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PedsQL™ Multidimensional Fatigue Scale in Sickle Cell Disease: Feasibility, Reliability and Validity

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Abstract

Background—Sickle cell disease (SCD) is an inherited blood disorder characterized by a chronic hemolytic anemia that can contribute to fatigue and global cognitive impairment in patients. The study objective was to report on the feasibility, reliability, and validity of the PedsQL™ Multidimensional Fatigue Scale in SCD for pediatric patient self-report ages 5–18 years and parent proxy-report for ages 2–18 years.

Procedure—This was a cross-sectional multi-site study whereby 240 pediatric patients with SCD and 303 parents completed the 18-item PedsQL™ Multidimensional Fatigue Scale. Participants also completed the PedsQL™ 4.0 Generic Core Scales.

Results—The PedsQL™ Multidimensional Fatigue Scale evidenced excellent feasibility, excellent reliability for the Total Scale Scores (patient self-report $\alpha = 0.90$; parent proxy-report $\alpha = 0.95$), and acceptable reliability for the three individual scales (patient self-report $\alpha = 0.77$ – 0.84 ; parent proxy-report $\alpha = 0.90$ – 0.97). Intercorrelations of the PedsQL™ Multidimensional Fatigue Scale with the PedsQL™ Generic Core Scales were predominantly in the large (> 0.50) range, supporting construct validity. PedsQL™ Multidimensional Fatigue Scale Scores were significantly

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Conflict of Interest Statement

Dr. Varni holds the copyright and the trademark for the PedsQL™ and receives financial compensation from the Mapi Research Trust, which is a nonprofit research institute that charges distribution fees to for-profit companies that use the Pediatric Quality of Life Inventory™.

worse with large effects sizes ($d = 0.80$) for patients with SCD than for a comparison sample of healthy children, supporting known-groups discriminant validity. Confirmatory factor analysis demonstrated an acceptable to excellent model fit in SCD.

Conclusions—The PedsQL™ Multidimensional Fatigue Scale demonstrated acceptable to excellent measurement properties in SCD. The results demonstrate the relative severity of fatigue symptoms in pediatric patients with SCD, indicating the potential clinical utility of multidimensional assessment of fatigue in patients with SCD in clinical research and practice.

Keywords

Sickle Cell Disease; PedsQL; fatigue; pediatrics; children; patient-reported outcomes; health-related quality of life

Introduction

Sickle cell disease (SCD) is an inherited blood disorder characterized by a chronic hemolytic anemia that contributes to fatigue and cognitive impairment [1]. Prior work describes biobehavioral factors which are hypothesized to increase the risk for acute and chronic fatigue in SCD, including anemia, painful crises, chronic inflammation, oxidative stress, decreased oxygen affinity of sickled hemoglobin, and disordered sleep-induced fatigue [2]. However, standardized multidimensional assessment of fatigue in pediatric patients with SCD has been previously reported in only one study [3].

The PedsQL™ Multidimensional Fatigue Scale is a generic symptom-specific instrument to measure fatigue across pediatric populations [4–10]. Importantly, it measures cognitive fatigue which focuses on problems with memory and attention, areas known to be affected in children with sickle cell disease [11,12]. Although the previous SCD fatigue study reported detailed information, internal consistency reliability of the PedsQL™ Multidimensional Fatigue Scale across age groups was not included, nor was the factor structure of the instrument, intercorrelations with the PedsQL™ 4.0 Generic Core Scales, or feasibility (missing values) [3]. Additionally, the healthy comparison sample for the PedsQL™ Multidimensional Fatigue Scale is now four times larger than previously available.

Consequently, the objective of this study was to examine feasibility, internal consistency reliability, construct validity and known-groups discriminant validity of the PedsQL™ Multidimensional Fatigue Scale in pediatric patients with SCD. We hypothesized the measure would distinguish between patients with SCD and healthy children [4–10], supporting known-groups discriminant validity. We expected the PedsQL™ Multidimensional Fatigue Scale would be significantly correlated with the PedsQL™ Generic Core Scales, with medium to larger effect sizes, based on the conceptualization of symptoms as causal indicators of generic HRQOL [13], supporting construct validity. We also hypothesized the measure would distinguish between patients with differing severity of SCD, and that the PedsQL™ Cognitive Fatigue Scale would distinguish between patients who had/did-not-have overt stroke, supporting sensitivity. Finally, based on research on the factor structure of the PedsQL™ Multidimensional Fatigue Scale [14], we hypothesized a 3-factor confirmatory factor analysis solution.

