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Comparison of Caregiver- and Child-Reported Quality of Life in Children With Sleep-Disordered Breathing

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Abstract

Objective. Caregivers frequently report poor quality of life (QOL) in children with sleep-disordered breathing (SDB). Our objective is to assess the correlation between caregiver- and child-reported QOL in children with mild SDB and identify factors associated with differences between caregiver and child report.

Study Design. Analysis of baseline data from a multi-institutional randomized trial

Setting. Pediatric Adenotonsillectomy Trial for Snoring, where children with mild SDB (obstructive apnea-hypopnea index <3) were randomized to observation or adenotonsillectomy.

Methods. The Pediatric Quality of Life Inventory (PedsQL) assessed baseline global QOL in participating children 5 to 12 years old and their caregivers. Caregiver and child scores were compared. Multivariable regression assessed whether clinical factors were associated with differences between caregiver and child report.

Results. PedsQL scores were available for 309 families (mean child age, 7.0 years). The mean caregiver-reported PedsQL score was higher at 75.2 (indicating better QOL) than the mean child-reported score of 67.9 ($P < .001$). The agreement between caregiver and child total PedsQL scores was poor, with intraclass correlation coefficients of 0.03 (95% CI, −0.09 to 0.15) for children 5 to 7 years old and 0.21 (95% CI, 0.03-0.38) for children 8 to 12 years old. Higher child age and health literacy were associated with closer agreement between caregiver and child report.

Conclusion. Caregiver- and child-reported global QOL in children with SDB was weakly correlated, more so for young children. In pediatric SDB, child-perceived QOL may be poorer than that reported by caregivers. Further research is needed to assess whether similar trends exist for disease-specific QOL metrics.

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Sleep-disordered breathing (SDB) in children is characterized by upper airway obstruction and poor sleep. While polysomnography defines the severity of obstruction in children presenting with SDB, it does not quantify the impact of SDB on a child's health and well-being. Indeed, prior research has demonstrated a poor correlation between polysomnography measures such as the apnea-hypopnea index (AHI) and quality of life (QOL).[1,2] Even children with mild SDB can experience poor QOL as compared with healthy peers in terms of sleep disturbance, physical and emotional symptoms, and daytime function.[3,4] Thus, it is important to assess QOL in children who present for evaluation and management of SDB. Guidelines from the American Academy of Otolaryngology–Head and Neck Surgery now recommend that providers inquire about symptoms in children with SDB that may improve with treatment, though they do not mention asking children directly.[5]

QOL can be assessed with validated instruments, which include global assessments such as the Pediatric Quality of Life Inventory (PedsQL) and disease-specific assessments such as the Obstructive Sleep Apnea–18 (OSA-18).[4] Given the challenges associated with interviewing children and a lack of validated child-reported QOL instruments, most published QOL outcomes in pediatric obstructive sleep apnea are based on caregivers' observations of the impact of a disease on their children's lives. The underlying assumption is that caregivers accurately observe and interpret their children's experience of disease, yet the correlation between caregiver and child report is not well understood.[6] Prior studies examining the level of agreement between caregiver- and child-reported QOL in healthy and chronically ill children have demonstrated mixed results: some researchers have reported a poor correlation while others have found moderate to high agreement.[7] How children with SDB report their own QOL is not well understood and could provide an important additional perspective on disease impact and outcomes.

The PedsQL instrument can be used to survey caregiver- and child-reported QOL.[8] Our objective is to determine whether caregiver-reported QOL is similar to child-reported QOL in school-aged children who present with adenotonsillar hypertrophy and mild SDB. We aim to assess the degree of correlation between caregiver and child report and identify factors associated with discrepancies between caregiver and child report. Given that prior studies have shown mixed results about the level of agreement between caregiver- and child-reported QOL, we hypothesized that there would be a weak correlation between parent and child QOL scores and an improved correlation with older children.

Methods

Study Design

The Pediatric Adenotonsillectomy Trial for Snoring is an ongoing multicentered single-blind randomized controlled trial that recruited patients between 2016 and 2020. Children with mild SDB who met inclusion criteria were randomly assigned to adenotonsillectomy or watchful waiting, in accordance with our previously published protocol.[9] The studies were approved by the institutional review board at each site (Children's Hospital of Philadelphia, Children's Hospital of The King's Daughters, Cincinnati Children's Hospital Medical Center, University of Michigan Medical Center, University Hospitals Rainbow Babies and Children's Hospital, and University of Texas Southwestern Medical Center).

