

Health-Related Quality of Life in Children and Adolescents with Cyclic Vomiting Syndrome: A Comparison with Published Data on Youth with Irritable Bowel Syndrome and Organic Gastrointestinal Disorders

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Objective To evaluate health-related quality of life (HRQoL) in children with cyclic vomiting syndrome (CVS) and to compare child self-reports with those of their parents and with published reports of children with irritable bowel syndrome (IBS), children with organic gastrointestinal disorders, and a healthy control group.

Study design Sixty-eight children aged 5-18 years with CVS confirmed in a gastroenterology clinic completed the Pediatric Quality of Life Inventory (PedsQL). Eighty-two parents completed the parent-proxy PedsQL for children aged 2-18 years. These results were compared with published data for children with IBS, organic gastrointestinal disorders, and a healthy control group using ANOVA. Intraclass correlation was used to evaluate concordance between child and parent reports of HRQoL.

Results HRQoL reported on the PedsQL by children with CVS was lower than that reported by children with IBS ($P < .01$) and healthy controls ($P < .001$), but did not differ from that reported by children with organic gastrointestinal disorders. Children with CVS also had lower HRQoL compared with healthy controls by parent-proxy report on the PedsQL ($P < .001$). Correlations between HRQoL reports by parents and children were moderate to good (intraclass correlation coefficients, 0.504-0.805; $P < .01$). Duration of CVS episodes, delay in CVS diagnosis, and number of school days missed due to CVS were associated with lower parent-rated HRQoL ($P = .01$).

Conclusion Children with CVS reported lower HRQoL compared with those with IBS, and both parents and children reported lower HRQoL compared with healthy controls. Parent and child ratings of HRQoL converged. Improved recognition of CVS and school support might help mitigate the impact of CVS on HRQoL. (*J Pediatr* 2013;163:493-7).

Cyclic vomiting syndrome (CVS) is a debilitating disorder characterized by recurring, stereotypic episodes of high-intensity vomiting lasting hours to days and accompanied by symptoms of unrelenting nausea, retching, and severe abdominal pain. Most of the time between episodes, patients are typically healthy and engage in normal activities.¹ Although CVS is associated with intense vomiting, resulting in the need for intravenous hydration in 58% of affected children, the lack of an identified pathophysiology has led to its classification as a functional disorder.¹

CVS is diagnosed either by the consensus criteria developed by international multidisciplinary committees^{2,3} or by International Classification of Headache Disorders, 2nd edition criteria.⁴ Typically, an extensive diagnostic evaluation is conducted to exclude other serious medical causes that can mimic its presentation, including intestinal malrotation, hydronephrosis, metabolic disorders, and increased intracranial pressure. Although CVS has a prevalence of approximately 2% in school-aged children,⁵ poor recognition leads to an average delay in diagnosis of 2.5 years.⁶

To investigate health-related quality of life (HRQoL) in children with CVS, we evaluated patients referred to the CVS clinic in a children's hospital. Our primary aim was to evaluate HRQoL in children and adolescents with CVS. To accomplish this, we compared child self-reports with parent-proxy (parent hereinafter) reports and with published reports of children with a specific functional gastrointestinal disorder (irritable bowel syndrome [IBS]), children with organic gastrointestinal disorders (including inflammatory bowel disease), and a healthy control group.

Methods

A research associate identified participants at a specialty clinic for CVS that met weekly at a children's hospital. Children aged 2-18 years who met the International Consensus Criteria for CVS² as determined by a pediatric gastroenterologist,

CVS	Cyclic vomiting syndrome
HRQoL	Health-related quality of life
IBS	Irritable bowel syndrome
ICC	Intraclass correlation coefficient
PedsQL	Pediatric Quality of Life Inventory

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were invited to participate in the study. The diagnostic criteria included: (1) recurrent severe, discrete episodes of vomiting; (2) normal health between episodes; (3) duration of vomiting from hours to days; and (4) no apparent cause of vomiting, as well as supportive criteria of stereotypical and self-limited episodes. Children who did not speak English and those with a major medical or developmental disorder were excluded from the analysis. Demographic and medical information were collected by parent interview and review of the medical record.

Children aged 5-18 completed the age-appropriate Pediatric Quality of Life Inventory (PedsQL; Mapi Research Trust, Lyon, France) 4.0 Generic Core Scale,⁷ a 23-item measure that yields a total HRQoL score and subscale scores of Physical-, Emotional-, Social-, and School-related quality of life, as well as a composite Psychosocial measure comprising the Emotional, Social, and School domains. The PedsQL 4.0 versions for young children (5-7 years), children (8-12 years), and adolescents (13-18 years) were used. Both the total HRQoL score and the individual domain scores range from 0 to 100, with higher scores indicating better HRQoL.