Methods

SCD Study Population and Procedures

The study population includes a convenience sample of patients and/or parents who presented for a clinic visit between June, 2010 and August, 2012 and who had completed the

PedsQL™ Multidimensional Fatigue Scale. Participants included children ages 5–18 years and parents of children ages 2–18 years with SCD (any genotype) from five clinical centers across the United States (Medical College of Wisconsin/Children's Hospital; University of Texas Southwestern/Children's Medical Center, Dallas; Baylor College of Medicine/Texas Children's Hospital, Houston; Jonathan Jaques Children's Cancer Center/Miller Children's Hospital, Long Beach, CA; University of Alabama, Birmingham/Children's of Alabama). Children were excluded from the study if known to the clinical team to have cognitive impairment that would prevent them from understanding questions on the instrument. This project was part of a larger study examining psychometric properties of the PedsQL™ Sickle Cell Disease Module [15]. Human subjects institutional review boards at each center approved the study.

Healthy comparison sample: PedsQL™ Multidimensional Fatigue Scale

The PedsQL™ Multidimensional Fatigue Scale healthy children comparison sample was derived from two previous studies [4,6]. Participants included healthy children and adolescents ages 2 to 19 years and their parents. The average age of the 143 males (55.2%) and 113 females (43.6%) was 12.2 years (SD = 4.0) (missing = 3 [1.2%]). There were 124 (47.9%) White non-Hispanics, 62 (23.9%) Hispanics, 28 (10.8%) Native American, 16 (6.2%) Black non-Hispanics and 11 (4.3 %) Asian/Pacific Islanders (Other = 14 [5.4%], Missing = 4 [1.5%]).

Measures

The PedsQL™ Multidimensional Fatigue Scale—The 18-item PedsQL™ Multidimensional Fatigue Scale encompasses three domains: (1) General Fatigue (6 items, e.g., “I feel tired.”; “I feel too tired to do things that I like to do.”), (2) Sleep/Rest Fatigue (6 items, e.g., “I feel tired when I wake up in the morning.”; “I rest a lot.”), and (3) Cognitive Fatigue (6 items, e.g., “It is hard for me to keep my attention on things.”; “It is hard for me to remember what people tell me.”). The PedsQL™ Multidimensional Fatigue Scale was developed based on our research and clinical experiences in pediatric chronic health conditions, and the instrument development literature, which consisted of a review of the extant literature on fatigue in both adult and pediatric patients, patient and parent focus groups and individual interviews, item generation, cognitive interviewing, pretesting, and subsequent field testing of the instrument [4,5]. The format, instructions, Likert response scale, and scoring method are identical to the PedsQL™ 4.0 Generic Core Scales [16], with higher scores indicating better HRQOL (lower fatigue symptoms). The instructions ask how much of a problem each item has been during the past one month.

The PedsQL™ Multidimensional Fatigue Scale comprises parallel child self-report and parent proxy-report formats. Child and adolescent self-report include ages 5–7, 8–12, and 13–18 years. Parent proxy-report includes ages 2–4 (toddler), 5–7 (young child), 8–12 (child), and 13–18 (adolescent), and assesses parent's perceptions of their child's fatigue. Items for each of the forms are essentially identical, differing in developmentally appropriate language, or first or third person tense. Scale scores are computed as the sum of items divided by the number of items answered; this accounts for missing data. If more than 50% of the items in the scale are missing, the scale score is not computed. This accounts for the differences in sample sizes for scales reported in Tables I, III and V. Although there are other strategies for imputing missing values, this is consistent with previous PedsQL™ publications and other well-established HRQOL measures [16–18]. The Total Mean Scale Score (18 items), is computed as the sum of the items divided by the number of items answered in the scales.

