

Quality of Life in Childhood Migraines: Clinical Impact and Comparison to Other Chronic Illnesses

Scott W. Powers, PhD*§; Susana R. Patton, PhD*; Kevin A. Hommel, PhD*; and Andrew D. Hershey, MD, PhD†§

ABSTRACT. *Objective.* Despite the high prevalence of headaches in youths, quality of life (QOL) has not been well examined. We examined QOL in a clinical sample of children with headaches and compared it with children with other chronic diseases.

Methods. A survey study was conducted of 572 consecutive patients (mean age, 11.4 ± 3.6 years) who presented with headaches to a children's headache center. Children and parents completed the Pediatric Quality of Life Inventory, Version 4.0 and a standardized headache assessment. Results were compared with established norms for healthy and chronically ill children.

Results. Most patients (99%) had a clinical diagnosis of migraine: 85% met the International Headache Society migraine criteria, and 40% had chronic daily headaches. Total Pediatric Quality of Life Inventory, Version 4.0 score was lower for the entire group (73.1 ± 14.4) compared with healthy norms (83.0 ± 14.8) and lowest for children with chronic daily headaches (70.5 ± 15.5). The impact on QOL of children with migraine was similar to that of children with arthritis and cancer.

Conclusions. QOL of children with headaches is significantly affected by their health condition. The impact of headaches on QOL is similar to that found for other chronic illness conditions, with impairments in school and emotional functioning being the most prominent. *Pediatrics* 2003;112:e1–e5. URL: <http://www.pediatrics.org/cgi/content/full/112/1/e1>; *pediatric, adolescents, headache, disability, headache treatment, migraine.*

ABBREVIATIONS. IHS, International Headache Society; QOL, quality of life; PedsQL 4.0, Pediatric Quality of Life Inventory, Version 4.0; CDH, chronic daily headache.

Headaches in children and adolescents are a common problem.¹ The majority of children who experience recurrent headaches have migraines. Prevalence estimates indicate that up to 10.6% of children ages 5 to 15 years² and 28% of adolescents between the ages of 15 and 19 years³ experience migraine headaches. Migraines have historically been diagnosed using clinical impression. To address the limitations of this method, the International Headache Society (IHS) developed defined

criteria for headache diagnosis.⁴ These criteria, however, have been criticized for incompletely diagnosing childhood migraine disorders.^{5,6} Revisions have been suggested and may be incorporated into the next update of the criteria, but currently the diagnosis of childhood migraine relies on both the IHS criteria and a clinical impression.^{7,8}

Recurrent headaches have an impact on a child's life in a number of ways, including school absences and reduction in performance, decreased home and family interactions, and decreased socialization with peers. Using the Pediatric Migraine Disability Assessment (PedMIDAS), a questionnaire that assesses disability in school, home, and play activities, children reported moderate to severe disability.⁹ Related to children's objective disability is their subjective evaluation of disability and the impact of headaches on their quality of life (QOL).

Health-related QOL is a multidimensional concept that reflects the impact of disease and treatment on a patient's subjective evaluation of his or her functioning and emotional well-being.^{10–12} QOL is an important construct to assess, especially as it relates to treatment effectiveness and patient satisfaction.^{13,14} There is little programmatic research investigating QOL as an outcome measure in pediatric chronic illness conditions.^{13,15} This is primarily because of a lack of appropriate and practical measures of QOL for children. The Pediatric Quality of Life Inventory, Version 4.0 (PedsQL 4.0) is a generic measure of QOL, which has been developed for use with children from age 2 to 18 years and allows a comparison of QOL effects across acute and chronic health conditions and with healthy children.¹⁶ It allows for child self-report and parent-proxy report of QOL. This measure has been validated for use with children with cancer, rheumatoid disease, diabetes, and orthopedic conditions.¹⁶ Results have indicated that children's QOL is adversely affected because of an acute or chronic health condition and that QOL is differentially affected by a child's health condition.¹⁶

There is little research examining the QOL of children with migraine headaches despite the high prevalence of this disorder. The few available studies have consistently found headaches to have an adverse impact on children's QOL. In a study of 20 headache patients ages 9 to 18 years, children experienced more somatic complaints, lower general well-being, and more physiologic anxiety and were less communicative than matched healthy control

From the Divisions of *Psychology and †Neurology, Cincinnati Children's Hospital Medical Center, §University of Cincinnati College of Medicine, Cincinnati, Ohio.

