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The Performance of the PedsQL™ Generic Core Scales in Children with Sickle Cell Disease

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Abstract

The objective of this study was to determine the feasibility, reliability and validity of the Pediatric Quality of Life Inventory™ generic core scales (PedsQL™ questionnaire) in children with sickle cell disease. This was a cross-sectional study of children from an urban hospital-based sickle cell disease clinic and an urban primary care clinic. The study participants were children ages 2 to 18 years who presented to clinic for a routine visit. Health-related quality of life (HRQL) was the main outcome. HRQL of children with sickle cell disease were compared to children without disease to test validity. Missing items were used to determine feasibility and Cronbach's alpha was used to determine reliability. Parents of 178 children (104 with sickle cell disease and 74 without disease) and 118 children (78 with sickle cell disease and 40 without disease) completed HRQL questionnaires. The PedsQL™ questionnaire was feasible and reliable. The parent-proxy and child self-report questionnaire differentiated between children with and without sickle cell disease. The parent proxy-report differentiated well between children with mild and severe sickle cell disease. The questionnaire performed well in children with sickle cell disease and is a feasible, reliable, and valid tool to measure HRQL in children with sickle cell disease.

Keywords

health-related quality of life; sickle cell disease; validity; reliability

Introduction

Determining the performance of a health-related quality of life (HRQL) questionnaire within the population to which it is applied is critical prior to utilizing the questionnaire as a patient reported outcome.[1,2] Understanding the basic psychometric properties such as validity and reliability of a measure help support its use within clinical trials and for drug labeling by the FDA.[1–4] Ultimately, the work done to understand the performance of a HRQL measure should help advance the concept that these questionnaires can be used in everyday clinical practice to monitor the HRQL of a patient.

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There are limited data on the HRQL of children with sickle cell disease[5–8] and even less is known about the performance of HRQL questionnaires within this population.[9] The Child Health Questionnaire (CHQ) is the only HRQL questionnaire that has been shown to be valid and reliable for use in children with sickle cell disease.[9] Currently, the CHQ is limited to a child self report version ages 10 to 18 years of age and to a parent report version ages 5 to 18 years of age. In addition, the child self report version is quite long and thus can be difficult to use in everyday clinical practice. The Pediatric Quality of Life Inventory™ generic core scales (PedsQL™ questionnaire) measure HRQL by proxy report for children as young as 2 years of age and by self report for children as young as 5 years of age. It is brief and takes only 5 to 10 minutes to complete. These characteristics make the PedsQL™ an appealing questionnaire to measure HRQL in children with sickle cell disease.

The objective of this study was to determine the performance of the PedsQL™ questionnaire in children with sickle cell disease. We hypothesized that the PedsQL questionnaire would perform well in children with sickle cell disease; specifically that the PedsQL™ questionnaire would be reliable, valid, and feasible to use in a clinic setting.

Materials and Methods

Study Setting and Subjects

This was a cross-sectional study conducted at the Medical College of Wisconsin pediatric sickle cell disease clinic from January, 2006 to June, 2007. Children 2 through 18 years of age who presented to the clinic for a routine check-up were eligible for the study.

Children were also recruited from an urban primary care clinic in Milwaukee, Wisconsin from January, 2007 through June, 2007 to represent a comparison group of children without sickle cell disease for the validity portion of this study only. Children presenting to either clinic with an acute illness were not eligible for the study since it was felt this illness would affect the child's baseline HRQL measurement.

The Institutional Review Board of the Medical College of Wisconsin/Children's Hospital of Wisconsin approved the study. Informed consent was obtained from the parent and assent was obtained from children 7 years of age or older.

Measurements

Demographic and medical information was obtained on all patients through parent report and review of the child's medical chart. For children with sickle cell disease, information was also obtained from the sickle cell disease center's comprehensive clinical database. Race data for the children was collected using a modified United States Census classification and reflect parent report based on the following choices: White, Black, Native Hawaiian or Other Pacific Islander, Asian, American Indian or Alaskan native, Other or Unknown.