The PedsQL™ Generic Core Scales—The 23-item PedsQL™ Generic Core Scales encompass: 1) Physical Functioning (8 items), 2) Emotional Functioning (5 items), 3) Social Functioning (5 items), and 4) School Functioning (5 items) [16]. The Physical Health Summary Score is the same as the Physical Functioning Scale. To create the Psychosocial Health Summary Score, the mean is computed as the sum of the items divided by the number of items answered in the Emotional, Social, and School Functioning Scales. The PedsQL™ Generic Core Scales are scored similarly to the Multidimensional Fatigue Scale, with higher scores indicating better HRQOL. The PedsQL™ Generic Core Scales have demonstrated reliability, validity, and responsiveness in SCD [3,19–23]. Parents also completed a modified PedsQL™ Family Information Form which contains demographic information [16].

Statistical Analysis—Feasibility was determined from the percentage of missing values [18]. Cronbach's coefficient alpha was utilized to determine scale internal consistency reliability [24]. Scales with internal consistency reliabilities of 0.70 or greater are recommended for comparing groups, while a value of 0.90 is recommended for analyzing individual scores [25]. Range of measurement was based on the percentage of scores at the extremes of the range, that is, the maximum possible score (ceiling effect) and the minimum possible score (floor effect). Surveys with small floor or ceiling effects (1% to 15%) are considered to meet acceptable measurement standards, while surveys with moderate floor or ceiling effects (> 15%) are considered less precise in measuring latent constructs at the extremes of the scale [26].

Factor analysis was conducted on the a priori hypothesized factor structure of the PedsQL™ Multidimensional Fatigue Scale. Since the purpose was to test an a priori hypothesized factor structure, confirmatory factor analysis (CFA) was utilized [27]. Given the commonly cited limitations of the chi-square statistic, and consistent with recommendations set forth in the literature [28–31], we examined different model indices of practical fit including the Root Mean Squared Error of Approximation (RMSEA)[30], the Comparative Fit Index (CFI)[28], the Tucker-Lewis Index (also known as the Non-Normed Fit Index; NNFI)[31], and the Normed Fit Index (NFI)[32]. Excellent model fit is suggested by RMSEA values 0.06, while acceptable model fit is suggested by RMSEA values between 0.06 and 0.08 [33,34]. For the NFI, NNFI and CFI indices, excellent model fit is suggested by values greater than or equal to 0.95, while acceptable model fit is suggested by values between 0.90 and 0.95 [28,32,33]. LISREL for Windows program was utilized for these analyses [35].

The sensitivity of a measurement instrument may be demonstrated through a cross-sectional analysis of differences between groups of patients with varying degrees of disease severity [36]. Sensitivity of the PedsQL™ Multidimensional Fatigue Scale was determined by comparing patients with severe and mild SCD, and sensitivity of the PedsQL™ Cognitive Fatigue Scale was determined by those who had/did-not-have overt stroke (abstracted from medical record), using independent samples *t*-tests. Disease status was classified a priori as mild or severe disease regardless of the child's SCD type which is consistent with prior work [19,23]. Patients were classified as having severe disease if they experienced one or more of the following complications of SCD: 1) overt stroke, 2) acute chest syndrome, 3) 3 or more hospitalizations for painful events in the prior 3 years. This classification was based on the criteria used for intervention with hydroxyurea or bone marrow transplantation [37–39]. All others were classified as having mild disease. Effect sizes were calculated to determine the magnitude of the differences [40]. Effect size as utilized in these analyses was calculated by taking the differences between the groups' sample means, divided by the pooled standard deviation. Effect sizes for differences in means are designated as small (0.20), medium (0.50), and large (0.80) [40].

Discriminant validity was determined utilizing the known-groups method [36]. This method compares scores across groups known to differ in the health construct being investigated. PedsQL™ Multidimensional Fatigue Scale scores in groups differing in health (patients with SCD and healthy children) were computed using independent samples t-tests. Effect sizes were also calculated [40].

An analysis of intercorrelations between the PedsQL™ Multidimensional Fatigue Scale with the PedsQL™ Generic Core Scales was used to further examine construct validity. Computing the intercorrelations provides additional information on the construct validity of an instrument [41]. Pearson Product Moment Correlation coefficients effect sizes are designated as small (0.10), medium (0.30), and large (0.50) [40].

Intraclass Correlation Coefficients (ICCs) were used to determine agreement between patient self-report and parent proxy-report [42]. The ICC provides an index of absolute agreement as it takes into account the ratio between subject variability and total variability [42]. ICCs are designated as 0.40 poor to fair agreement, 0.41–0.60 moderate agreement, 0.61–0.80 good agreement, and 0.81–1.00 excellent agreement. Statistical analyses were conducted using SPSS Version 19.0 for Windows [43].

