]. A total of 137 patients with asthma participated. Two participants had missing scores for one of the PROMIS measures. One of the participants ended the survey early, so the missing score was the last measure in the survey.

Cancer sample

Pediatric patients were recruited from the Children's National Medical Center in Washington, DC; Nebraska Medical Center in Omaha, Nebraska; Children's Hospital Los Angeles in California; Palmetto Health Children's Hospital in Columbia, South Carolina; and Emory University in Atlanta, Georgia. In addition to the general inclusion and exclusion criteria cited above, eligible patients were currently receiving curative cancer treatment (defined as disease-directed therapy within the past 45 days) or had completed cancer treatment and were disease-free and in follow-up care (survivorship group). An additional exclusion criterion included patients who were receiving end-of-life care (defined as supportive treatment following a decision against resuscitation or favoring terminal care with possible hospice involvement). Participants completed the PROMIS pediatric measures of depressive symptoms, anxiety, anger, pain interference, peer relationships, fatigue, upper extremity functioning, and mobility (see Appendix Table 1). The within-group comparisons were made based on whether patients were in active treatment (defined as disease-directed therapy within the past 45 days) or had completed cancer treatment, were disease-free, and in follow-up care (survivorship group). A total of 200 patients participated. Sixteen (8%) had missing scores for at least 1 of the PROMIS measures. Thirteen of these 16 participants (6.5%) ended the survey early, so the missing measures were at the end of the survey [23].

Chronic kidney disease sample

Pediatric patients were recruited through the Midwest Pediatric Nephrology Consortium from 16 participating member institutions. In addition to the general inclusion and exclusion criteria cited above, eligible patients had to have physician confirmed chronic kidney disease, defined dialysis or kidney transplant dependence, estimated glomerular filtration rate (eGFR) < 90 ml/min/1.73m^2, or nephrotic syndrome [24]. A lower eGFR represents worse kidney function, with eGFR ≤ 15 representing kidney failure. Participants completed the PROMIS measures of depressive symptoms, anxiety, pain interference, peer relationships, fatigue, and mobility (see Appendix Table 1).

For the within group comparisons, children with kidney disease were grouped based on their glomerular filtration rate (eGFR) < 90 ml/min/1.73m^2. A lower eGFR represents worse kidney function, with eGFR ≤ 15 representing kidney failure. We grouped patients into 3 categories that correspond to established stages of chronic kidney disease: 1. eGFR ≥ 60, which represents those with mild and normal GFR (Stages 1 and 2); 2. eGFR < 60 and ≥ 15 (moderate and severe decreases in GFR; Stages 3 and 4); and 3. eGFR was < 15, which represents kidney failure and a need for dialysis or transplant (Stage 5). Patients who had already received kidney transplants were excluded from this analysis, as they are usually grouped into their own category but represent a range of health and functioning. In total, 384

children with chronic kidney disease participated in this study. A total of 13 children (3.4%) were missing one or more of the PROMIS domain scores. Twelve of the 13 patients with missing PROMIS scores ended the survey early.

Obesity sample

Pediatric patients were recruited from five participating sites including an academic obesity clinic, three private pediatric practices, and a federally qualified health center in North Carolina. In addition to the general inclusion and exclusion criteria cited above, eligible patients had an age adjusted body mass index (BMI) ≥ 85th percentile. Participants completed the PROMIS measures of depressive symptoms, anxiety, anger, pain interference, peer relationships, fatigue, upper extremity functioning, and mobility (see Appendix Table 1). Patients with obesity were categorized into two groups: those with an age-adjusted BMI ≥ 99th percentile and those with age-adjusted BMI <99th percentile. A total of 136 patients with obesity participated. Seven participants (5%) had missing scores for at least one of the PROMIS measures. Six of these seven participants ended the survey early, so measures administered at the end of the survey were missing responses.