For children with sickle cell disease, disease status was classified a priori as mild or severe disease regardless of the child's sickle cell phenotype. Children with a history of a sickle cell related stroke, acute chest syndrome, 3 or more hospitalizations in the prior 3 years, or recurrent priapism were classified as having severe disease based on criteria used for intervention with hydroxyurea or bone marrow transplantation.[10–12] All others were classified as having mild disease. Despite recent advances in the care and treatment of children with sickle cell disease, there is currently not a scale available to determine clinical severity. Therefore, given the considerable variability in the expression of the clinical phenotypes of sickle cell disease, classification into mild and severe disease was based largely on what was observed in the past for each patient. The primary outcome was health-

related quality of life as measured by the PedsQL™ parent and child self-report form of the generic core scales.

The PedsQL™ is a 23 item generic HRQL questionnaire that has a child self report for ages 5 through 18 years and a proxy report for children ages 2 through 18 years.[13] The questionnaire takes 5 to 10 minutes to complete. The questionnaire yields information on the physical, emotional, social and school functioning of the child during the previous 4 weeks. It has been extensively tested in both healthy children and children with chronic disease. [14–20] Mean scores are calculated based on a 5-point response scale for each item and transformed to a 0 to 100 scale with a higher score representing better quality of life. The PedsQL™ yields 3 summary scores: a total scale score, a physical health summary score, and a psychosocial health summary score. There are 4 scale scores: physical functioning, emotional functioning, social functioning, and school functioning. The total score is comprised of the average of all items in the questionnaire. The psychosocial summary score is comprised of the average of the items in the emotional, social, and school functioning scales. The physical health summary score is comprised of the average of items in the physical functioning scale and is the same score as the physical functioning score. Missing items were accounted for based on the developer's recommendation.[13]

The PedsQL in paper form was completed in the clinic by the parent/and or child after appropriate introduction for completion of the questionnaire was given by one member of the research team (L.F.). As the guidelines for administration of the PedsQL recommend, [13] children and parents self-completed the questionnaire independently. In addition, as recommended, children ages 5 to 7 years of age completed the questionnaire with the assistance of one member of the research team (L.F.).

Feasibility and Floor/Ceiling Effects

To determine feasibility, missing values for each item were determined. In addition, the percentage of scores that were at the ceiling (top of the scale) or floor (bottom of the scale) were calculated for each scale.

Reliability

Although the internal consistency reliability is known for the PedsQL questionnaire in healthy children and children with other chronic diseases,[16–22] it is not known within the population of patients with sickle cell disease. The internal consistency reliability was calculated to determine whether the items within each scale of the PedsQL generic parent and self report questionnaire were consistent with each other. A Cronbach's alpha coefficient of greater than 0.70 was considered acceptable for group-level analysis.[19]

Validity

Validity can be determined using a known-groups comparison method to determine if a questionnaire measures what it intends to measure. To determine the discriminant validity of the PedsQL parent-proxy and child self-report questionnaire, comparisons were made: 1) between children with and without sickle cell disease and 2) between children with mild and severe sickle cell disease.

Factor Analysis

To further determine validity of the PedsQL questionnaire an exploratory factor analysis was performed to determine if items correlated as expected for the scale structure.

Analysis

Descriptive statistics were calculated for child and disease characteristics. Categorical variables are presented as observed frequencies and proportions while continuous variables (child age) are presented as sample medians. Differences between child demographic characteristics were compared using Chi-square tests and Fisher's Exact Test, where appropriate, for categorical variables. Child age was compared between children with and without sickle cell disease using a Wilcoxon Rank-Sum Test. Internal reliability was assessed using Cronbach's alpha for each of the four subscales of the PedsQL as well as for the summary and total scores.

