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Reliability and validity of PROMIS® pediatric family relationships short form in children 8–17 years of age with chronic disease

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Abstract

Purpose Families play a key role in managing pediatric chronic illness. The PROMIS® pediatric family relationships measure was developed primarily within the general pediatric population. We evaluated the Family Relationships short form in the context of pediatric chronic diseases.

Methods Children aged 8–17 years with asthma ($n=73$), type 1 diabetes ($n=122$), or sickle cell disease ($n=80$) completed the Family Relationships 8a short form and the PROMIS Pediatric Profile-25′s six domains representing physical, mental, and social health. Parents ($N=275$) of these children completed the parent versions of the same measures. We evaluated reliability of the Family Relationships measure using Cronbach's alpha and IRT-based marginal reliability, and the standard error of measurement (SEM). Convergent/discriminant validity were assessed from correlations between the Family Relationships domain and the PROMIS-25 domains.

Results SEM increased for scores above the normative mean of 50. Cronbach's alpha and IRT-estimated marginal reliabilities exceeded 0.80 for children and parents across diseases, except in asthma, where marginal reliability was 0.75 for parents. Scores displayed small to large correlations in the expected directions with social and mental health domains. The largest correlations occurred with parents' proxy reports of children's depressive symptoms in sickle cell disease and asthma, $r=-0.60$ (95% CI −0.74, −0.48) and $r=-0.58$ (95% CI −0.68, −0.48) respectively.

Conclusions The Family Relationships 8-item short form demonstrated adequate reliability and convergent/discriminant validity for use in pediatric chronic conditions, though scores above the mean displayed greater uncertainty. Evidence of the measure's reliability and validity in multiple contexts furthers the case for its use.

Keywords Family relationships · PROMIS® · Patient-reported outcomes · Children · Survey validation · Social health · Chronic disease

Introduction

Children with chronic illnesses rely on their families in many ways: Parents and other family members provide key support for managing a child's disease, and gradually they support their children in taking over that management themselves. Further, many studies have shown that family support is strongly linked to both improved health as well as better psychosocial outcomes for chronically ill children [1–8]. Family relationships and family functioning often change

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over time, as children go through different developmental stages and eventually achieve autonomy from their parents [9]. Families of children with chronic illness are thus faced with the challenge of balancing the child's autonomy and ongoing development on the one hand, while also making sure that disease management behaviors occur [10–15].

Despite the important role that families play for chronically ill children, there are few validated measures available that assess a child's perceptions of family relationships [16–18]. Acknowledging the important role of family relationships and the lack of assessment tools, the National Institutes of Health (NIH) supported the development and validation of an item bank measuring children's experience with their families, the Pediatric Family Relationships measure, as part of the Patient-Reported Outcomes Measurement Information System® (PROMIS®). The measure was developed for self-report by children aged 8–17 years and report by parents of children aged 5–17 years. In accordance with PROMIS methodological standards for measure development and validation, the items were psychometrically evaluated in two large field studies in general populations in the United States [19]. However, evidence of the reliability and validity of this new measure for use in clinical settings with chronically ill children is needed.

This paper presents the findings from our investigation as to whether the Family Relationships measure demonstrates adequate reliability and validity when applied in a clinical population of chronically ill children and their parents. For this evaluation, we selected three chronic illnesses—asthma, type 1 diabetes, and sickle cell disease. About 6.5 million US children, or approximately 1/3 of all US children with a chronic illness, have been diagnosed with one of these diseases [20–23]. Our hypotheses were: (1) the error of measurement will vary across the range of PROMIS Family Relationships scores, (2) the measure will demonstrate adequate internal consistency and reliability, and (3) the measure will display higher correlations with PROMIS social and mental health domains, and smaller correlations with physical health domains.

Methods

Subjects and procedures

Children with asthma, type 1 diabetes, or sickle cell disease ($N = 275$) were recruited from the pediatric specialty clinics of two Midwestern tertiary care centers from March 2016 to May 2018. During the recruitment period, care team members asked each potentially eligible family about interest in the study. Eligibility criteria for the study included being an English-speaking child who was 8–17 years of age with one of the three chronic diseases and with an English-speaking parent or legal guardian, since, at study initiation, the PROMIS Family Relationships measure was only available in English. Assessments were completed on paper or electronically (REDCap). The Institutional Review Board at the primary study site approved the study. All parents provided informed consent. Children aged 14–17 years also gave informed consent, while children aged 8–13 years provided assent. We did not collect any data on families who declined to participate.