Rheumatic disease sample

Patients with rheumatic disease were recruited from rheumatology clinics at four academic medical centers in California, North Carolina, Ohio, and Washington State. In addition to the general inclusion and exclusion criteria cited above, eligible patients had a physician-confirmed diagnosis of juvenile idiopathic arthritis (JIA), childhood systemic lupus erythematosus (cSLE) or juvenile dermatomyositis (JDM) as well as some patients who had overlapping conditions. Participants were administered the following PROMIS measures: anger, anxiety, depressive symptoms, fatigue, pain interference, peer relationships, upper extremity functioning, and mobility (see Appendix Table 1). We also collected the Childhood Health Assessment Questionnaire (CHAQ) [25], parental ratings of children's overall well-being, numeric rating scale of average pain intensity over the past seven days, and school days missed due to illness.

For the within-group comparisons, patients were grouped by type of rheumatic disease (e.g., JIA, cSLE, or JDM). We also looked at number of school days missed as an indicator of disease severity. A total of 362 patients participated, 269 (74.3%) with JIA, 42 (11.6%) with cSLE, 23 (6.3%) with JDM, and 28 (7.7%) with overlapping conditions. Four participants (1.1%) had missing scores for at least one of the PROMIS measures. Three of these participants ended the survey early,

Sickle cell disease sample

Pediatric patients were recruited from sickle cell disease programs at Emory University and Duke University. In addition to the general inclusion and exclusion criteria cited above, eligible patients had a physician diagnosis of sickle cell disease. Participants were recruited at clinic visits for routine care, hydroxyurea monitoring, or chronic transfusions. The hemoglobin genotypes were consistent with that of the general clinic population: SS (76.5%), SC (16.7%), Sickle B+ thalassemia (4.7%), and Sickle B0 thalassemia (1.3%). At

the time of the study, 19.1% of the participants were receiving chronic transfusions and 45.5% were taking hydroxyurea.

Participants were administered the following domains: anger, anxiety, depressive symptoms, fatigue, pain interference, peer relationships, upper extremity functioning, and mobility (see Appendix Table 1). Researchers also collected frequency of hospital and emergency department visits for pain management, frequency of home pain management, and presence of hip or joint problems related to sickle cell disease. For the within group comparison, patients with sickle cell disease were categorized into two groups: those who had received home treatment for pain in the past week and those who had not. A total of 235 patients participated. Four participants (1.7%) had missing scores for at least one of the PROMIS measures. One of these participants ended the survey early, and the others missed a measure in the middle of the survey.

Pediatric self-report item banks

The PROMIS Pediatric item banks were developed using a strategic item generation methodology adopted by the PROMIS Network [26]. Six phases of item development were implemented: identification of existing items, item classification and selection, item review and revision, focus group input on domain coverage, cognitive interviews with individual items, and final revision before field testing. Because physical function includes both upper extremity functioning and mobility item banks and emotional distress includes anger, anxiety, and depressive symptoms item banks, for the present study, a total of 8 content domains were tested [2-8]. Participants were administered a combination of PROMIS Short Forms or complete item banks. Higher scores indicate more of the measured symptom being experienced, which signifies worse health for depression, anxiety, anger, fatigue, and pain interference and better health for mobility, upper extremity functioning, and peer relationships. For example, higher scores on the emotional distress scales indicate more (worse) emotional distress; higher scores on the physical functioning scales indicate higher (better) levels of physical functioning. All scales have recommended short forms with 8 items, except fatigue (10 items) and anger (6 items), as previously described [2-8]. All items had a 7-day recall period and used standardized 5-point response options (e.g., *never*, *almost never*, *sometimes*, *often*, *almost always*; or, *with no trouble*, *with a little trouble*, *with some trouble*, *with a lot of trouble*, *not able to do*). The PROMIS Pediatrics T score of 50 was anchored as the mean of the calibration population, which was mixed with healthy children and chronically ill children. As such, the score of 50 does not represent any one group, but the same scoring metric is used for all applications, which allows for comparability across populations.

Statistical Analysis

Comparisons within and across chronic health conditions—Mean PROMIS scores within each pediatric chronic health condition category were compared using independent samples t-tests when two disease categories were being contrasted and Analysis of Variance (ANOVA) with Tukey post-hoc tests when more than 2 disease categories were being contrasted. The Tukey's post hoc tests were only utilized when there was a significant

omnibus ANOVA *F*-test. Given the exploratory nature of the study, we did not control for the number of statistical tests.

For the comparison of mean PROMIS scores across chronic health conditions, we used independent sample t-tests, as we divided the sample into two groups based on whether or not patients had been admitted to the hospital in the past six months (Yes/No categories).