Inclusion Criteria

Eligible children had (1) tonsillar hypertrophy (Brodsky size ≥ 2 tonsils[10]; ie, tonsils obstructing at least 50% of the airway), (2) caregiver-reported snoring at least 3 nights a week, and (3) a baseline polysomnography that demonstrated mild SDB (obstructive AHI <3 and obstructive apnea index <1). Participants were excluded from the study if they had recurrent tonsillitis, a body mass index (BMI) z score ≥ 3 (morbid obesity), arterial oxyhemoglobin saturation <90% with obstructive events, severe comorbidities (eg, craniofacial anomalies, cerebral palsy, psychiatric disorders), and/or neurobehavioral delay. Children with attention-deficit/hyperactivity disorder were eligible for inclusion. Children in the Pediatric Adenotonsillectomy Trial for Snoring who completed the PedsQL at their baseline visit (ages, 5-12 years inclusive) were included in analysis.

Outcomes

The PedsQL is a validated instrument that measures global health-related QOL in children 5 to 18 years old.[7] Trained research assistants helped children complete the instrument, reading the questions to children who could not read. Questions focus on physical, emotional, social, and school function. The instrument includes caregiver- and child-reported versions, with 1 of 3 child versions administered based on age (5-7, 8-12, and 13-18 years). The versions are similar but differ in developmentally appropriate language and first- or third-person tense. The survey includes 23 items, each with a 5-point response scale for caregivers and children ≥ 8 years old and a simplified 3-point response scale for younger children. The PedsQL yields total, physical health, and psychosocial health scores, which each range from 0 to 100. While validated PedsQL threshold scores that distinguish children with poor QOL are lacking, lower scores indicate diminished QOL. The OSA-18 is a validated caregiver-completed 18-question tool to assess disease-specific QOL in children aged 6 months to 12 years presenting with SDB.[11] Scores on the OSA-18 range from 18 to 126, with higher scores indicating worse QOL. Children with scores >40 are considered to have at least a mild impact of SDB on QOL.

Additional family assessments obtained were the Parenting Stress Index,[12] the Family Assessment Device,[13] the Parenting Style Questionnaire,[14] the Experiences of Discrimination assessment,[15] and the Rapid Estimate of Adult Literacy in Medicine (REALM).[16] The Parenting Stress Index assesses the caregiver-reported degree of stress between caregiver and child, with higher scores representing higher levels of stress. The Family Assessment Device measures family functioning in the domains of problem solving, communication, roles, affective responsiveness and involvement, and behavior control, with a higher score representing more problematic functioning. The Parenting Style Questionnaire assesses the degree to which caregivers identify with authoritative, authoritarian, or permissive parenting styles. The Experiences of Discrimination assesses perceptions of racial discrimination, with higher summary scores representing increased perception of racial discrimination. The REALM is an assessment of caregiver health literacy, where higher scores represent higher health literacy.

Additional covariates assessed were the demographic factors of age, caregiver-reported race/ethnicity, and sex; the clinical characteristics of caregiver-reported history of attention-deficit/hyperactivity disorder, BMI and BMI percentile, and AHI; and the family characteristics of number of siblings, maternal education (less than high school or high school or above), household income (<\$20,000 or ≥\$20,000), caregiver smoking report, and co-sleeping (child sleeping ≥3 nights weekly with a caregiver/another child).

Statistical Analysis

Descriptive analysis was performed for demographic characteristics, clinical history, family characteristics, and QOL scores among participants who completed the PedsQL. Intraclass correlations (based on a single-measurement, absolute-agreement, 2-way random effects model) were computed to examine the level of agreement between caregiver- and child-reported PedsQL scores. Intraclass correlation is a measurement of the reliability or agreement between ≥2 raters; intraclass correlations <0.4 were indicative of poor agreement, 0.40 to 0.59 fair, 0.60 to 0.74 good, and 0.75 to 1.00 excellent.[17] Pearson correlations were calculated to test the association between PedsQL and OSA-18 scores. Paired *t* tests were used to evaluate the difference between caregiver- and child-reported PedsQL scores in each age group, and Bland-Altman plots were used to display trends in these differences. Finally, multivariable regression analyses of the absolute difference between caregiver- and child-reported PedsQL scores examined a baseline model composed of characteristics determined *a priori* to be important for analysis (age, BMI percentile, AHI, race, maternal education, and co-sleeping), as well as a series of adjusted models that each added 1 measure of family functioning to the baseline regression model (Parenting Stress Index, Family Assessment Device, REALM, Experiences of Discrimination, and PSQ).