PROMIS measures

We administered PROMIS measures to all child and parent participants. For children, we administered the PROMIS Pediatric Short Form v1.0—Family Relationships 8a, which includes eight items using a 4-week recall period and 1–5-point response options from never to always. The items cover multiple facets of family relationships, such as sense of family (e.g. "I had a strong relationship with my family"), trust, dependability, and support, (e.g. "I got all the help I needed from my family"), love and caring, value and acceptance, enjoyment, and communication. Children also received the PROMIS Pediatric-25 Profile v2.0, which includes six four-item short forms covering social (peer relationships), mental (anxiety, depressive symptoms), and physical health (fatigue, pain interference, and physical function-mobility) plus a single pain intensity item. The Profile-25 domains use a 7-day recall period. All items use standard 1–5-point response options except pain intensity, which is 0–10. For parents, we included the corresponding PROMIS Parent Short Form v1.0—Family Relationships 8a and the PROMIS Parent Proxy-25 Profile v2.0. Item Response Theory (IRT)-based T-scores were calculated for all measures except pain intensity (single item on 0–10 numerical rating scale). For the PROMIS measures included in our study, a mean T-score of 50 and standard deviation of 10 represents the general US population, including both healthy and chronically ill children [24]. Higher scores indicate greater levels of the construct. For example, for family relationships and peer relationships, higher scores are more favorable, but for fatigue and anxiety, higher scores are less favorable.

Other measures

Participant characteristics

Children completed a standard, single item reflecting overall health status (five categories: poor, fair, good, very good, excellent). Parents completed items reflecting child age (continuous; 8–17 years), child gender (male, female, or other), child race (Black or African-American, White, American-Indian or Alaskan Native, Asian, Native Hawaiian or other Pacific Islander, or other; aggregated to Black

or African-American, White, and Multi-race or other), and child ethnicity (Hispanic versus all other), as well as parent age (continuous; 27–64 years), parent education (less than high school, high school diploma, some college, bachelor's degree, or post-graduate degree), and relationship to the child (12 options such as biological mother, biological father, stepmother, stepfather, guardian, grandmother, grandfather, or other; which were aggregated to biological, adoptive, or stepmother versus all other).

Analyses

We used means (M) with standard deviations (SD) and proportions to describe participants. Within each chronic disease, the standard error of measurement (SEM) for individual scores was calculated in SAS using algorithms provided by PROMIS. We assessed the possibility that the scores have different levels of certainty at different levels of the score by graphing the SEM of the T-score over the entire range of scores within each disease type. We also assessed the percentage of scores with SEM > 4, corresponding to a true variance of 10 and reliability of 0.85. For each chronic disease, IRT-estimated marginal reliability and Cronbach's alpha reflecting internal consistency were calculated for child and parent reports. Convergent and discriminant validity were assessed from Spearman's correlations of the Family Relationships scores with PROMIS-25 domains within each chronic disease. Results are reported as the correlation coefficients and boot-strapped 95% confidence intervals (CI). We regarded a two-tailed $p < 0.05$ as significant for this analysis, and correlation coefficients of < 0.30 as small, r = 0.30 to r = 0.49 as medium, and ≥ 0.50 as large.

Results

Participant characteristics

A total of 275 families contributed data for this work. Children's mean ages were 12.2 (asthma), 13.1 (type 1 diabetes), and 12.0 (sickle cell disease) years within the three disease groups, respectively (Table 1). In asthma and sickle

Table 1 Family characteristics by disease type ($N = 275$)