Results

SCD Study Population

A total of 319 families participated (240 children ages 5–18 years and 303 parents/caregivers of children ages 2–18 years; 16 children completed the measure without parent/caregiver completion). The average age of the 153 males (48%) and 166 females (52.0%) was 9.70 years (SD = 4.83). With respect to race/ethnicity, the sample contained 313 (98.1%) self-reported Black non-Hispanic, 2 (0.6%) White non-Hispanic, 2 (0.6%) Hispanic, and 2 (0.6%) Other. With respect to parent education (n=319), 19.1% of mothers and 14.8% of fathers did not complete high school; 17.9% of mothers and 18.2% of fathers had a high school degree; 35.4% of mothers and 20.3% of fathers completed some college; 14.4% of mothers and 6.9% of fathers had a college degree; and 3.8% of mothers and 5.0% of fathers had a graduate degree (missing: 9.4% mothers and 34.8% fathers). The distribution of participants by site is as follows: Medical College of Wisconsin/Children's Hospital of Wisconsin n=148; University of Texas Southwestern/Children's Medical Center, Dallas, n=100; Baylor College of Medicine/Texas Children's Hospital, Houston n=23; Jonathan Jaques Children's Cancer Center/Miller Children's Hospital, Long Beach, CA n=26; University of Alabama at Birmingham/Children's of Alabama n=22.

Known-Groups Discriminant Validity

Table I contains the means and standard deviations of the PedsQL™ Multidimensional Fatigue Scale scores for patients with SCD and healthy children. For all scores, patients and their parents reported statistically significant greater fatigue than healthy children. All effect sizes were in the large range.

Feasibility/Missing Item Responses and Range of Measurement

The percentage of missing item responses on the PedsQL™ Multidimensional Fatigue Scale was 0.78% and 0.55% for child self-reports and parent proxy-reports, respectively. The percentage of scores at extremes of the scaling range (floor effects reflecting lowest possible scores [more fatigue] and ceiling effects reflecting highest possible scores [less fatigue]) demonstrated acceptable effects overall (Table II). For self-report, there were no significant floor or ceiling effects. For proxy-report, there were no significant floor effects, and small to medium ceiling effects for two scales.

Internal Consistency Reliability and Parent/Child Agreement

Internal consistency reliability coefficients across ages show that all scales exceed the minimum reliability of 0.70 for group comparisons (Table III). The Total Scale Scores for both child self-report and parent proxy-report meet the reliability criterion of 0.90 recommended for analyzing individual patient scores. The majority of the ICCs between child and parent report were in the poor to fair and moderate agreement range (Total Fatigue Score, 0.434; General Fatigue, 0.385; Sleep/Rest Fatigue, 0.340; Cognitive Fatigue, 0.416).

Confirmatory Factor Analysis

The results demonstrate that the 18 items of the self-report version loaded on three latent variables consistent with the a priori hypothesized factor structure [14]. Goodness of fit statistics were RMSEA=0.072, NFI=0.93, CFI=0.96 and NNFI=0.96. For proxy-report, the a priori hypothesized factor structure did not fit the data well. In order to improve the overall model fit, error covariance between items and an additional path from the General Fatigue Scale to the second item of the Sleep/Rest Fatigue Scale were added. Goodness of fit statistics for the modified proxy-report model were RMSEA=0.080, NFI=0.97, CFI=0.98 and NNFI=0.98. These results demonstrate acceptable to excellent model fit.

Intercorrelations between PedsQL™ Multidimensional Fatigue Scale and Generic Core Scales and Sensitivity

Greater fatigue was significantly correlated with lower generic HRQOL (Table IV). The correlations were mostly in the large effect size range. There were no significant differences between mild and severe SCD for self-report (Table V). Parent proxy-report demonstrated statistically significant greater fatigue in patients with severe disease than patients with mild disease. Patients with overt stroke ($n = 21$) self-reported nonsignificantly greater cognitive fatigue than patients without overt stroke ($n = 217$; 53.8 vs. 60.3, $p = 0.24$, effect size = 0.26). Parents of patients with overt stroke ($n = 25$) proxy-reported significantly greater cognitive fatigue than parents of patients without overt stroke ($n = 275$; 47.8 vs. 68.0, $p < 0.001$, effect size = 0.74).