Multiple imputation by chained equations was used to account for missing data in the predictors and the outcome of the regression models: 10 imputed data sets were created, and

Table 1. Characteristics of Children in PATS Who Completed the Child-Reported PedsQL (n = 309).

Characteristic	Mean ± SD or No. (%)
Clinical	
Age, y	7.0 ± 1.7
Male sex	152 (49.2)
Race/ethnicity	
Non-Hispanic White	144 (46.6)
Non-Hispanic Black	86 (27.8)
Hispanic	59 (19.1)
Other	20 (6.5)
Body mass index, kg/m^2	18.5 ± 4.6
Obesity	74 (23.9)
ADHD[a]	38 (12.3)
Obstructive AHI	0.7 ± 0.6
Family	
No. of siblings[b]	2.3 ± 2.0
Maternal education[c]	
Less than high school	58 (18.9)
High school or above	249 (81.1)
Household income, \$[d]	
<20,000	56 (19.8)
≥20,000	227 (80.2)
Caregiver smoking[e]	32 (10.5)
Co-sleep with caregiver and/or another child[c]	108 (35.2)

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; AHI, apnea-hypopnea index; PATS, Pediatric Adenotonsillectomy Trial for Snoring; PedsQL, Pediatric Quality of Life Inventory.
[a]Missing for 1 patient.
[b]Missing for 11 patients.
[c]Missing for 2 patients.
[d]Missing for 26 patients.
[e]Missing for 3 patients.

point estimates and variances were combined across each data set per the standard Rubin method.[18,19] All statistical analyses were performed with SAS version 9.4 (SAS Institute) and R version 3.5.1 (R Core Team).

Results

We included 309 children who were >5 years old and completed the child version of the PedsQL. Their mean age was 7 years. There was equal frequency of male and female participants. The largest ethnic group (46.6%) self-identified as non-Hispanic White (**Table 1**).

Comparisons Between Caregiver and Child PedsQL Scores

Caregiver-reported total PedsQL scores were higher than child-reported scores by 7.1 points on average (*P* < .001; **Table 2**). The Bland-Altman plots in **Figure 1** display the absolute agreement between the caregiver- and child-reported PedsQL total and subscale scores. The x-axis of these plots shows the average of the caregiver and child scores,

Table 2. Quality of Life Scores Reported by Caregivers and Children.[a]

| | Score, mean (95% CI) | | |
Characteristic	Caregiver	Child	P value
PedsQL			
Physical health (n = 305)[b]	79.7 (77.7-81.6)	73.9 (71.9-75.8)	<.001
Psychosocial health (n = 304)[c]	72.5 (70.9-74.1)	65.0 (63.0-67.0)	<.001
Total score (n = 305)[b]	75.0 (73.5-76.4)	67.9 (66.1-69.7)	<.001
OSA-18 (n = 307)[d]	51.7 (49.8-53.6)	—	

Abbreviations: OSA-18, Obstructive Sleep Apnea–18; PedsQL, Pediatric Quality of Life Inventory.
[a]Higher scores on the PedsQL reflect better overall quality of life. Higher scores on the OSA-18 reflect worse disease-specific quality of life.
[b]Missing for 3 patients.
[c]Missing for 1 patient.
[d]Missing for 2 patients.

estimating the child's overall QOL, while the y-axis shows the difference between the caregiver and child scores, representing bias in the caregiver report relative to the child report. The gray reference line represents perfect agreement, and the orange trend line represents the extent to which the bias between caregiver and child report varies by QOL. The plots suggest that the agreement between caregiver and child report is generally poor, with caregivers consistently reporting higher PedsQL scores than their children. The negative trend line for PedsQL total and psychosocial scores suggests that this caregiver overestimation is more pronounced for children with worse QOL (**Figure 1a**, **1c**), whereas caregiver overestimation is fairly constant relative to QOL for reported physical health (**Figure 1b**).