Parents of children and adolescents aged 2-18 years completed the age-appropriate PedsQL for their child (preschool, age 2-4 years; young child, age 5-7; school-age child, age 8-12; adolescent, age 13-18). The PedsQL inventories are validated instruments with satisfactory internal reliability.^{8,9}

Comparison group data were derived from a study by Varni et al,¹⁰ which included children with IBS and organic gastrointestinal disorders (eg, inflammatory bowel disease, gastritis, fatty liver disease), and a healthy control group, including their caregivers. The hospital's Institutional Review Board approved this study as expedited research. Parents and children provided written consent/assent before participation.

Statistical analyses were performed with SPSS version 18.0 for Macintosh (IBM, Armonk, New York). One-way ANOVA was used to examine differences in HRQoL among children with CVS and the other 2 groups. The Bonferroni method was used for post hoc comparisons when the overall ANOVA result was significant. Effect sizes were calculated using the Cohen *d*, with 0.20 indicating a small effect size, 0.50 a moderate effect size, and 0.80 a large effect size. Intraclass correlation coefficients (ICCs) were used to evaluate agreement between children with CVS and their parents. ICC values were interpreted as 0.40, poor agreement; 0.41-0.60, moderate agreement; 0.61-0.80, good agreement; and 0.81 and higher, excellent agreement. Pearson correlation coefficients were used to evaluate demographic and CVS characteristics in relation to HRQoL. Missing data for any dependent variable were excluded from the analysis. The significance level was set at $P = .01$ to control for type 1 error.

Results

Eighty-five families participated in this study. Sixty-eight children aged 5-18 years completed the age-appropriate self-report version of the PedsQL (5-7 years, $n = 21$; 8-12

years, $n = 27$; 13-18 years, $n = 20$). Eighty-two parents of children aged 2-18 years completed the age-appropriate PedsQL for their child, covering 12 preschool-age children (age 2-4), 18 young children (age 5-7), 29 school-age children (age 8-12), and 23 adolescents (age 13-18). Data were collected over a 29-month period. The vast majority (82%) of eligible children with CVS were enrolled in the study. Of the 19 eligible children not enrolled, 6 declined to participate, 6 were missed in the clinic, and 5 were not enrolled for miscellaneous reasons (eg, illness during the clinic visit, no parent available for consent). There were no significant differences between enrolled participants and eligible participants not enrolled with regard to age, sex, or ethnicity (Table I).

Comparison of Child-Reported HRQoL with Published Data

The PedsQL demonstrated excellent internal consistency for school-age children's and adolescents' self reports (Cronbach $\alpha = 0.907-0.921$), whereas reliability was lower but still psychometrically acceptable (Cronbach $\alpha = 0.787$) for the young children's self-reports. The Social scale of the PedsQL differed significantly across age groups ($F = 7.80$; $df = 2, 65$; $P < .001$). A Bonferroni post hoc comparison found significantly lower Social scores for young children compared with adolescents (mean difference, 25.77; $P = .001$). The young children ranked their ability to do things that other children can do as their lowest-rated item in the Social domain (Social scale score, 43 vs 86 for adolescents). Overall, the lowest score in children with CVS across all age groups was in the School domain, whereas the highest score was in the Social domain averaged across age groups (Table II). The PedsQL total score and Psychosocial, Social, and School domain scores were significantly lower in children with CVS compared with those with IBS, another functional gastrointestinal disorder. There were no significant differences in self-reported HRQoL in children with CVS and those with organic gastrointestinal disorders. Children with CVS reported significantly lower HRQoL than healthy controls for the total HRQoL score and all domain scores. Effect sizes for these differences were moderate to large (0.68-1.33; Table III).

Table I. Patient characteristics

Characteristic	Value
Age, y, mean (SD)	9.8 (4.1)
Sex, n (%)	
Males	39 (46)
Females	46 (54)
Ethnic minority, n (%)	7 (8)
Annual number of CVS episodes, mean (SD)	8.6 (12.7)
Duration of CVS episodes, d, mean (SD) [median]	3 (2.8) [2]
Annual emergency department visits for CVS, mean (SD) [range]	1 (1.9) [0-12]
Time from symptom onset to visit, y, mean (SD)	4.5 (3.1)
Time from symptom onset to diagnosis of CVS, y, mean (SD)	2.20 (1.85)
Annual number of school days missed, mean (SD) [range]	11.5 (12.8) [0-60]

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