Mean scores for HRQL for the summary scores and each of the subscales were calculated using PedsQL developer's guidelines.[23] Because of the skewed distribution of the summary and subscale scores, differences in mean scores between 1) children with and without sickle cell disease and 2) children with mild and severe disease are reported as medians and Interquartile ranges (IQR) and compared using Wilcoxon Rank Sum Tests. To control for the possibility of false positives due to multiple testing, the false discovery rate (FDR) approach was applied to the subscale analysis, with control set to 5%.[24]

A preliminary exploratory factor analysis was performed for both the patient self-report and parent proxy-report for children ages 5 to 18 years to test the underlying dimensions of the PedsQL items within a sickle cell population. The extracted factors were based on the eigenvalue > 1.0 criterion and were rotated using the Promax oblique rotation. Ages 2 to 4 years were not included in the factor analysis as the PedsQL parent report for ages 2 to 4 years does not include all of the school functioning items. All analyses were performed using SAS v9.1.3 (SAS, Cary, NC).

Results

One hundred and four parents of children with sickle cell disease and 74 parents of children without disease completed the parent report of the PedsQL™ questionnaire. Seventy-eight children with sickle cell disease and 40 children without disease completed the self report PedsQL questionnaire. Table 1 shows the demographic characteristics of children with and without sickle cell disease. Children with sickle cell disease were older than the children without sickle cell disease and more likely to be African American. However, the majority of children without sickle cell disease were African American. Approximately 73% of patients with hemoglobin SS disease were classified as having severe disease. Six of these patients reported having chronic orthopaedic, bone or joint problems. The children in both groups reported similar medical illnesses such as asthma. Two patients with sickle cell disease classified as mild disease had a history of stroke. One of these patients was diagnosed with a perinatal stroke as a neonate and the other had stroke with meningitis as a baby. Neither had further therapy related to the stroke. As a result, these strokes were not thought to be secondary to sickle cell disease so these patients were classified as mild sickle cell disease.

Feasibility and Floor/Ceiling Effects in Children with Sickle Cell Disease

Feasibility was determined by calculating the number of missing item responses from both the parent and child self report questionnaires for children with sickle cell disease. There was less than 5% missing for each item except for items in the school functioning scale which had up to 8.6% of one item missing. The floor and ceiling effects (Table 2) for the parent and child self report of the PedsQL™ questionnaire were similar to that of a population based sample of children.[18] Our sample did have a lower ceiling effect in the physical functioning items compared to the population based sample of children.

Reliability

The reliability (Table 2) of the PedsQL questionnaire in children with sickle cell disease was acceptable in all scales and in the summary scores as evidenced by a Cronbach's alpha greater than 0.7.

Validity between children with and without sickle cell disease

Differences in median summary scores were analyzed between children with and without sickle cell disease. (Table 3). Parent proxy-reports showed children with sickle cell disease had worse HRQL in all summary scores when compared to children without sickle cell disease. Looking at differences at the scale level, the HRQL of children with sickle cell disease was the worst in the area of physical functioning as might be expected given that pain is a predominant symptom in children with sickle cell disease. Children also had worse social and school functioning compared to children without sickle cell disease. There was no difference between children with and without sickle cell disease in the area of emotional functioning.

When examining child self reports (Table 3), children with sickle cell disease had worse physical functioning than those without disease. There were no differences in HRQL scores in other areas.

Validity between children with mild and severe sickle cell disease

The parent proxy-report of the PedsQL questionnaire differentiated between children with mild and severe sickle cell disease in all summary scores (Table 4). At the scale level, there were differences between mild and severe disease in the areas of physical functioning and school functioning. The differences in the physical functioning area of HRQL was expected given that classification of children into mild and severe disease reflects complications that largely impact the child's physical functioning. In addition, children in the severe sickle cell disease group would be expected to have more school functioning problems as they have had more hospitalizations and complications such as stroke.

Unlike the parent proxy-report, the child self-report did not differentiate between mild and severe sickle cell disease in any area (Table 4). Overall, children in both the mild and severe groups tended to rate their HRQL better than their parents did.