	Asthma (n=73)		Diabetes (n=122)		Sickle cell (n=80)	
Child characteristics						
Age, years [mean (SD)]	12.2	(2.6)	13.1	(2.7)	12.0	(2.5)
8–12 years, % (n)	61.6%	(45)	48.4%	(59)	63.8%	(51)
13–17 years, % (n)	38.4%	(28)	51.6%	(63)	36.3%	(29)
Female, % (n)	35.6%	(26)	47.5%	(58)	52.5%	(42)
Race, % (n)						
Black or African-American	54.8%	(40)	7.4%	(9)	91.3%	(73)
White	28.8%	(21)	83.6%	(102)	0.0%	(0)
Multi-race or other	9.6%	(7)	8.2%	(10)	3.8%	(3)
Ethnicity, % (n)						
Hispanic or Latino	17.8%	(13)	9.8%	(12)	5.0%	(4)
Health status, child report, % (n)						
Poor	1.4%	(1)	0.8%	(1)	2.5%	(2)
Fair	6.8%	(5)	4.1%	(5)	11.3%	(9)
Good	45.2%	(33)	33.6%	(41)	30.0%	(24)
Very good	32.9%	(24)	41.8%	(51)	36.3%	(29)
Excellent	12.3%	(9)	17.2%	(21)	18.8%	(15)
Parent characteristics						
Age, years [mean (SD)]	41.3	(7.4)	41.1	(6.1)	37.3	(7.4)
Relationship to child, mother, % (n)	82.2%	(60)	86.9%	(106)	82.5%	(66)
Education, % (n)						
Less than high school	11.0%	(8)	3.3%	(4)	15.0%	(12)
High school diploma	21.9%	(16)	3.3%	(4)	16.3%	(13)
Some college	28.8%	(21)	38.5%	(47)	32.5%	(26)
Bachelor's degree	15.1%	(11)	32.8%	(40)	10.0%	(8)
Post-graduate degree	11.0%	(8)	12.3%	(15)	7.5%	(6)

Values may not add to 100% due to rounding or non-response

cell disease, about 60% of participants were 8–12 years of age, but in type 1 diabetes, participants were nearly evenly split between 8–12-year and 13–17-year olds. With regard to race, the majority of children with type 1 diabetes were White, while the majority of children with asthma or sickle cell disease were either Black, multi-race or other. Most children reported their health as good, very good, or excellent. Most parent respondents were mothers (84%), with varying levels of educational attainment.

Family Relationship scores by chronic disease type

Across the three diseases, mean children's Family Relationship scores were similar (M = 53.0 among children with asthma, M = 53.2 in type 1 diabetes, and M = 54.6 in sickle cell disease; Table 2). Parent scores differed significantly between the three diseases, with higher scores reported by parents of children with asthma (M = 56.2) and sickle cell disease (M = 56.2), than by parents of children with type 1 diabetes (M = 51.1, $p < 0.001$).

Standard error of measurement of individual PROMIS Family Relationship scores

Figure 1 shows SEMs across the range of estimated true scores for all three diseases, for children and parents. The maximum Family Relationships score was 63.9 for both children and parents, while the minimum was 17.8 for children and 25.8 for parents. The SEMs were similar across diseases. SEMs for those estimated to have true values below 50 were fairly constant and small, especially for parents. However, SEMs were larger for estimated scores above the normative mean of 50.

Among parent reports of Family Relationships, 54%, 35% and 64% of scores have an SEM above four points for asthma, type 1 diabetes, and sickle cell, respectively (Table 3). Corresponding values for children are 23%, 27%, and 38%, respectively.

IRT-estimated marginal reliability and internal consistency

For children, IRT-estimated marginal reliability was ≥ 0.84 in each of the three disease groups (Table 4). For parents, IRT-estimated marginal reliability was highest among parents of children with type 1 diabetes (0.85) and lowest for parents of children with asthma (0.75). For sickle cell disease, the IRT-estimated reliability for parents was 0.80. Within each of the three chronic illnesses, internal consistency for both child and parent responses was good with Cronbach's alpha ≥ 0.88.