Discussion

These findings support the feasibility, reliability and validity of the PedsQL™ Multidimensional Fatigue Scale in pediatric patients with SCD. The PedsQL™ Multidimensional Fatigue Scale should be a useful symptom-specific instrument that can be integrated with the PedsQL™ Generic Core Scales and the PedsQL™ SCD Module to provide a comprehensive assessment of generic and disease-specific HRQOL in pediatric patients with SCD.

Items on the PedsQL™ Multidimensional Fatigue Scales had minimal missing responses and an acceptable range of responses, suggesting that children and parents are willing and able to provide good quality data regarding the child's fatigue. Internal consistency reliabilities exceeded the minimum standard of 0.70 for group comparison, while Total Scale Scores met an α of 0.90, recommended for individual patient analysis [25].

The PedsQL™ Measurement Model emphasizes the child's perceptions. Fatigue items included were derived from measurement properties of the self-report scales, while proxy-report scales were constructed to directly parallel the self-report items [4]. Our finding that patients with SCD and their parents demonstrated poor to fair and moderate agreement is consistent with the extant literature that information provided by proxy-respondents is not equivalent to that reported by the patient, particularly for domains that are less observable and more internal such as fatigue [44]. However, parents may provide information that is

complementary and unique to the child's [44]. Thus, we recommend that self-report be the primary measure of fatigue and proxy-report a secondary measure, particularly since parents rated the patient's fatigue as less problematic than the patients with SCD, and thus may under-identify this symptom.

Large effect size differences between patients with SCD and healthy children highlight the salience of patients' fatigue experience. During our patient qualitative methods interviews in the development of the PedsQL™ SCD Module [45], fatigue and its impact on daily functioning was mentioned as a prominent concern. Thus, it is not surprising that quantitative assessment of fatigue in these patients would demonstrate significant differences with healthy children. In fact, the patient self-reported PedsQL™ Multidimensional Fatigue Scale Total Score for these patients demonstrates a 7-point difference (greater fatigue) than newly-diagnosed pediatric cancer patients receiving chemotherapy and radiation treatment [4], further demonstrating the severity of the fatigue symptoms in patients with SCD in comparison to cancer patients who manifest significant fatigue during treatment.

In the present study, there was no difference in cognitive fatigue based on self-report for patients with overt stroke. However, children were excluded from self-report if they were known to the clinical team to have cognitive impairment that would prevent them from understanding the questions, which may have attenuated differences. Parents of children with overt stroke did report significant differences in cognitive fatigue for their children. This is not unexpected given that items within this domain measure memory and attention, and prior findings in patients with stroke demonstrated significantly lower Cognitive Fatigue Scale scores in comparison to healthy children [46]. It should be noted that the Cognitive Fatigue Scale has demonstrated differences between healthy children and pediatric patients with expected cognitive functioning problems [4–10]. Additionally, recent analyses of factorial invariance across age and gender for the PedsQL™ Multidimensional Fatigue Scale have indicated that a bifactor model is appropriate; that is, a bifactor model of the 18 items with one general factor (fatigue) influencing all the items and three domain-specific factors representing the General, Sleep/Rest, and Cognitive Fatigue domains [14]. Taken together, including the CFA data in the present study, the data support a multidimensional conceptual framework for pediatric fatigue, which includes cognitive fatigue as one dimension, all measuring the general factor "fatigue".

Compared to the previous SCD PedsQL™ Multidimensional Fatigue Scale study [3], we found greater self-reported and proxy-reported fatigue. It should be noted there were gender differences between our study and the previous study that may affect comparisons [3]. Specifically, our study had 52% females and 48% males, while the previous study had 47% females and 53% males. Given gender differences in fatigue in large epidemiological studies of adolescents (females report more fatigue) [47,48], the two studies may not be directly comparable.