Intercorrelations among the scale latent variables—Finally, intercorrelations among the latent variables for each of the eight PROMIS pediatric scales were estimated using the data from all of the chronic health conditions combined. Because the original development of the scales used a complex sampling design with the items spread across multiple forms [2-8], this is the first large sample with item response data for all scales; that makes this computation feasible. To estimate the latent correlations, we used the published item parameters as fixed values [2-8], as they are for computing IRT scores, to estimate the correlations among the latent variables directly. We used the Metropolis-Hastings Robbins-Monro algorithm [27] as implemented in the software IRTPRO [28] to compute the latent variable covariances, and standardized those to obtain the correlations.

Results

Comparisons within chronic health conditions

Comparisons within chronic health conditions are in Table 2. Summaries of differences observed within each of the health conditions are provided below.

Pediatric asthma—Patients with good asthma control reported significantly higher (better) mobility and upper extremity functioning than patients with poor asthma control. Patients with poor asthma control reported significantly higher (worse) depressive symptoms, anxiety, anger, pain interference, and fatigue than patients with good asthma control.

Pediatric cancer—Pediatric survivors of childhood cancer reported significantly higher (better) mobility, upper extremity functioning, and peer relationships than patients on active cancer treatment. Pediatric patients on active cancer treatment reported significantly higher (worse) depressive symptoms, anxiety, pain interference, and fatigue than pediatric survivors of childhood cancer.

Pediatric chronic kidney disease—Patients with chronic kidney disease reported significant differences for physical functioning, including both mobility and upper extremity functioning, depending on the CKD stage. Specifically, patients with eGFR >15 reported better mobility and upper extremity functioning than patients with end stage kidney disease (eGFR ≤ 15). There were no significant differences between the CKD stages in the other domains. For the subset of patients with nephrotic syndrome (NS), patients with active NS (defined by the presence of edema) had lower mobility and higher anxiety, pain interference, and fatigue than those whose NS was not active.

Pediatric obesity—Children with higher BMIs reported significantly lower mobility and higher anger and fatigue than patients with a BMI percentile < 99th.

Pediatric rheumatic disease—There were no significant differences across the domains between patients with Juvenile Dermatomyositis, Juvenile Idiopathic Arthritis, and Systemic Lupus Erythematosus. Given the heterogeneity of these groups, we also looked at number of school days missed as an indicator of disease severity. Patients with rheumatic disease who had missed three or more school days in the past six months reported lower mobility and higher pain interference and fatigue than patients who had missed zero to two school days.

Pediatric sickle cell disease—Patients who had been treated for pain reported lower mobility and upper extremity functioning and higher depressive symptoms, anxiety, pain interference, and fatigue than patients who had not.

Comparison across chronic health conditions

It was clear from the within-group comparisons that patients within each chronic health condition experienced a wide range of functioning and symptoms. Given the heterogeneity of these groups, we sought an indicator of disease severity that was administered to all groups in order to make across-group comparisons. We used a variable, parent-reported number of hospital admissions (e.g., overnight stays) in the past 6 months, as an indicator of disease severity. This item was administered to parents of children in four of the chronic illness groups: cancer, chronic kidney disease, rheumatic disease, and sickle cell disease.

Across the 4 chronic health conditions (N = 1136), 72.1% of the parents reported that their child had not been hospitalized in the past six months. Among those whose children had been hospitalized, 13.8% (n = 157) had been hospitalized one time; 6.1% (n = 69) had been hospitalized twice; 3.5% had been hospitalized three times; and the remaining 4.5% had been hospitalized four or more times in the past 6 months. For this analysis, patients were categorized into 2 groups, those who had not been hospitalized and those who had been hospitalized 1 or more times.

Patients who had been hospitalized in the past 6 months showed significantly worse functioning in all areas, except anger. They endorsed higher levels of depressive symptoms, anxiety, pain interference, and fatigue. In addition, they reported more problems in the areas of mobility, upper extremity functioning, and peer relationships (Table 3).