Factor analysis

Table 5 and Table 6 show the results of the exploratory factor analysis done on the parent proxy and child self-report of the PedsQL questionnaire for ages 5 to 18 years. Our analysis found 5 factors (latent constructs) for the parent proxy-report (Table 5). This is similar to what has been found in other factor analysis of the parent proxy-report of the PedsQL™ questionnaire.[22,25,26] Our results showed differences related to physical items which likely is due to the prominent role pain plays in sickle cell disease. The physical functioning items "hurt or ache" and "low energy" loaded with school functioning items, "miss school/ not well" and "miss school-doctor appointment" and with an emotional functioning item "have trouble sleeping". In addition, the physical functioning items "hard to walk more than a block", "hard to take bath or shower" and "hard to do chores around house" loaded with emotional items "feel angry" and "worry about what will happen". Our factor analysis also showed school functioning items loading with a social item "trouble getting along with peers".

In the child self-report, a six factor structure resulted from the factor analysis (Table 6). Social functioning items loaded predominately together with emotional functioning items for two of the factors in our factor analysis. School functioning items loaded into 3 different

factors with 2 of the 3 factors having physical functioning items loading with the school functioning items. The remaining factor had physical and emotional items that loaded together.

Discussion

The PedsQL™ questionnaire performed well when used in a group of children with sickle cell disease. It differentiated children with sickle cell disease from those without disease and was reliable. In addition, it was feasible and showed no floor effects and a smaller ceiling effect than what has been shown in healthy children and in children with other chronic diseases.[22] This study provides the necessary psychometric properties of one of the most commonly used generic HRQL tools and supports the use of this questionnaire to measure HRQL in children with sickle cell disease. The brevity of the questionnaire and a child self report in children as young as 5 years of age make its use in a clinical setting possible.

As expected, the proxy-report of the PedsQL™ questionnaire differentiated between children with severe and mild sickle cell disease and those with no disease. In addition, the child self report showed worse physical HRQL in children with sickle cell disease compared to children without disease. This was expected given the a priori grouping of children with sickle cell disease based on physical symptoms. The child self-report questionnaire did not, however, distinguish between those with mild and severe sickle cell disease. Furthermore, children with sickle cell disease did not have significantly worse HRQL in the area of school, social and emotional functioning compared to their peers without sickle cell disease. This may be due to the non-specific nature of this generic questionnaire which may not capture the areas uniquely different such as self esteem issues secondary to delayed puberty or icterus that many of these children have. A disease specific companion module for this generic questionnaire would help address this limitation. However, our findings are similar to a prior study of the HRQL of urban school children.[27] This study showed that the HRQL of urban school children, who were largely African American, was quite low compared to healthy norms and were similar to children with a chronic disease.[22]

Prior to this study, we validated the CHQ and found it also performs well in children with sickle cell disease.[9] Similar to the PedsQL™ questionnaire, we found the CHQ was a valid and reliable tool to measure HRQL in children with sickle cell disease. The PedsQL™, however, includes self report to children as young as 5 years of age and is brief and thus easier to administer in our clinical setting. There are no other data on the performance of HRQL questionnaires in children with sickle cell disease.

The exploratory factor analysis extends our understanding of the underlying structure of the PedsQL™ questionnaire within our population. The “missing school” items on the PedsQL seem to be measuring physical limitations such as pain and low energy which is similar to what has been shown in other populations of children who are ill [25] but different than healthy populations.[22] In addition, other school items such as “having a hard time paying attention” or “keeping up with school work” loaded with social functioning items such as “getting along with others” which suggests that some school problems are related to the difficulty these children have with social functioning.