Correlations with other PROMIS-25 domains

Within each of the three disease groups, children's Family Relationships scores correlated significantly and in the expected direction with scores on the PROMIS social health and mental health domains (Table 5). Specifically, within each of the three disease groups, moderate positive correlations with peer relationships, moderate negative correlations with depressive symptoms, and small to moderate negative

Table 2 Pediatric PROMIS domain scores

PROMIS domain	Child report[a]						Parent report[a]					
	Asthma (*n*=71)		Diabetes (*n* =120)		Sickle cell (*n*=79)		Asthma (*n*=70)		Diabetes (*n*=120)		Sickle cell (*n*=80)	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
Social health												
Family relationships[b]	53.0	(9.2)	53.2	(9.0)	54.6	(9.1)	56.2	(7.9)	51.1	(9.2)	56.2	(9.6)
Peer relationships[b]	49.6	(9.4)	52.4	(9.7)	50.1	(10.9)	49.8	(11.3)	51.2	(9.8)	50.3	(11.3)
Mental health												
Anxiety	48.6	(11.3)	45.8	(10.3)	47.3	(11.7)	44.2	(9.4)	45.7	(11.0)	44.5	(11.2)
Depressive symptoms	48.8	(10.0)	45.1	(9.5)	46.3	(11.0)	45.1	(9.8)	45.6	(10.2)	44.3	(10.5)
Physical health												
Fatigue	49.0	(10.1)	45.3	(10.8)	48.2	(11.0)	48.6	(9.9	45.2	(10.5)	48.9	(12.2)
Pain interference	51.1	(10.6)	44.9	(9.7)	52.0	(12.0)	51.2	(9.6)	45.4	(8.6)	52.0	(12.5)
Physical function—mobility[b]	48.7	(8.7)	53.1	(6.2)	49.5	(8.9)	47.1	(8.5)	53.5	(5.3)	47.9	(9.4)
Pain intensity[c]	3.1	(2.3)	1.9	(2.2)	3.8	(3.6)	2.4	(2.6)	1.1	(1.6)	3.0	(3.4)