Correlations among the latent variables

Correlations among the latent variables are shown in Table 4. Some of the very highly correlated scales are among subdomain scores within domains. For example, the three emotional health scales (anger, anxiety, and depressive symptoms) were all correlated between 0.67 and 0.79, and the two physical functioning scales (upper extremity and mobility) were correlated 0.75. Fatigue was highly correlated with many other scales, over 0.55 (in absolute value) with all of the other scales except peer relationships. Pain interference was correlated over 0.6 with mobility and around 0.6 with the emotional health scales. Peer relationships generally had the lowest correlations with the other scales.

Discussion

Our results demonstrate consistent differences across subgroups within particular chronic health conditions. Moreover, this study illustrates the importance of looking at subgroups within disease category rather than across diseases. It is very clear that scores in a disease category such as asthma will vary greatly depending on severity of disease and that a child with severe asthma is likely to look more like a child with severe symptoms of another disease than a child with mild asthma.

This study also demonstrates the usefulness of PROMIS instruments across a number of different diseases and measures of severity within diseases. Effects of disease status on mobility or anxiety can be assessed using general measures rather than attempts to attribute symptoms to an individual disease. Given that most patients have more than one disease, measures that are disease agnostic allow much more flexibility and interpretability. Below we discuss the chronic health-specific findings for each group in the context of the extant literature.

Pediatric asthma

Our findings are generally consistent with previous studies showing children with poor asthma control were more likely to experience lower functioning compared with children with good asthma control [29; 30]. Specifically, our study suggests that compared with participants with good asthma control, participants with poor asthma control had poorer mobility and upper extremity functioning; more depressive symptoms, anxiety and anger; and more somatic symptoms, including fatigue and pain.

Pediatric cancer

Our findings indicate significantly better scores for all indicators except anger for survivors compared with participants in active cancer treatment. This is consistent with other reports that long-term survivors of pediatric cancer experienced better physical health, psychosocial health, and emotional functioning than those undergoing treatment [13; 31]. Moreover, several studies have found that survivors of childhood cancer demonstrate positive psychological adjustment in areas such as life satisfaction, overall happiness, depression symptoms, anxiety, self-esteem, that are similar to and even superior to healthy, population norms [32-34]. There is some evidence that the experience of surviving cancer improves the individual's ability to cope and become more resilient, which helps to explain these findings [34; 35].

Pediatric chronic kidney disease

Similar to other disease groups in this study, different categories of illness within kidney disease reveal important differences in PROs. The present study identified that mobility and upper extremity functioning were worse in children with CKD who had lower eGFR. Previous reports of HRQOL in children with CKD have demonstrated variable results. In the US national Chronic Kidney Disease in Children study, worse HRQOL was demonstrated when compared with published normative controls in the domains of social, school, physical, and emotional functioning [36]. A subsequent study from the United Kingdom

evaluated children with CKD and demonstrated remarkably preserved HRQOL and suggested this perception of normal HRQOL may result from the subjective nature of self-reported HRQOL [37].

Pediatric obesity

Results of this study are consistent with prior investigations of HRQOL among children with obesity. Obese children have demonstrated worse HRQOL in the domains of physical, emotional, social, and school functioning and fatigue when compared with healthy controls [38-40]. A recent meta-analysis derived from a total of 13,210 study participants demonstrated that based on self-reports, children and adolescents with above-normal BMI had significantly lower total, physical, and psychosocial HRQOL, with a clear dose relationship across all BMI categories [41]. Consistent with the literature, evaluations of functioning in children with BMI ≥ 99th percentile with the PROMIS scales showed that these children had worse scores in the depressive symptoms, anger, fatigue, and mobility domains relative to children with BMI from the 85th-99th percentiles.

Pediatric rheumatic disease

Studies of HRQOL in children with rheumatic disease have generally reported reduced HRQOL compared with healthy controls, most prominently in physical functioning [42-44]. When children with these conditions are evaluated according to disease activity or measures of severity, these findings are temporized. Ringold found the majority of children with the polyarticular form of JIA with inactive disease scored similarly to healthy children in all areas except fatigue [44]; children with JIA showed more fatigue. In a clinical sample of 941 JIA patients, Seid and colleagues found that most patients had no or minimal symptoms according to four clinical measures, with only 7.9% of those patients having suboptimal scores on the PedsQL™ total score [43]. They further note that the majority of patients with mild symptoms have “optimal” HRQOL. Overall, participants in our study appeared to have low clinical impairment based on the CHAQ.