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Reprint requests to (S.W.P.) Headache Center, Division of Psychology, Cincinnati Children's Hospital, MLC: D-3015, 3333 Burnet Ave, Cincinnati, OH 45229-3039. E-mail: Scott.Powers@cchmc.org
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subjects.¹⁷ Adolescents ($n = 159$) with headaches reported worse psychological functioning, more physical symptoms, a poorer functioning status, and less satisfaction with life and health than healthy adolescents.¹⁸ No research has examined the QOL of young children with headaches or evaluated the impact of headaches on QOL in comparison with other chronic illness conditions. Advances in pharmacological and biobehavioral treatments for headache over the last several years make the assessment of QOL in children essential. The present study reports on the QOL of a large clinical sample of children with headaches. Also, QOL in children with headaches is compared with data for a number of other pediatric disorders, including arthritis and cancer.

METHODS

Subjects

Children were referred by their primary care physician to the Headache Center at Cincinnati Children's Hospital Medical Center. For the children between the ages of 5 and 18 years, data were collected from both children and parents. For the children between 2 and 4 years old, data were collected from the parents only. Families completed a detailed questionnaire describing features of their child's headaches and general health as well as the age-appropriate version of the PedsQL 4.0 at the child's initial appointment. These data were reviewed with families during their clinic visit to ensure accuracy and to assist in headache diagnosis and treatment. Clinical diagnoses and a diagnosis using the IHS criteria⁴ were obtained on the basis of medical history and neurologic examination. Families who attend the Headache Center agreed for information collected during clinical care to be used for research purposes and were informed that all data are presented as group findings with no individual identifiers. A generally uniform and effective multidisciplinary treatment program is provided by the Headache Center.^{19–28}

The normative comparison group ($N = 730$) included healthy children who were assessed either in physicians' offices during well-child checks or by telephone and whose parents did not report the presence of a chronic health condition.¹⁶ The comparison group of children with cancer ($N = 339$) included individuals with acute lymphocytic leukemia (50%), brain tumor (7%), non-Hodgkin's lymphoma (6%), Hodgkin's lymphoma (3%), Wilm's tumor (6%), and other cancers (28%).²⁹ The comparison group of children with rheumatologic disease ($N = 271$) included individuals with juvenile rheumatoid arthritis (30%), systemic lupus erythematosus (8%), juvenile fibromyalgia (13%), spondyloarthritis (11%), and other rheumatic diseases (38%).³⁰

Measures

On the Headache Center intake questionnaire, patients indicated the average severity of their headaches using a 10-point scale (10 = most severe pain). The duration of headache pain was reported according to the duration of their shortest, longest, and average headaches. Headache frequency was reported as the average number of headache days that occurred per month during the past 3 months. Diagnosis was made using both clinical impression and the IHS criteria. The IHS criteria for migraine without aura are having at least 5 headaches that last untreated between 2 and 48 hours for children younger than 15 years or 4 to 72 hours if older than 15 years, having 2 of 4 features (pulsatile quality, focal location, aggravated by physical activity, and moderate to severe pain), having associated symptoms of nausea and/or vomiting or photophobia and phonophobia, and having a normal neurologic examination and the headache not associated with a secondary cause.⁴

The PedsQL 4.0^{16,31} is a 23-item measure that takes ~5 minutes to complete and evaluates children's QOL in 4 areas of functioning: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items). The PedsQL 4.0 has 2 forms: a child self-report form and a parent-report form. The child self-report includes 3 age ranges: young child (5–7 years), child (8–12 years), and adolescent (13–18

years). The parent report includes an additional toddler (2–4 years) age range. To complete the PedsQL 4.0, respondents are asked to indicate how much of a problem each item has been during the past month. For the child self-report (8–18 years) and the parent-report forms, respondents use a 5-point Likert scale to rate the item severity (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). However, for the younger children (5–7 years), a simplified 3-point Likert scale, anchored with a happy and a sad face, is used (0 = not at all a problem; 2 = sometimes a problem; 4 = a lot of a problem).