The present study has several strengths, including the large sample size, the broad age-range of participants, and representation of participants from across the country. Limitations include lack of information on families who chose not to participate. Patient self-report did not discriminate across scales when comparing patients with mild and severe disease. There is no well accepted disease severity classification for patients with sickle cell disease. Thus, consistent with prior work, we relied upon classifying a patient's disease severity based upon phenotypic expression of disease, generally whether or not they have experienced known complications such as hospitalizations for pain or acute chest syndrome. However, this does not take into account degree of anemia or whether patients may have experienced a silent stroke which can contribute to cognitive difficulties and which, if known for our

study, might have helped better demonstrate known-group differences. Furthermore, our healthy comparison sample of patients was composed of 47.9% White non-Hispanics, 23.9% Hispanics, and only 6.2% Black non-Hispanics which may limit generalizability given findings that Caucasians may have less fatigue than African-American and Hispanic populations [49,50].

In our study, parent proxy-report showed some ceiling effects which may limit those scales' ability to detect greater improvement in health. However, in chronic health conditions, it is typically floor effects (when the lower values mean more of the symptom) that are of most concern. Some ceiling effects, but not floor effects, had been reported in the SCD PedsQL™ Multidimensional Fatigue Scale study [3]. Additionally, the intercorrelations among the PedsQL™ Multidimensional Fatigue Scale and the PedsQL™ Generic Core Scales may reflect, in part, shared method variance. Also, our sample was drawn from a group of tertiary health care centers at arbitrary sites in the United States and may not be generalizable. Finally, future research will need to investigate whether the construct "cognitive fatigue" as measured by the PedsQL™ Cognitive Fatigue Scale items is measuring attentional or cognitive difficulties resulting from stroke or measuring "mental fatigue." Addressing this question will be essential in determining potential treatment options for these patients.

Further research to demonstrate additional psychometric properties of the PedsQL™ Multidimensional Fatigue Scale in SCD are needed including test-retest reliability and responsiveness (ability to detect change over time) to further demonstrate the utility of the instrument within this population. In addition, further research is needed to assess fatigue and the impact of acute events. Nevertheless, these data contribute to a greater understanding of the burden of fatigue that patients with sickle cell disease experience, which presents an opportunity to consider fatigue as an important patient outcome to measure. Lastly, measurement of fatigue across different settings such as school and home may provide useful clinical information to help inform clinical interventions and monitor treatment progress over time.

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Abbreviations

PedsQL™	Pediatric Quality of Life Inventory™
SCD	Sickle Cell Disease
HRQOL	health-related quality of life
MFS	Multidimensional Fatigue Scale

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PedsQL™ Multidimensional Fatigue Scale Scores Comparisons with Healthy Children Scores for Child Self-Report and Parent Proxy-Report for Sickle Cell Disease (SCD) Sample

Table 1

	SCD		Healthy		Differences	Effect Size
	Mean	SD	Mean	SD		
Multidimensional Fatigue Scale	(n = 240)		(n = 209)			
Child Self-Report						
Total fatigue	61.1	19.8	81.8	12.5	20.7*	1.28
General fatigue	65.4	22.7	86.1	13.6	20.7*	1.14
Sleep/rest fatigue	58.2	23.3	76.8	16.3	18.6*	0.94
Cognitive fatigue	59.8	24.4	82.4	16.5	22.6*	1.11
Parent Proxy-Report	(n = 303)		(n = 259)			
Total fatigue	67.4	21.5	88.2	11.1	20.8*	0.95
General fatigue	66.6	23.7	88.8	12.3	22.2*	1.23
Sleep/rest fatigue	69.3	23.5	87.6	13.5	18.3*	0.99
Cognitive fatigue	66.3	28.4	88.2	16.0	21.9*	0.99

Note:

* p<.001 based on independent samples t-tests. Higher scores equal better HRQOL (less fatigue). SD = standard deviation. Effect sizes are designated as small (0.20), medium (0.50), and large (0.80).

Table II

PedsQL™ Multidimensional Fatigue Scale Percent Floor and Ceiling Effects for Pediatric Patients with Sickle Cell Disease for Child Self-Report and Parent Proxy-Report

Multidimensional Fatigue Scale	% Floor*	% Ceiling*
Child Self-Report		
Fatigue Total Score	0	0
General Fatigue	0	8.4
Sleep/Rest Fatigue	0.9	3.1
Cognitive Fatigue	0.9	5.3
Parent Proxy-Report		
Total Fatigue Score	0.3	7.8
General Fatigue	0.3	13.7
Sleep/Rest Fatigue	0.9	16.8
Cognitive Fatigue	2.5	22.1

* The percentage of scores at the extremes of the scaling range, that is, the maximum possible score (ceiling effect) and the minimum possible score (floor effect). Higher scores equal better HRQOL (less fatigue). Surveys with small floor or ceiling effects (1% to 15%) are considered to meet acceptable measurement standards, while surveys with moderate floor or ceiling effects (> 15%) are considered less precise in measuring latent constructs at the extremes of the scale.