Pediatric sickle cell disease

The results from our study are consistent with the largest previous HRQOL study of children with SCD [45]. In that study, 1393 children were administered the self-report version (age ranges 5-7, 8-12, and 13-18) of the 23-item PedsQL™ 4.0 Generic Core Scales (physical, emotional, social and school functioning) and the 18-item PedsQL™ Multidimensional Fatigue Scale (General Fatigue, Sleep/Rest Fatigue, and Cognitive Fatigue) [45]. Children with 1-3 or ≥4 hospitalizations compared with those with no hospitalizations in the previous two years scored worse in all child-reported PedsQL™ functioning and fatigue scales. In our study, children with recent pain episodes had worse scores across several domains, including physical functioning, emotional distress, fatigue, and pain interference. The fact that having a recent need for treatment of pain was the defining characteristic of one group, we expected large differences for the pain interference domain.

Correlations among the scales

This study reports, for the first time, estimates of the latent variables correlations among eight PROMIS pediatric scales. The patterns of intercorrelations are unsurprising, but they provide useful background information for investigators who plan to use several of the scales in their research; this large dataset, including participants from several chronic disease groups, provided more data for the computation of these correlations than will likely be available from many single-purpose studies. Adding these correlations to the literature expands the web of construct validation of the eight scales. Investigators now have a reference point for selecting scales and understanding the expected correlations when using multiple scales.

Limitations

Although this study demonstrates the broad usefulness of PROMIS pediatric measures across several chronic illnesses, there are important limitations to the conclusions we can draw. Most importantly, the samples were not drawn to be broadly representative of the disease category and we specifically oversampled specific subcategories of disease (e.g., children with nephrotic syndrome and specific types of cancer). Because of this approach, we cannot assume that the mean level of functioning or symptom for a disease category would represent the population with that disease. For this reason, we are not able to provide a mean and distribution of scores that represent the disease categories broadly (e.g., the population of sickle cell disease has a mean score of X). This study does provide evidence that differences within disease by severity of illness are likely more important than average PRO scores for a general category of disease. This effect may also reflect that many patients with a chronic illness have other comorbidities that can affect PROs. Although this makes it difficult to attribute symptoms or quality of life to one illness, it does capture what is important to patients, which is how they feel and function regardless of the cause. It is also possible that in some of the populations, our tests are comparisons between moderate severity and high severity without an adequate test of mild severity compared with moderate severity. Larger population based samples may help to establish more refined categories.

These data collections were conducted to meet a variety of needs for further development of PROMIS measures. As such, not all participants in each group completed every questionnaire. Fortunately, our design randomly allocated some questionnaires within a disease group. For this reason, we believe the estimated scores should reflect the whole enrolled population. Additionally, this is a cross-sectional study and differences across groups do not represent a measurement of change.

In conclusion, the present findings provide support for the measurement properties of these PROMIS pediatric self-report scales in the chronic health conditions studied. Specifically, this data provides preliminary evidence of known-groups validity (that is the ability to discriminate PRO scores between different clinically meaningful subgroups of individual diseases). Using measurement scales like PROMIS can provide comparable and nuanced views into the health experience of children across chronic illnesses. Further research is needed to determine the responsiveness of the PROMIS pediatric scales to change over time in the chronic health conditions studied and across other pediatric chronic health conditions.

In addition, data on a nationally representative healthy or general pediatric population are necessary to give greater meaning to the standardized scores utilized in future PROMIS pediatric comparison studies.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

PROMIS®	Patient Reported Outcomes Measurement Information System
NIH	National Institutes of Health