The emotional functioning items seemed to split and load highly into a social-emotional factor and physical-emotional factor. This may reflect both the difficulty children with sickle cell disease have socially such as getting along with peers and others not wanting to be friends with them and their emotional issues of feeling afraid or scared and sad or blue. In addition, their difficulty with some physical functioning items such as walking more than a block or doing chores loaded highly with emotional items such as feeling angry and

worrying about what will happen which suggests their physical limitations are partly related to emotional distress. A disease specific HRQL tool would be able to develop constructs such as pain and social and emotional issues more specific to sickle cell disease which would help address more distinctly the interplay of limitations related to this chronic illness.

This study was conducted in one geographic area and may not be generalizable to other regions. However, it is unlikely that our patients with sickle cell disease and children without disease from the urban clinic are inherently different from those in other areas. We are also limited by a smaller sample size for our factor analysis. Further testing on larger numbers of patients will be needed to confirm our findings. In addition, it is critical to determine if the measure is responsive, or sensitive to change over time, to further support the use of the PedsQL in this population and prior to using it to evaluate the effect of treatment interventions. Lastly, to better understand how therapies, such as hydroxyurea and chronic blood transfusions, affect the HRQL of children with sickle cell disease, further work will need to be done to determine treatment impact on HRQL of these children.

We showed that the PedsQL™ is a valid and reliable tool and was feasible to measure HRQL in children with sickle cell disease. Understanding the underlying psychometrics of another commonly used generic HRQL questionnaire, the PedsQL™ questionnaire, within children with sickle cell disease lays the groundwork for its use in future clinical research trials. The next step involves developing a disease specific sickle cell disease companion HRQL module for the PedsQL™ to increase the specificity of HRQL measurement in these children. In addition, further testing to determine whether the questionnaire is sensitive to changes over time in this population will be necessary prior to being able to interpret findings within a clinical trial.

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TABLE 1

Demographic Characteristics of Children With and Without Sickle Cell Disease

	Children with Sickle Cell Disease n (%)	Children without Sickle Cell Disease n (%)	p-value
n	104	74	
Age, median (years)	10.0	7.0	0.014[W]
Gender, female	52 (50.0)	42 (56.8)	0.374
Race[†, ‡]			<0.001
Black or African-American	98 (94.2)	58 (78.4)	
Asian or Native Hawaian/other Pacific Islander	0 (0.0)	2 (2.8)	
White	0 (0.0)	5 (6.8)	
Other	1 (1.0)	6 (8.1)	
Unknown	0 (0.0)	1 (1.4)	
Medical co-morbidities[†]			
Asthma	20 (29.0)	28 (39.4)	0.193
Chronic allergies	6 (8.7)	11 (15.3)	0.230
Chronic orthopaedic, bone or joint problems	9 (13.0)	3 (4.2)	0.059
Chronic rheumatic disease	1 (1.4)	0 (0.0)	0.489[F]
Diabetes	1 (1.4)	1 (1.4)	0.999[F]
Epilepsy	4 (5.8)	1 (1.4)	0.205[F]
Other chronic medical condition	2 (2.9)	5 (7.1)	0.443[F]
Mild Disease Status	49 (47.1)		
Stroke[*]	2		
Vaso-occlusive crises			
Hospitalized for crisis < 3 times in last 3 years	19		
Severe Disease Status	55 (52.9)		
Stroke	12		
Acute Chest Syndrome	40		
Recurrent Priapism	2		
Vaso-occlusive crises			
Hospitalized for crisis < 3 times in last 3 years	10		
Hospitalized for crisis ≥ times in last 3 years	33		
Phenotype			
Hb SS	66 (63.5)		
Hb SC	26 (25.0)		
Hb $S\beta^+$ thalassemia	9 (8.7)		
Hb $S\beta^0$ thalassemia	1 (1.0)		

	Children with Sickle Cell Disease n (%)	Children without Sickle Cell Disease n (%)	p-value
Other	2 (1.9)		

† Some data missing

‡ Based on United States Census classification and reflect parent report based on the following choices: White, Black, Native Hawaiian or Other Pacific Islander, Asian, American Indian or Alaskan native, Other or Unknown.