[a]Sample sizes for children and parents differ due to non-response

[b]Higher scores indicate better health

[c]On a scale of 0–10, where 10 is worst pain

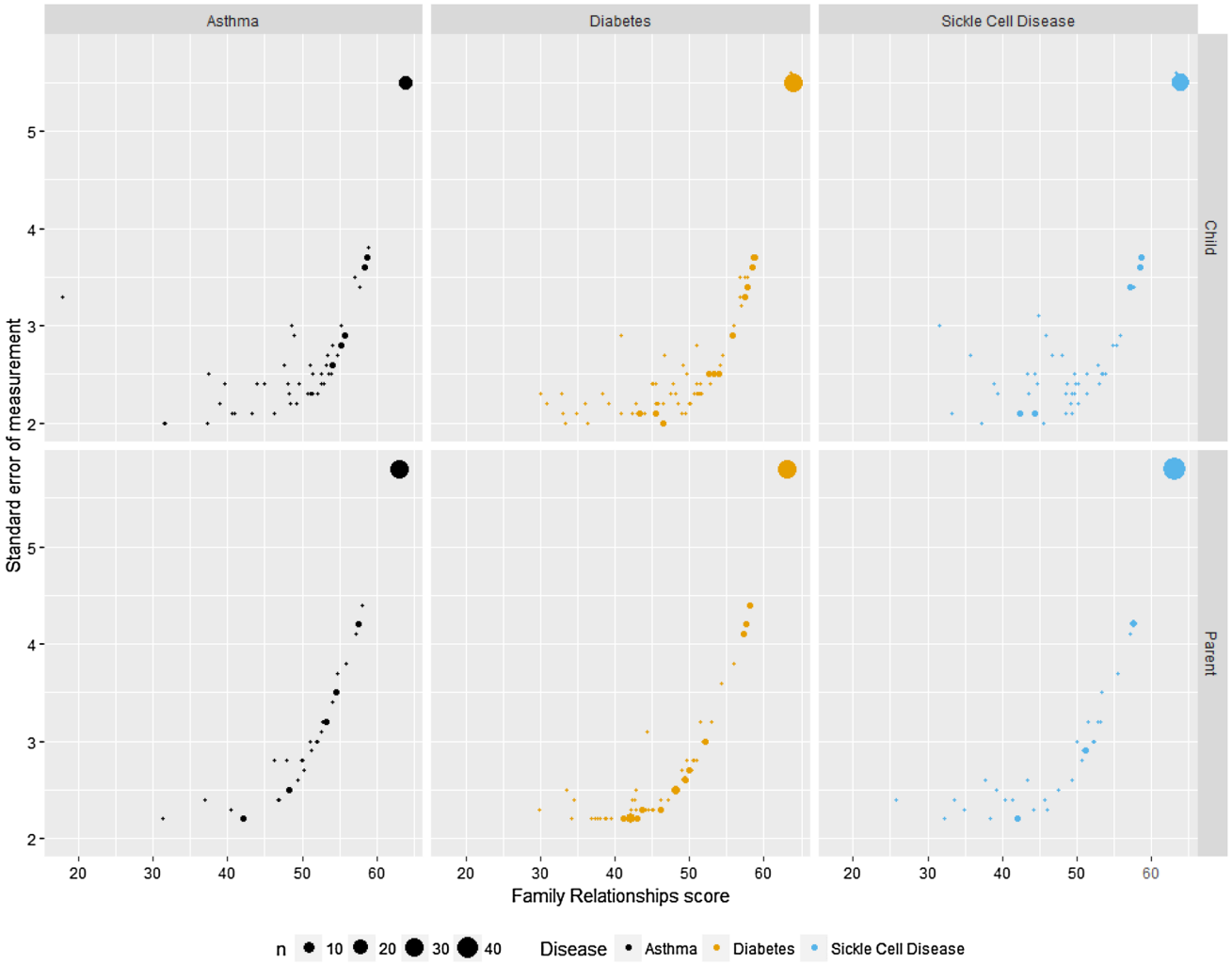

Fig. 1 Standard error of measurement by Family Relationships score for children and parents by chronic disease

Table 3 Overall standard errors of measurement (SEM) of PROMIS Family Relationships short form scores for chronically ill children 8–17 years old

	Child report					Parent report				
	n	Overall SEM	Minimum SEM	Maximum SEM	Percentage SEM above 4	n	Overall SEM	Minimum SEM	Maximum SEM	Percentage SEM above 4
Asthma	71	3.53	2.0	5.5	22.5	70	4.58	2.2	5.8	54.3
Diabetes	120	3.63	2.0	5.6	26.7	119	3.84	2.2	5.8	34.5
Sickle cell	79	4.00	2.0	5.6	38.0	80	4.81	2.2	5.8	63.8

correlations with anxiety were found for child respondents. Similar patterns were seen among parent responses.

For children with type 1 diabetes and sickle cell disease, Family Relationships scores also correlated significantly and in the expected direction, but to a lesser degree, with PROMIS physical health domains. For example, fatigue exhibited a moderate negative correlation with Family Relationships among children with type 1 diabetes and a small negative correlation among children with sickle cell disease. Among children with type 1 diabetes, Family Relationships exhibited small negative correlations with pain interference and pain intensity, as well as small positive correlation

Table 4 Reliability of PROMIS Family Relationships short form scores for chronically ill children 8–17 years old

	Child report			Parent report		
	n	IRT-estimated marginal reliability	Cronbach's alpha (95% CI)	*n*	IRT-estimated marginal reliability	Cronbach's alpha (95% CI)
Asthma	71	0.87	0.92 (0.84, 0.96)	70	0.75	0.88 (0.75, 0.94)
Diabetes	120	0.86	0.93 (0.89, 0.95)	119	0.85	0.91 (0.88, 0.93)
Sickle cell	79	0.84	0.89 (0.82, 0.93)	80	0.80	0.94 (0.89, 0.96)

with mobility. However, this was not the case for children with asthma. For parents, similar results were seen for these PROMIS domains.

Discussion

We sought to understand whether the PROMIS Family Relationships measure demonstrates adequate reliability and validity when applied in a clinical population of chronically ill children and their parents. Findings from this work extend evidence for the reliability and validity of the PROMIS Family Relationships v1.0 8-item short forms for use with the 6.5 million US children who are impacted by one of these three chronic diseases. In analyses of data from chronically ill children and their parents, we found that children's assessments of their family relationships were similar across the diseases, while parent scores were significantly higher in asthma and sickle cell disease than in type 1 diabetes. Standard errors of measurement for Family Relationships scores were smallest for low scores, suggesting greater certainty for assessments that would raise concern (i.e. worse relationships). Across all three diseases, the measure demonstrated adequate reliability for both children and their parents. In addition, convergent and discriminant validity were supported, as the measure displayed expected correlations with other PROMIS health domains. For children with one of the three chronic diseases included in our study, the PROMIS Family Relationships short form offers a reliable and valid approach to assessing family relationships, from both the child and parent perspective.