Table 1

Sociodemographic Characteristics

	Asthma N = 137 (%)	Cancer N = 200 (%)	Chronic Kidney Disease N = 384 (%)	Obesity N = 136 (%)	Rheumatic Disease N = 362 (%)	Sickle Cell Disease N = 235 (%)
Mean Age (SD)	12.04 (2.63)	12.87 (2.86)	13.40 (2.85)	11.90 (2.65)	12.83 (2.78)	12.49 (2.82)
Age Range	8-17	8-17	8-17	8-17	8-17	8-17
Gender						
Male	72 (52.6)	111 (55.5)	222 (57.8)	62 (45.6)	91 (25.1)	118 (50.2)
Female	65 (47.4)	89 (44.5)	162 (42.2)	74 (54.4)	271 (74.9)	117 (49.8)
Child Race						
White	58 (42.3)	108 (54.8)	224 (58.3)	40 (29.4)	273 (75.4)	0
Black or African American	63 (46.0)	41 (20.8)	102 (26.6)	81 (59.6)	25 (6.9)	222 (94.5)
American Indian/ Alaskan Other	3 (2.2)	0	7 (1.8)	2 (1.5)	3 (.8)	0
Asian	2 (1.5)	8 (4.1)	17 (4.4)	1(.7)	18 (5.0)	0
Native Hawaiian/ Pacific Islander	0	0	0	0	5 (1.4)	0
Other	6 (4.4)	28 (14.2)	13 (3.4)	4 (2.9)	16 (4.4)	3 (1.3)
Multiple Races	1 (.7)	12 (6)	20 (5.2)	8 (5.9)	20 (5.5)	10 (4.3)
Not provided/ Missing	4 (2.9)	3 (1.5)	1 (.3)	0	2 (.6)	0
Child Ethnicity						
Non Hispanic	106 (77.4)	160 (80)	358 (93.0)	127 (93.4)	309 (85.4)	221 (94.0)
Hispanic	19 (13.9)	40 (20)	26 (6.8)	9 (6.6)	51 (14.1)	13 (5.5)
Not Provided/ Missing	12 (8.8)	0	1 (.3)	0	2 (.6)	1 (.4)
Guardian Relationship to Child						
Mother or stepmother	109 (79.6)	167 (83.5)	296 (77.1)	116 (85.3)	299 (82.6)	185 (78.7)
Father or stepfather	14 (10.2)	22 (11.0)	61 (15.9)	12 (8.8)	52 (14.4)	29 (12.3)
Grandparent	8 (5.9)	7 (3.5)	14 (3.6)	4 (2.9)	6 (1.7)	13 (5.5)
Guardian or Other	5 (3.6)	4 (2.0)	12 (3.1)	4 (2.9)	5 (1.4)	7 (3.0)
Missing	1 (.7)	0	1 (.3)	0	0	1 (.4)
Guardian's Education Level						

	Asthma N = 137 (%)	Cancer N = 200 (%)	Chronic Kidney Disease N = 384 (%)	Obesity N = 136 (%)	Rheumatic Disease N = 362 (%)	Sickle Cell Disease N = 235 (%)
< = 8th grade	3 (2.2)	4 (2.0)	7 (1.8)	3 (2.2)	1 (.3)	5 (2.1)
Some high school	10 (7.3)	5 (2.5)	26 (6.8)	8 (5.9)	8 (2.2)	13 (5.5)
High school degree/ GED	29 (21.2)	42 (21.0)	103 (26.8)	23 (16.9)	51 (14.1)	38 (16.2)
Some college/ technical degree	50 (36.5)	74 (37.0)	126 (32.8)	63 (46.3)	125 (34.5)	91 (38.7)
College degree	29 (21.2)	49 (24.5)	92 (24.0)	33 (24.3)	120 (33.1)	63 (26.8)
Advanced degree	15 (10.9)	26 (13.0)	29 (7.6)	6 (4.4)	57 (15.7)	25 (10.6)
Missing	1 (.7)	0	1 (.3)	0	0	0
Child's History of Other Health Problems						
No other health problems	55 (40.1)	39 (19.5)	134 (34.9)	70 (51.5)	176 (48.6)	133 (56.6)
Yes = 1 other health problem	47 (34.3)	29 (14.5)	112 (29.2)	37 (27.2)	109 (30.1)	69 (29.4)
Yes >=2 other health problems	33 (24.3)	132 (66.0)	138 (35.9)	29 (21.3)	77 (21.3)	33 (14.0)
Missing	2 (1.5)	0	0	0	0	0
Most Common Other Health Problems						
Asthma	NA	25 (12.5)	51 (13.3)	37 (27.0)	18 (5.0)	60 (25.5)
ADD/ ADHD	34 (24.8)	12 (6.0)	41 (10.7)	22 (16.1)	40 (11.0)	14 (6.0)
Cerebral Palsy	< 3%	< 3%	< 3%	< 3%	< 3%	< 3%
Chronic Pain	5 (3.6)	< 3%	< 3%	< 3%	116 (32.0)	22 (9.4)
Diabetes	5 (3.6)	< 3%	< 3%	7 (5.1)	< 3%	< 3%
Epilepsy or other seizure disorder	5 (3.6)	< 3%	< 3%	< 3%	< 3%	< 3%
High blood pressure	5 (3.6)	11 (5.5)	177 (46.1)	13 (9.5)	13 (3.6)	13 (5.5)
Hard of hearing	< 3%	6 (3.0)	< 3%	< 3%	< 3%	< 3%
Intestinal Disorder (Inflammatory Bowel Syndrome, Crohns Disease, or other)	< 3%	< 3%	< 3%	< 3%	< 3%	< 3%
Kidney Disease	< 3%	< 3%	NA	< 3%	28 (7.7)	< 3%
Mental health condition	16 (11.7)	11 (5.5)	27 (7.0)	10 (7.3)	25 (6.9)	< 3%
Overweight	24 (17.5)	14 (7.0)	32 (8.3)	NA	15 (4.2)	< 3%
Premature birth	17 (12.4)	11 (5.5)	56 (14.6)	11 (8.0)	28 (7.7)	14 (6.0)
Requires assistance to get around	< 3%	7 (3.5)	< 3%	< 3%	< 3%	< 3%
Rheumatic Disease	5 (3.6)	<3%	21 (5.5)	< 3%	NA	< 3%