The PedsQL 4.0 is designed to yield a total QOL score; 2 summary scores—the Physical Health Summary Score and the Psychosocial Health Summary Score—and 3 subscale scores—Emotional, Social, and School Functioning—(yielding a total of 1 total score and 5 summary/subscale scores). To obtain a total score, the items are reverse-scored and transformed to a 0 to 100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). The 3-point Likert scale is scored 0 = 100, 2 = 50, and 4 = 0. The Physical Health Summary Score (8 items) is the same as the Physical Functioning Subscale. The Psychosocial Health Summary Score (15 items) is a mean score (computed as the sum of the items divided by the number of items answered in the Emotional, Social, and School Functioning Subscales).¹⁶ Scale scores are computed as the sum of the items divided by the number of items answered.¹⁶ Previous research with the PedsQL 4.0 demonstrates good internal consistency (α child = 0.88, α parent = 0.90) and construct validity in healthy children and children with acute or chronic illnesses.^{16,31}

RESULTS

Demographics and Headache Parameters

This study evaluated 572 children (aged 2–4: 14; aged 5–7: 72; aged 8–12: 257; aged 13–18: 229). Ninety-nine percent had a clinical diagnosis of migraine; 85% met the IHS criteria for migraine or migraine with aura, a difference that reflects the sensitivity of the IHS criteria among children.^{3,6–8} Forty percent of children met criteria for chronic daily headaches (CDHs).^{19,32} Children's mean age at study enrollment was 11.4 ± 3.6 years. In contrast, the mean age of onset for headaches was 8.1 ± 3.6 years. The sample was nearly split on gender (316 girls versus 256 boys). The racial distribution of children was as follows: 509 white, 56 black, and 7 other. Children's mean headache frequency was 13.4 ± 10.5 headaches per month. The mean severity of headaches was 6.7 ± 1.8 . The mean duration of children's typical headaches was 8.9 ± 13.0 hours.

PedsQL 4.0 Scores

Table 1 presents means and standard deviations for each subscale of the PedsQL 4.0 for children with clinical migraine, IHS migraine, and CDH compared with the healthy children population scores¹⁶ for all ages. Internal consistency reliability coefficients³³ are presented for the headache samples only. Parallel descriptive data are presented for parent-report scales in Table 2 along with internal consistency reliability data for the headache samples.

Comparisons With Healthy Children

One sample t test found that children with migraine headaches reported lower QOL than children in the healthy comparison sample (PedsQL 4.0 Total Score) ($t[1,554] = -16.15, P < .01$). Parent report of QOL for children in the headache group was also significantly lower than parent report in the healthy sample (PedsQL 4.0 Total Score) ($t[1,567] = -23.89,$

TABLE 1. PedsQL 4.0 Child Self-Report (All Ages)

	Healthy (n = 730)		Headache (n = 572)		IHS (n = 486)		CDH (n = 230)	
	Mean ± SD	Mean ± SD	α*	Mean ± SD	α*	Mean ± SD	α*	
Total score	83.0 ± 14.8	73.1 ± 14.4	0.89	73.0 ± 14.1	0.88	70.5 ± 15.5	0.89	
Physical Health	84.4 ± 17.3	76.2 ± 17.9	0.82	76.2 ± 17.6	0.81	72.0 ± 19.3	0.83	
Psychosocial Health	82.4 ± 15.5	71.5 ± 15.4	0.84	71.3 ± 15.3	0.84	69.6 ± 16.5	0.86	
Emotional Functioning	80.9 ± 19.6	67.3 ± 20.1	0.72	67.2 ± 20.3	0.73	64.3 ± 20.9	0.74	
Social Functioning	87.4 ± 17.2	83.2 ± 17.6	0.77	83.2 ± 17.8	0.78	83.5 ± 18.5	0.80	
School Functioning	78.6 ± 20.5	63.9 ± 20.5	0.77	63.4 ± 20.1	0.75	60.9 ± 21.5	0.78	

SD indicates standard deviation.

* The child self-report scale met the minimum reliability standard of 0.70²⁴ for group comparisons across subscales for all ages.

TABLE 2. PedsQL 4.0 Parent Report (All Ages)

	Healthy (n = 730)		Headache (n = 572)		IHS (n = 486)		CDH (n = 230)	
	Mean ± SD	Mean ± SD	α*	Mean ± SD	α*	Mean ± SD	α*	
Total score	87.6 ± 12.3	73.2 ± 14.4	0.89	72.9 ± 14.1	0.89	70.5 ± 15.7	0.91	
Physical Health	89.3 ± 16.3	76.7 ± 17.6	0.83	76.3 ± 17.1	0.82	73.2 ± 18.8	0.84	
Psychosocial Health	82.4 ± 15.5	71.3 ± 15.6	0.86	71.1 ± 15.6	0.86	68.9 ± 17.1	0.89	
Emotional Functioning	82.6 ± 17.5	66.3 ± 20.1	0.76	66.2 ± 20.2	0.77	62.6 ± 21.0	0.79	
Social Functioning	91.6 ± 14.2	82.6 ± 18.1	0.81	82.6 ± 18.3	0.81	82.0 ± 19.7	0.84	
School Functioning	85.5 ± 17.6	64.8 ± 20.6	0.78	64.4 ± 20.3	0.78	62.2 ± 21.4	0.79	

* The parent-report scale met the minimum reliability standard of 0.70²⁴ for group comparisons across subscales for all ages.