In general, the distribution of PROMIS Family Relationships scores in our sample of chronically ill children is similar to those of the general population in which the measure was developed, although mean values for the scores are higher in our sample [19]. Specifically, both populations had maximum Family Relationship scores of 63–64. Standard deviations for the scores within each of the three disease groups were similar to those of the general population (10) for both children (9.8) and parents (9.0). Among the general population, positive skew and ceiling effects were noted, similar to those in our population. As with the general population, the PROMIS Family Relationships measure appears to be more useful for discriminating among scores for children with poorer relationships than for those with better relationships [19]. Hence, individual scores are estimated most precisely in the range of most clinical concern.

Despite these similarities, for each of the three diseases in our study, children's mean Family Relationships scores were about three points (0.3 SD) higher than the general population mean (51.6). Mean parent Family Relationships scores were also higher by as much as six points (0.6 SD) in sickle cell disease and asthma, compared to the general population (51.2), but similar to the general population mean for parents of children with type 1 diabetes. This is in contrast to findings from prior work in the general population, in which parents of children with chronic illness reported lower Family Relationships scores with a significant effect size of 0.2 [19]. However, in this same study, having a chronic illness was not associated with children's Family Relationship scores. In addition, the specific chronic conditions that children in the general population sample had are unknown, and the severity and impact of the chronic conditions may differ substantially. In the general population study, parents reported whether their child had a chronic condition that "lasted or was expected to last at least 12 months AND interferes with his/her activities." Mean Family Relationships scores for children and parents in our sample were also higher than those reported in a study focused on children with cancer, both on and off therapy [25].

Other possible explanations for the higher Family Relationships scores in this work may lie in differences in the characteristics of the samples, beyond just the presence and type of chronic illness. For example, we recruited only children who presented for care of their chronic illness at a clinic, whereas other studies in general populations did not limit recruitment to clinical sites. Thus, children in this study had families who ensured they received healthcare for their chronic disease. A second potential explanation may be differences in the socio-demographic make-up of the two samples. Specifically, our sample included more children 8–12 years of age than in the general population on which the measure was developed. Younger children and their parents have been noted to have higher Family Relationship scores. In addition, Black or African-American children, whose parents within the general population reported better

Table 5 Spearman correlation and 95% confidence interval of PROMIS Family Relationships with PROMIS 25 domains for chronically ill children

PROMIS Measure	Asthma				Diabetes				Sickle cell			
	Child report (n=70)		Parent report (n=69)		Child report (n=120)		Parent report (n=119)		Child report (n=78)		Parent report (n=80)	
Social health												
Peer relationships	**0.32**	**(0.15, 0.50)**	**0.25**	**(0.07, 0.43)**	**0.47**	**(0.35, 0.59)**	**0.56**	**(0.45, 0.67)**	**0.39**	**(0.22, 0.57)**	**0.40**	**(0.23, 0.55)**
Mental health												
Anxiety	**−0.27**	**(−0.45, −0.09)**	**−0.26**	**(−0.43, −0.10)**	**0.39**	**(−0.50, −0.26)**	**−0.29**	**(−0.41, −0.16)**	**−0.26**	**(−0.42, −0.10)**	**−0.38**	**(−0.54, −0.22)**
Depressive symptoms	**−0.30**	**(−0.48, −0.11)**	**−0.32**	**(−0.50, −0.13)**	**−0.40**	**(−0.51, −0.25)**	**−0.58**	**(−0.68, −0.48)**	**−0.39**	**(−0.56, −0.23)**	**−0.60**	**(−0.74, −0.48)**
Physical health												
Fatigue	−0.11	(−0.30, 0.08)	−0.06	(−0.25, 0.13)	**−0.39**	**(−0.51, −0.26)**	**−0.42**	**(−0.54, −0.30)**	**−0.22**	**(−0.38, −0.05)**	**−0.19**	**(−0.37, −0.01)**
Pain interference	−0.06	(−0.23, 0.12)	0.06	(−0.13, 0.25)	**−0.25**	**(−0.38, −0.13)**	**−0.20**	**(−0.34, −0.07)**	0.03	(−0.15, 0.21)	−0.11	(−0.27, 0.06)
Mobility	0.05	(−0.14, 0.24)	−0.08	(−0.28, 0.11)	**0.20**	**(0.06, 0.33)**	**0.29**	**(0.15, 0.42)**	0.11	(−0.06, 0.27)	**0.18**	**(0.01, 0.36)**
Pain intensity	0.04	(−0.13, 0.23)	0.03	(−0.16, 0.22)	**−0.25**	**(−0.38, −0.12)**	**−0.27**	**(−0.41, −0.13)**	−0.01	(−0.19, 0.16)	**−0.22**	**(−0.39, −0.04)**