Table 2

Child Reported PROMIS Scores by Disease Category

		Mobility	Upper Extremity	Peer Relationships	Depressive Symptoms	Anxiety	Anger	Pain Interference	Fatigue
	N	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Asthma									
Good asthma control	78	50 (8)	51 (7)	50 (10)	48 (10)	46 (10)	47 (11)	47 (9)	45 (11)
Poor asthma control	59	43 (7)	46 (9)	48 (10)	55 (12)	54 (12)	55 (13)	55 (9)	53 (12)
T Statistic		5.50	3.66	0.97	3.80	4.15	3.60	4.80	4.31
Differences		***	***	NS	***	***	***	***	***
Cancer									
Active treatment	93	42 (9)	46 (9)	45 (11)	50 (11)	49 (13)	47 (11)	50 (11)	53 (13)
Survivorship	107	51 (9)	51 (8)	52 (9)	46 (9)	46 (11)	49 (11)	45 (11)	44 (12)
T Statistic		6.45	3.56	4.70	2.56	1.95	0.68	3.44	4.99
Differences		***	***	***	**	*	NS	***	***
Chronic Kidney Disease									
CKD Stage 1 and 2 (eGFR ≥ 60)[a]	169	53 (8)	53 (7)	50 (10)	47 (11)	46 (12)	NA	46 (11)	45 (12)
CKD Stage 3 and 4 (eGFR 16-59)[b]	80	52 (8)	51 (8)	50 (11)	45 (10)	44 (10)	NA	46 (8)	46 (11)
CKD Stage 5 (eGFR ≤ 15)[c]	26	46 (8)	48 (9)	49 (8)	49 (9)	49 (9)	NA	48 (11)	50 (9)
F Statistic		6.69	3.83	0.30	1.20	1.86	NA	0.16	0.95
Differences		a > c** b > c**	a > c*	NS	NS	NS		NS	NS
Nephrotic Syndrome (NS) cohort only	151								
Active NS	53	49 (10)	52 (7)	48 (11)	48 (13)	50 (13)	NA	51 (10)	51 (14)
Inactive NS	96	54 (7)	52 (7)	51 (10)	45 (10)	44 (10)	NA	44 (11)	41 (12)
T Statistic		3.25	0.57	1.56	1.60	3.45	NA	2.82	3.0
Differences		**	NS	NS	NS	**		**	**
		Mobility	Upper Extremity	Peer Relationships	Depressive Symptoms	Anxiety	Anger	Pain Interference	Fatigue
Obesity									
BMI percentile < 99th	69	52 (6)	51 (7)	48 (9)	46 (8)	46 (10)	47 (10)	46 (9)	43 (10)
BMI percentile ≥ 99th	67	48 (8)	51 (7)	46 (9)	49 (10)	48 (12)	51 (11)	49 (9)	48 (12)