PedsQL™ Multidimensional Fatigue Scale Cronbach's Alpha Internal Consistency Reliability* for Child Self-Report and Parent Proxy-Report by Age and Summary Score/Scale

Table III

Multidimensional Fatigue Scale	Age Group				Total Sample
	(2-4) n = 0	(5-7) n = 46	(8-12) n = 79	(13-18) n = 91	
Child Self-Report					n = 216
Total fatigue	N/A	0.91	0.88	0.92	0.90
General fatigue	N/A	0.79	0.81	0.89	0.84
Sleep/rest fatigue	N/A	0.77	0.74	0.80	0.77
Cognitive fatigue	N/A	0.81	0.85	0.85	0.84
Parent Proxy-Report	n = 61	n = 51	n = 84	n = 85	n = 281
Total fatigue	0.97	0.95	0.93	0.95	0.95
General fatigue	0.96	0.94	0.88	0.92	0.93
Sleep/rest fatigue	0.91	0.87	0.89	0.93	0.90
Cognitive fatigue	0.96	0.96	0.97	0.97	0.97

* Scales with internal consistency reliabilities of 0.70 or greater are recommended for comparing patient groups, while an internal consistency reliability criterion of 0.90 is recommended for analyzing individual patient scores.

Table IV

Intercorrelations among PedsQL™ Multidimensional Fatigue Scale and PedsQL™ 4.0 Generic Core Scales for Child Self-Report and Parent Proxy-Report for Sickle Cell Disease Sample

PedsQL™ Scales	Child Self-Report*				Parent Proxy-Report*			
	Total Fatigue	General Fatigue	Sleep/Rest Fatigue	Cognitive Fatigue	Total Fatigue	General Fatigue	Sleep/Rest Fatigue	Cognitive Fatigue
Generic Core Scales								
Total Score	0.767	0.747	0.522	0.674	0.776	0.757	0.662	0.579
Physical Health	0.701	0.720	0.508	0.549	0.658	0.667	0.594	0.443
Psychosocial Health	0.722	0.682	0.473	0.672	0.772	0.735	0.637	0.608
Emotional	0.696	0.655	0.535	0.581	0.724	0.697	0.705	0.477
Social Functioning	0.512	0.493	0.293	0.504	0.558	0.535	0.444	0.449
School Functioning	0.664	0.622	0.395	0.662	0.663	0.630	0.457	0.591

Note:

* p<0.01 for all intercorrelations. Effect sizes are designated as small (0.10), medium (0.30), and large (0.50) for Pearson's Product Moment correlations.

PedsQL™ Multidimensional Fatigue Scale Scores Comparisons with Pediatric Patients with Mild and Severe Sickle Cell Disease for Child Self-Report and Parent Proxy-Report

Table V

Multidimensional Fatigue Scale	Severe		Mild		Differences	Effect Size	p-value
	Mean	SD	Mean	SD			
Child Self-Report	(n = 104)		(n = 136)				
Total Fatigue Score	59.8	21.4	62.1	18.5	2.3	0.12	0.371
General Fatigue	63.4	24.9	66.9	21.0	3.5	0.15	0.239
Sleep/Rest Fatigue	58.3	22.3	58.1	24.1	0.2	0.01	0.958
Cognitive Fatigue	57.9	25.4	61.3	23.6	3.4	0.14	0.293
Parent Proxy-Report	(n = 128)		(n = 175)				
Total Fatigue Score	61.2	21.6	72.0	20.3	10.8	0.52	<0.001
General Fatigue	60.1	23.8	71.4	22.6	11.3	0.49	<0.001
Sleep/Rest Fatigue	64.3	23.2	72.9	23.0	8.6	0.37	0.002
Cognitive Fatigue	59.1	29.6	71.6	26.3	12.5	0.45	<0.001

Note: p-values based on independent samples t-tests. Effect sizes are designated as small (0.20), medium (0.50), and large (0.80). Higher scores equal better HRQOL (less fatigue).