We then stratified scores by 2 age groups: younger (ages, 5-7 years) and older (ages, 8-12 years) children. Caregivers reported significantly higher QOL as compared with children 5 to 7 years old (mean score, 75.9 vs 66.3; $P < .001$). In addition, caregiver- and child-reported PedsQL showed poor agreement in this age group for the total score (ICC, 0.03; 95% CI, –0.09 to 0.15; $P = .33$), the physical health subscale (ICC, –0.04; 95% CI, –0.16 to 0.09; $P = .71$), and the psychosocial health subscale (ICC, 0.09; 95% CI, –0.04 to 0.21; $P = .08$; **Table 3**).

In contrast to the younger group, there were no significant differences in total PedsQL scores between older children (mean, 70.7) and their caregivers (mean, 73.3; $P = .14$). In general, there was greater caregiver/child agreement (stronger ICCs) for older children than for younger children (**Table 3**). However, the agreement between total PedsQL scores for caregivers and older children was still relatively weak, with an intraclass correlation of 0.21 (95% CI, 0.03-0.38; $P = .01$). The strongest agreement was fair at best between caregiver and child report in the psychosocial functioning subscale (ICC, 0.32; 95% CI, 0.15-0.48; $P < .001$) for older children.

Correlation Between PedsQL and OSA-18 Scores

The caregiver report for the total and subscale PedsQL scores was moderately correlated with the OSA-18 total scores ($r = 0.32-0.62$, all $P < .001$; Supplemental Figure S1, available

online). In contrast, the child-reported PedsQL scores exhibited at most a weak correlation with the caregiver-reported OSA-18 ($r = 0.02-0.24$).

Regression Analysis

In the initial baseline model, age and BMI were significant predictors of the mean absolute difference between caregiver and child total PedsQL scores when adjusted for sex, race, AHI, maternal education, and co-sleeping, where greater absolute differences represented a larger discrepancy (**Table 4**). Discrepancies between child- and caregiver-reported QOL decreased by an average of 1.07 points with increased age (95% CI, –1.96 to –0.18; $P = .02$). There was also a decreased discrepancy seen with overweight children, with an estimate of –4.69 (95% CI, –8.44 to –0.94; $P = .01$). In the models where measures of family functioning were added, higher health literacy as assessed by the REALM was associated with a smaller discrepancy between caregiver and child report, with an estimate of –1.09 (95% CI, –2.13 to –0.06; $P = .04$). Parenting style, parenting stress, Family Assessment Device, and Experiences of Discrimination did not predict differences in QOL after adjusting for sex, race, AHI, maternal education, and co-sleeping.

Discussion

Caregivers report poor QOL in children with SDB, but the correlation between caregiver- and child-reported QOL in SDB has not been previously assessed. In this analysis of 309 children and their caregivers enrolled in a randomized controlled trial, we found overall low correlations between caregiver- and child-reported global QOL scores in children with SDB. Caregivers tended to report better QOL than children. In addition to increased age, higher health literacy was associated with a smaller discrepancy between caregiver and child report. Caregiver report is commonly used in clinical and research settings, but the perspective of children is also important to consider as they are directly experiencing the disease.