		Mobility	Upper Extremity	Peer Relationships	Depressive Symptoms	Anxiety	Anger	Pain Interference	Fatigue
	N	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**
T Statistic		3.12	0.25	1.33	1.90	0.96	2.10	1.82	2.51
Differences		**	NS	NS	NS	NS	*	NS	*
Rheumatic Disease									
Juvenile Dermatomyositis	23	50 (11)	48 (9)	57 (7)	44 (8)	40 (7)	38 (6)	46 (9)	43 (12)
Juvenile Idiopathic Arthritis	269	50 (10)	51 (8)	53 (10)	46 (10)	46 (11)	46 (12)	45 (10)	42 (11)
Systemic Lupus Erythematosus	42	51 (8)	51 (7)	48 (8)	50 (13)	49 (10)	44 (8)	47 (11)	46 (12)
F Statistic		0.09	2.19	2.50	1.28	1.65	0.71	0.48	1.76
Differences		NS	NS	NS	NS	NS	NS	NS	NS
3 or more school days missed	137	48 (11)	50 (9)	51 (10)	48 (11)	47 (12)	48 (12)	49 (11)	45 (12)
0 to 2 school days missed	169	51 (9)	51 (8)	52 (10)	46 (10)	47 (10)	45 (12)	44 (10)	41 (10)
T Statistic		2.56	1.05	0.77	1.04	0.32	0.98	3.78	2.60
Differences		*	NS	NS	NS	NS	NS	***	**
Sickle Cell Disease									
Home treatment for pain in past week	72	47 (10)	49 (8)	48 (9)	48 (10)	50 (13)	46 (12)	56 (12)	54 (12)
No home treatment for pain in past week	162	52 (7)	51 (7)	49 (11)	44 (10)	43 (10)	46 (13)	45 (13)	44 (12)
T Statistic		3.62	2.76	0.48	3.29	3.52	0.01	6.15	5.88
Differences		**	*	NS	**	**	NS	***	***

Note:

* $p < .05$,

** $p < .01$,

*** $p < .001$.

Values in the parentheses are standard deviations.

Table 3

Comparison of PROMIS scores for children hospitalized at least once in the past 6 months with those not hospitalized, pooling sickle cell disease, cancer, kidney disease, and rheumatic disease.

	Child has been hospitalized one or more times	N	Mean (SD)	T Statistic
Mobility	0 (No)	759	51 (9)	7.53***
	1 (Yes)	284	46 (10)	
Upper Extremity	0	813	51 (8)	4.05***
	1	311	49 (8)	
Peer Relationships	0	588	51 (10)	3.98***
	1	269	47 (11)	
Depressive Symptoms	0	630	46 (10)	2.79**
	1	295	48 (11)	
Anxiety	0	587	45 (11)	3.20**
	1	267	48 (12)	
Anger	0	172	47 (12)	0.24
	1	65	47 (11)	
Pain Interference	0	679	45 (11)	6.08***
	1	256	51 (12)	
Fatigue	0	623	44 (12)	5.81***
	1	241	50 (14)	

Note:

* $p < .05$,

** $p < .01$,

*** $p < .001$.

Values in the parentheses are standard deviations.

Table 4

Correlations among the PROMIS Pediatric Domain Latent Variables.

	Anger	Anxiety	Depressive Symptoms	Peer Relationships	Fatigue	Pain Interference	Upper Extremity	Mobility
Anger	1.00							
Anxiety	0.67	1.00						
Depressive Symptoms	0.78	0.79	1.00					
Peer Relationships	-0.33	-0.41	-0.44	1.00				
Fatigue	0.63	0.66	0.69	-0.38	1.00			
Pain Interference	0.57	0.59	0.63	-0.33	0.73	1.00		
Upper Extremity	-0.39	-0.48	-0.47	0.39	-0.55	-0.47	1.00	
Mobility	-0.43	-0.49	-0.52	0.35	-0.67	-0.63	0.75	1.00