F p-value from Fisher's Exact Test

W p-value from Wilcoxon Rank Sum Test

* One subject with perinatal stroke, one subject with stroke secondary to meningitis

TABLE 2

Floor/Ceiling Effects and Internal Consistency Reliability of the PedsQL Parent Proxy-Report and Child Self-Report in Children with Sickle Cell Disease

PARENT PROXY-REPORT			
Scale	**n**	**% Floor / % Ceiling**	**Cronbach's α**
Total Score	104	0.0 / 4.8	0.930
Psychosocial Health*	104	0.0 / 6.7	0.887
Physical Health*	104	0.0 / 10.6	0.905
Emotional Functioning	104	0.0 / 15.4	0.813
Social Functioning	104	1.0 / 14.4	0.768
School Functioning	97	1.0 / 12.4	0.829
CHILD SELF-REPORT			
Scale	**n**	**% Floor / % Ceiling**	**Cronbach's α**
Total Scale Score	78	0.0 / 1.3	0.903
Psychosocial Health*	78	0.0 / 2.6	0.879
Physical Health*	78	0.0 / 6.4	0.787
Emotional Functioning	78	0.0 / 12.8	0.733
Social Functioning	77	0.0 / 19.5	0.807
School Functioning	77	0.0 / 3.9	0.73

* Psychosocial Health represents Psychosocial Health Summary Score and Physical Health represents Physical Health Summary Score

TABLE 3

Comparison of Median HRQL for Children with and without Sickle Cell Disease based on PedsQL Parent Proxy-Report and Child Self-Report

	Children without Sickle Cell Disease			Children with Sickle Cell Disease	
Scale	**n**	**Median (IQR)**	**n**	**Median (IQR)**	**p†**
PARENT PROXY-REPORT					
Total Scale Score	74	80.7 (58.7, 92.4)	104	67.4 (50.0, 83.5)	**0.006**
Psychosocial Health*	74	75.0 (56.7, 91.7)	104	68.1 (52.5, 82.5)	**0.041**
Physical Health*	74	87.5 (56.3, 96.9)	104	68.8 (50.0, 87.5)	**0.006**
Emotional Functioning	74	75.0 (55.0, 90.0)	104	72.5 (60.0, 90.0)	0.797
Social Functioning	74	86.3 (60.0, 100.0)	104	75.0 (55.0, 90.0)	**0.026**
School Functioning	69	66.7 (50.0, 90.0)	97	55.0 (40.0, 70.0)	**0.006**
CHILD SELF-REPORT					
Total Scale Score	40	75.5 (64.1, 81.0)	78	68.3 (53.3, 79.3)	0.234
Psychosocial Health*	40	71.7 (55.8, 79.2)	78	65.8 (50.0, 83.3)	0.661
Physical Health*	40	81.3 (71.9, 93.8)	78	68.8 (56.3, 81.3)	**0.045**
Emotional functioning	40	70.0 (45.0, 82.5)	78	65.8 (55.0, 85.0)	0.673
Social functioning	40	80.0 (62.5, 90.0)	77	80.0 (55.0, 95.0)	0.673
School functioning	40	65.8 (57.5, 77.5)	77	56.3 (40.0, 75.0)	0.134

†FDR adjusted p-values based on Wilcoxon Rank-Sum Test

IQR – Interquartile Range

*Psychosocial Health represents Psychosocial Health Summary Score and Physical Health represents Physical Health Summary Score

TABLE 4

Median Summary and Scale Scores for Children with Sickle Cell Disease by Disease Severity