While the majority of data on QOL in children with SDB focus on caregiver-reported outcomes,[20] the Childhood Adenotonsillectomy Trial examined child-reported QOL in
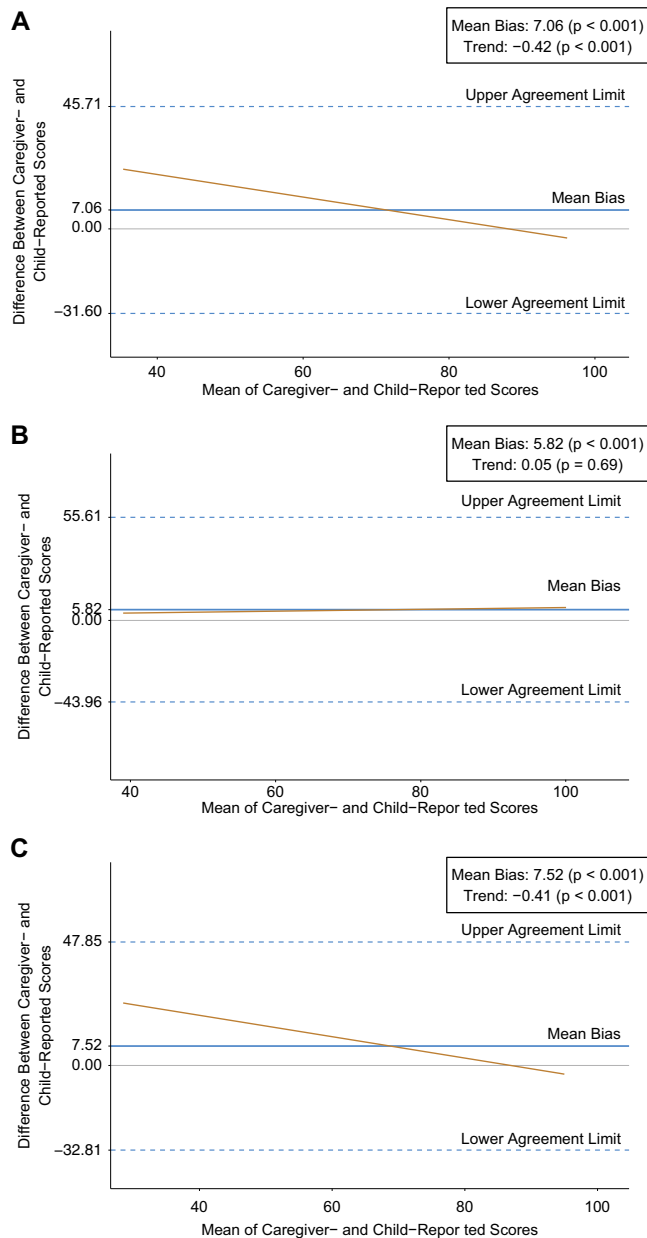
Figure 1. Bland-Altman plots for PedsQL scores: (a) total, (b) physical functioning, and (c) psychological functioning. The solid blue line indicates the average bias between caregiver and child PedsQL reports (dashed lines for 95% CI). PedsQL, Pediatric Quality of Life Inventory.

authors did not examine the agreement between caregiver- and child-reported QOL.

Studies have described differences between caregiver and child report for other disease processes.[22] For example, in the child psychology literature, numerous articles have focused on ''informant discrepancies,'' defined as inconsistencies in reports among children, caregivers, teachers, and so on.[23] There is growing acknowledgment that while a child's perspective of his or her health may be different from the caregiver's, it is equally valid. Recent research in this arena has moved away from an effort to determine whether the caregiver or child is the more ''accurate'' informant and has instead focused on how differences in reports may provide further insight into the disease studied.[24] This is especially true for sleep disorders: while children may not have complete insight into daytime symptoms, caregivers may underreport nighttime symptoms, so soliciting both perspectives can provide complementary information.

In this study, we found stronger correlations in QOL reporting between caregivers and older children (8-11 years) vs younger children, especially in the realm of psychosocial functioning. This finding was previously described[7] and may be explained by the improved communication skills in older children, which allow for experiences and emotions to be more accurately reported to caregivers. The current study highlights clinical factors beyond age that may contribute to discrepancies in QOL scores reported by children and caregivers, notably health literacy. Health literacy has implications directly for QOL (low health literacy is correlated with lower QOL[25]) and indirectly for QOL assessment (caregivers with low health literacy likely have a harder time completing QOL instruments).

Our results suggest that caregivers tend to report a smaller impact of SDB on QOL as compared with their children. Other studies have similarly found that healthy children report poorer QOL than caregivers.[7] It is unclear why caregivers report higher QOL than children with SDB, but it may be related to caregivers' lack of awareness of poor sleep and its impact. When providers are using caregiver-reported QOL to assess symptom burden, they should be aware that these scores may not fully represent the disease burden experienced by pediatric patients with SDB. Our findings highlight the importance of directly soliciting the child's input in the evaluation and management of SDB.

The OSA-18 disease-specific QOL survey is used as a clinical tool to assess symptom burden in children with SDB. OSA-18 scores can also help direct treatment, as one recent study demonstrated that children with mild obstructive sleep apnea with baseline scores ≥60 benefited from adenotonsillectomy.[3] However, few studies examine how caregiver-reported OSA-18 QOL scores correlate with children's perceived disease-specific QOL. Our study found that child-reported global QOL scores did not correlate with OSA-18 scores, which could be explained by source bias as the OSA-18 is completed by caregivers.