$P < .01$). Figures 1 and 2 show comparisons of QOL for children with headache and healthy norms according to child and parent report, respectively. A Bonferroni correction ($P < .001$) was applied to analyses comparing QOL in healthy children with children with clinical migraine, IHS migraine, and CDHs. Across all parent and child report scores on the PedsQL 4.0, significant differences remained for children with headaches versus healthy children.

Parent/Child Response Concordance

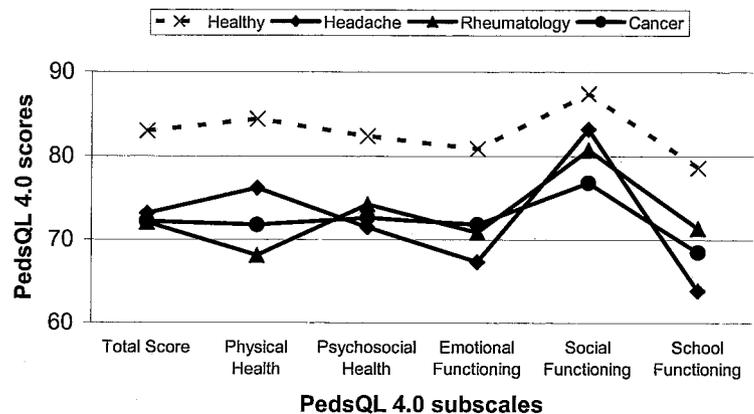
Bivariate correlation analyses were conducted to examine the relationship between parent and child responses on the PedsQL 4.0 for the Total Score and the 5 summary/subscale scores. All correlations were statistically significant ($P < .01$) and ranged from 0.62 to 0.75. Parent-report and child self-report correlations were in the medium to large effect size range.³⁴

Comparisons With Children With Chronic Illness

The present sample of headache patients demonstrated PedsQL 4.0 scores that were similar to other chronic disease groups.^{29,30} According to child self-

report data, statistical comparisons of QOL for children with headaches and children with rheumatoid conditions or cancer found no differences in total QOL scores. Differences were found when comparing children on subscale scores ($P < 0.002$). Children with headaches reported higher physical functioning and higher social functioning than children with rheumatoid conditions or cancer. They reported lower school functioning and emotional functioning than children with rheumatoid conditions or cancer. For parent report data, no differences were found when total QOL scores were compared. Differences were observed for individual subscale scores ($P < 0.002$). Similar to child self-report, parents of children with headaches reported higher physical functioning and higher social functioning than parents of children with rheumatoid conditions or cancer. Parents of children with headaches reported lower school functioning and emotional functioning when compared with parents of children with rheumatoid disease. However, there were no differences in these subscale scores when parents of children with headaches were compared with parents of children with cancer. Figures 1 and 2 present data across these 3

Fig 1. PedsQL 4.0 child self-report scores across disease groups. Data presented for healthy children, children with headaches, and children with rheumatoid diseases and cancer. The full range of the PedsQL 4.0 is 0 to 100. This figure uses a more limited range for presentation.



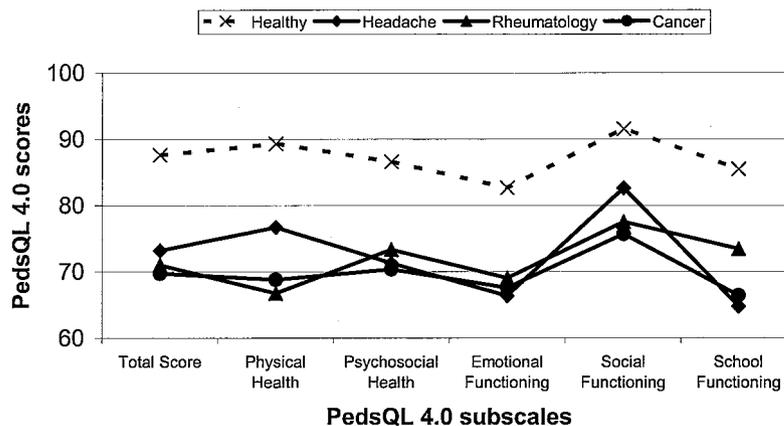


Fig 2. PedsQL 4.0 parent-report scores across disease groups. Data presented for healthy children, children with headaches, and children with rheumatoid diseases and cancer. The full range of the PedsQL 4.0 is 0 to 100. This figure uses a more limited range for presentation.

disease groups for child self-report and parent-report data, respectively.