	Mild Disease		Severe Disease		
Scale	**n**	**Median (IQR)**	**n**	**Median (IQR)**	**p†**
PARENT PROXY-REPORT					
Total Scale Score	49	72.8 (59.8, 88.0)	55	60.7 (47.8, 73.8)	**0.002**
Psychosocial Health*	49	71.7 (61.7, 87.5)	55	65.0 (46.7, 75.0)	**0.005**
Physical Health*	49	78.6 (62.5, 93.8)	55	59.4 (40.6, 78.1)	**0.001**
Emotional functioning	49	75.0 (65.0, 90.0)	55	68.8 (55.0, 85.0)	0.064
Social functioning	49	75.0 (65.0, 95.0)	55	70.0 (50.0, 85.0)	0.069
School functioning	44	63.8 (50.0, 91.7)	53	45.0 (35.0, 60.0)	**0.002**
CHILD SELF-REPORT					
Total Scale Score	30	68.9 (54.5, 79.3)	48	66.8 (52.8, 80.4)	0.890
Psychosocial Health*	30	70.0 (48.1, 85.0)	48	65.0 (52.5, 85.0)	0.890
Physical Health*	30	73.4 (62.5, 81.3)	48	67.2 (50.0, 82.8)	0.890
Emotional functioning	30	70.0 (55.0, 80.0)	48	65.0 (52.5, 85.0)	0.890
Social functioning	29	75.0 (50.0, 95.0)	48	80.0 (57.5, 95.0)	0.890
School functioning	30	60.0 (45.0, 80.0)	47	50.0 (40.0, 75.0)	0.890

† FDR adjusted p-values based on Wilcoxon Rank-Sum Test

IQR - Interquartile Range

* Psychosocial Health represents Psychosocial Health Summary Score and Physical Health represents Physical Health Summary Score

TABLE 5

Promax Rotated Factor Loadings for PedsQL Parent Proxy-Report in Children with Sickle Cell Disease (Ages 5–18)

	Factor	Factor	Factor	Factor	Factor
Scale / Item	**1**	**2**	**3**	**4**	**5**
Physical functioning					
Hard to walk > 1 block	**0.59**	**−0.08**	**−0.01**	**0.01**	**0.43**
Hard to run	**0.81**	**−0.11**	**0.09**	**−0.07**	**0.22**
Hard to do sports or exercise	**0.75**	**−0.03**	**0.21**	**0.11**	**−0.01**
Hard to lift heavy things	**0.77**	**0.09**	**0.12**	**−0.08**	**−0.06**
Hard to take bath/shower	**0.07**	**0.04**	**−0.01**	**0.06**	**0.79**
Hard to do chores around house	**0.15**	**−0.15**	**0.13**	**0.16**	**0.66**
Hurt or ache	**0.18**	**−0.01**	**0.78**	**−0.05**	**−0.08**
Have low energy	**0.30**	**−0.21**	**0.64**	**0.07**	**0.10**
Emotional functioning					
Feel afraid or scared	**−0.02**	**0.71**	**0.37**	**−0.06**	**−0.08**
Feel sad or blue	**0.19**	**0.73**	**0.24**	**−0.08**	**−0.09**
Feel angry	**−0.15**	**0.56**	**0.09**	**−0.02**	**0.55**
Trouble sleeping	**0.07**	**0.08**	**0.46**	**0.02**	**0.34**
Worry about what will happen	**0.00**	**0.49**	**0.04**	**−0.11**	**0.46**
Social functioning					
Trouble getting along w/ peers	**−0.11**	**0.08**	**0.19**	**0.59**	**0.21**
Others don't want to be friends	**0.03**	**0.75**	**−0.17**	**0.19**	**0.07**
Teased	**0.00**	**0.79**	**−0.12**	**0.18**	**−0.02**
Doing things other peers do	**0.62**	**0.49**	**−0.15**	**−0.07**	**0.12**
Hard to keep up when play with others	**0.73**	**0.21**	**−0.12**	**0.24**	**−0.12**
School functioning					
Hard to concentrate	**0.02**	**−0.02**	**0.02**	**0.82**	**0.17**
Forget things	**0.08**	**0.08**	**0.13**	**0.79**	**−0.29**