Bolded values indicate $p < 0.05$

family relationships than parents of White children, made up 44% of our sample. However, in the general population, Black or African-American children did not report better family relationships than their White peers [19].

Among children with asthma, type 1 diabetes, or sickle cell disease, the reliability of the PROMIS Family Relationships 8a short form, while certainly adequate for group comparisons, was lower than that seen in the general population. Specifically, among the general population, internal consistency assessed with Cronbach's alpha was 0.94 for children and 0.91 for parents [19]. To date, the published literature does not contain IRT marginal reliabilities for the measure within the general population, but our evaluation of this parameter suggests adequate reliability among the three disease types for both children and parents. Further, our results suggest that in some but not all of our respondent groups, the measure also achieves the higher reliability threshold (> 0.9) recommended for individual patient assessment [26].

Convergent and discriminant validity were supported through expected correlations with other PROMIS domains. Specifically, for both children and parents, moderate, positive correlations were consistently seen with aspects of social or mental health, across all three diseases. This was as expected, given family relationships are an element of social health, which "encompasses the ways in which individuals connect with important others, including communication, companionship and understanding, and the quality, reciprocity and size of an individual's social network" [27]. Further, these findings are consistent with prior concept elicitation work to develop the PROMIS Family Relationships measure, in which children themselves articulated how their family relationships influence peer relationships, through friend selection [19]. In addition, Family Relationship scores displayed small to moderate negative correlations with both anxiety and depression, as reported by children and parents. This is consistent with accepted diagnostic criteria for these entities, which requires functional impairment in social or family settings [28].

Our study has several limitations. For this evaluation, we included only English-speaking families whose child had at least one of three chronic diseases—asthma, type 1 diabetes, or sickle cell disease. Although these diseases represent over 1/3 of children with pediatric chronic illness, generalizing our findings to the entire population of children with chronic conditions should be done with caution. Further, because we recruited participants from a tertiary care facility, the children with asthma may well have more severe disease than those with asthma who are cared for predominantly by primary care physicians. Future work could evaluate reliability and validity of the Spanish-language version of the instrument, which is now available, and also validate the measure among children

with other pediatric chronic illnesses. As expected within the three disease groups included in our sample, participants were predominantly White or African-American. The geographic diversity of our sample was limited, though we recruited participants from two large centers that capture both rural and urban families. Families were aware of study participation, potentially leading to higher scores for Family Relationships, as a result of socially desirable survey responses. Lastly, we included only children 8–17 years of age and their parents, aligning with the age group for which pediatric PROMIS measures have been designed for child self-report.

In summary, this study's findings add to the evidence for reliability and validity of the PROMIS Pediatric and Parent Short Form v1.0 Family Relationships 8a for use with children who have a chronic disease. Our results suggest adequate psychometric properties for use among three chronic diseases that encompass 1/3 of the children with a chronic condition. In addition, the measure's properties appear consistent between children with chronic disease in this study and children from the general population on which the measure's initial rigorous development occurred. These conclusions complement qualitative work demonstrating the content validity of the PROMIS Family Relationships short form among children with chronic diseases and their parents [29]. Evidence of the measure's reliability and validity in multiple contexts furthers the case for its widespread use. Ultimately, the measure could be used to evaluate outcomes from interventions that focus on improving family interactions and also could support healthcare organizations and researchers in identifying families who may need additional support.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent All participating parents provided informed consent. Participating children ages 14–17 years also gave informed consent, while children ages 8–13 years provided assent.

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