DISCUSSION

Children's QOL is an emerging area of research with potential relationships to treatment effectiveness and families' satisfaction with their care.^{13,14} Previous research investigating QOL in children with headaches has used standardized self-report measures that evaluate the impact of recurrent headaches on children's psychological functioning or a disease-specific measure of QOL.^{17,18} The use of standardized self-report measures can evaluate symptoms that are related to QOL but cannot offer an estimate of the impact of recurrent headaches on other important areas of functioning (eg, school, social activities).¹³ Disease-specific QOL measures preclude the ability to compare children's QOL scores across chronic illness conditions, which limits the scope of these studies.¹³ The PedsQL 4.0 offers a practical measure of QOL, which can be administered in a busy clinic setting and offers the opportunity to compare QOL across disease conditions.

Findings of this study demonstrate that the PedsQL 4.0 can be an effective measure of QOL for children with migraine, a common yet understudied disorder of childhood. This measure demonstrates adequate internal consistency and interrater reliability between parents and children. We found that children's QOL is adversely affected in all areas of functioning when compared with norms for healthy children. Specific areas of functional impairment were noted on the Psychosocial Health Factor Score and the School Functioning subscale. Comparisons made within the headache sample found that children with CDH reported the greatest impairment compared with healthy norms. Notable areas of impairment included the School Functioning subscale, Emotional Functioning subscale, and Physical Health Factor Score. Children who met IHS criteria for migraine also reported impaired QOL with specific deficits noted in the common areas of School Functioning, Emotional Functioning, and the Psychosocial Health Factor Score. Children's QOL scores were comparable between children who met a clinical diagnosis of migraine versus those who also met IHS criteria.

The PedsQL 4.0 scores of children with migraine were compared with scores obtained from children with other chronic illness conditions. To date, there are no studies that specifically compare the QOL of children who have headaches with children who have other chronic health conditions. However, previous research with adults with migraine found them to report more impairment on measures of pain, role disability, and social functioning than adults with hypertension, osteoarthritis, and type 2 diabetes.³⁵ We found that children with migraines reported a similar pattern of disability as children with rheumatoid disease or cancer. When compared statistically, children with migraine self-reported more impairment in School Functioning and Emotional Functioning than children in the other chronic illness groups. Because of the unpredictable nature of migraine headaches, families must react to headache episodes with little advanced preparation. Without advance warning, it is difficult to "plan" for school absences by collecting classroom lessons or homework assignments in advance. On returning to school, children with headaches may spend a significant amount of time completing old assignments while learning new material. This burden may contribute to parents' and children's perception of greater impairment in school functioning. Their emotional functioning may also suffer if migraines are perceived as unpredictable and severe. These comparisons help to provide a context for understanding the impact of headaches on children's QOL and suggest that children with migraines can experience comparable or more severe impairment as children with other serious chronic illness conditions.

Although the current sample is representative of the population of children seen at the Cincinnati Children's Headache Center and the Cincinnati metropolitan area, additional research is needed with other samples to determine the generalizability of these findings. It will be important to evaluate other variables such as the type of health care facility, geographical location, family ethnicity, and other demographic characteristics. QOL was measured by both self-report and parent report, showing agreement across sources. However, self- and other report methods are vulnerable to subject bias, and objective measures of the impact of headaches on children's

daily life should be added in future investigations. Although the PedsQL 4.0 provides a valid and practical means of evaluating QOL in children and families within a busy clinic setting, it does not provide a complete assessment of the many specific psychosocial variables that may compose the QOL construct; variables such as family functioning, depression, and social support would be better assessed through multiple measures. This study suggests that future investigation of QOL in children with headaches could help to optimize evaluation and management of this common health problem. Such investigation should incorporate general measures of QOL and disease-specific measures (eg, Pediatric Migraine Disability Assessment [PedMIDAS]),⁹ as this combination approach to the assessment of QOL is becoming the standard for the field.^{13,29,30}

CONCLUSIONS

Headaches are common in children and adolescents. This report validates the use of PedsQL 4.0 in migraine patients who are aged 2 to 18. It further demonstrates that headaches in children and adolescents affect QOL at levels equivalent to or greater than other chronic illnesses of childhood—illnesses that are often considered more severe and debilitating than “having headaches.” Pediatricians often see children and adolescents with migraine. Knowing that the headaches can significantly affect QOL could lead to better headache evaluation and management for this very common condition of childhood.

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