	Factor	Factor	Factor	Factor	Factor
Scale / Item	**1**	**2**	**3**	**4**	**5**
Trouble keeping with schoolwork	**0.20**	**0.00**	**−0.08**	**0.71**	**0.19**
Miss school .not well	**0.01**	**0.15**	**0.79**	**−0.06**	**0.13**
Miss school .doctor appointment	**−0.26**	**0.12**	**0.65**	**0.38**	**0.02**
Eigen Values	8.94	2.53	1.68	1.52	1.18
Percent Variance	38.9%	11.0%	7.3%	6.6%	5.1%

Total variance explained = 68.9%

Highlighted cells denote factor loadings > 0.40

TABLE 6

Promax Rotated Factor Loadings for PedsQL Patient Self-Report in Children with Sickle Cell Disease (Ages 5−18)

	Factor	Factor	Factor	Factor	Factor	Factor
Scale / Item	**1**	**2**	**3**	**4**	**5**	**6**
Physical functioning						
Hard to walk > 1 block	**0.18**	**0.37**	**−0.11**	**0.33**	**0.16**	**−0.40**
Hard to run	**−0.10**	**0.43**	**0.35**	**0.38**	**0.06**	**−0.20**
Hard to do sports or exercise	**−0.17**	**0.55**	**0.27**	**0.27**	**−0.09**	**−0.09**
Hard to lift heavy things	**0.11**	**0.56**	**−0.01**	**−0.35**	**0.49**	**0.11**
Hard to take bath/shower	**0.13**	**0.03**	**0.04**	**0.11**	**0.01**	**0.75**
Hard to do chores around house	**−0.19**	**0.17**	**0.09**	**0.07**	**0.78**	**0.18**
Hurt or ache	**0.05**	**0.86**	**−0.22**	**0.05**	**0.04**	**0.02**
Have low energy	**−0.09**	**0.62**	**0.08**	**0.22**	**0.13**	**0.03**
Emotional functioning						
Feel afraid or scared	**0.67**	**−0.05**	**−0.04**	**0.28**	**−0.10**	**0.22**
Feel sad or blue	**0.47**	**0.02**	**0.11**	**0.35**	**0.14**	**−0.08**
Feel angry	**0.28**	**−0.08**	**0.00**	**−0.02**	**0.68**	**−0.20**
Trouble sleeping	**0.47**	**−0.15**	**0.53**	**0.00**	**0.01**	**0.15**
Worry about what will happen	**0.03**	**−0.08**	**0.11**	**0.70**	**0.19**	**0.25**
Social functioning						
Trouble getting along w/ peers	**0.74**	**−0.11**	**0.08**	**0.13**	**0.15**	**0.07**
Others don't want to be friends	**0.33**	**0.12**	**−0.12**	**0.70**	**−0.28**	**0.07**
Teased	**0.66**	**−0.07**	-0.30	**0.14**	**0.30**	**0.07**
Doing things other peers do	**0.75**	**0.22**	**0.13**	**−0.03**	**−0.19**	**−0.10**
Hard to keep up when play with others	**0.73**	**0.17**	**0.16**	**0.05**	**0.01**	**0.02**
School functioning						
Hard to concentrate	**0.07**	**−0.21**	**0.83**	**0.02**	**0.20**	**−0.03**
Forget things	**0.44**	**0.15**	**0.49**	**−0.16**	**0.08**	**−0.14**

	Factor	Factor	Factor	Factor	Factor	Factor
Scale / Item	**1**	**2**	**3**	**4**	**5**	**6**
Trouble keeping with schoolwork	**0.00**	**0.18**	**0.69**	**0.03**	**−0.21**	**0.20**
Miss school –not well	**0.19**	**0.71**	**0.00**	**−0.17**	**−0.08**	**0.22**
Miss school –doctor appointment	**0.03**	**0.34**	**0.03**	**0.28**	**0.15**	**0.47**
Eigen Values	7.48	2.18	1.57	1.34	1.23	1.19
Percent Variance	32.5%	9.5%	6.8%	5.8%	5.3%	5.2%

Total variance explained = 65.1%

Highlighted cells denote factor loadings > 0.40