The data must be interpreted in the context of the study design. One of the limitations of this study is that the caregiver

pediatric patients with nonsevere obstructive sleep apnea.[21] Caregiver and child versions of the PedsQL assessed QOL at baseline and follow-up. After 7 months, there were larger improvements in the PedsQL caregiver-reported total score in the adenotonsillectomy group as compared with the watchful waiting group, with the school and physical function domains accounting for most of the difference. However, this did not bear out in the child report, where no significant differences in PedsQL change scores were found between the groups after 7 months. The authors hypothesized that this result may be due a lack of awareness among some children of their own sleepiness, irritability, or decreased concentration, though the

Table 3. Intraclass Correlation Analysis Between Caregiver and Child PedsQL Scores (n = 304).[a]

Caregiver	Child, age 5-7 y (n = 193)		Child, age 8-12 y (n = 111)	
	ICC (95% CI)	P value	ICC (95% CI)	P value
PedsQL	0.03 (−0.09 to 0.15)	.33	0.21 (0.03 to 0.38)	.01
Physical	−0.04 (−0.16 to 0.09)	.71	−0.10 (−0.28 to 0.09)	.84
Psychosocial	0.09 (−0.04 to 0.21)	.08	0.32 (0.15 to 0.48)	<.001

Abbreviations: ICC, intraclass correlation coefficient; PedsQL, Pediatric Quality of Life Inventory.
[a]Caregiver- and/or child-reported PedsQL scores were missing for 5 individuals.

Table 4. Multivariable Regression Analysis of the Absolute Difference Between Caregiver- and Child-Reported PedsQL Scores (n = 309).

	Estimate	95% CI	P value
Baseline model[a]			
Age	−1.07	−1.96 to −0.18	.02
Female	2.51	−0.32 to 5.33	.08
BMI percentile			.04
Normal/underweight	Reference	—	
Overweight	−4.69	−8.44 to −0.94	
Obese	−2.18	−5.79 to 1.43	
AHI	1.23	−0.99 to 3.46	.28
Maternal education high school or less	2.57	−1.17 to 6.31	.18
Co-sleep with caregiver and/or other children	1.39	−1.76 to 4.55	.39
Models with addition of measures of family functioning			
Parenting Stress Index	0.01	−0.15 to 0.18	.87
Family Assessment Device	−3.12	−6.89 to 0.65	.11
REALM	−1.09	−2.13 to −0.06	.04
Experiences of Discrimination	−0.15	−1.09 to 0.78	.75
Parenting Style Questionnaire			.37
Authoritarian	0.38	−2.41 to 3.17	
Authoritative	1.76	−2.38 to 5.91	
Permissive	−1.79	−4.09 to 0.52	

Abbreviations: AHI, apnea-hypopnea index; BMI, body mass index; PedsQL, Pediatric Quality of Life Inventory; REALM, Rapid Estimate of Adult Literacy in Medicine.
[a]Also adjusted for race (point estimates not shown).

and child versions of the PedsQL are independent instruments that are not necessarily designed to correlate, although both measure global health-related QOL. The findings related to child age may represent differences in the age versions of the PedsQL and the more limited scale in the PedsQL for younger children. There is also a lack of data on caregiver well-being, which may play a role as prior studies have demonstrated that parents who report poor QOL for themselves are likely to report poor QOL for their children.[26,27] Additionally, a global QOL instrument was used to assess the correlation between parent and child scores because there are no instruments that assess child-reported disease-specific QOL for pediatric SDB. For example, a validated child-reported version of the widely utilized OSA-18 has yet to be developed. Thus, it remains unknown if correlation between caregiver and child scores improves when age- and disease-specific QOL instruments are utilized to assess symptom burden. As far as QOL

perceptions between children and caregivers go, surveys that more accurately assess children's perceptions of their health and well-being as well as their health literacy would be useful in clinical care and research.

This is one of the first studies to report on the correlation between caregiver- and child-reported QOL in a population of children with mild SDB and tonsil hypertrophy. It was strengthened by a large, diverse, multi-institutional patient population in which validated instruments were utilized as outcomes.

Conclusion

Further research is needed to determine how best to clinically assess children's perceptions of their health and disease. Providers who use caregiver-reported global QOL surveys as a proxy to assess child QOL should be aware that, especially in younger children, caregivers' scores may not correlate with

their children's self-reported QOL, and children should be directly questioned when possible. Future studies are needed to refine and validate age- and disease-specific QOL instruments that can be utilized to directly assess disease impact on child-reported symptom burden and QOL.

Author Contributions

Phoebe Kuo Yu, study design and conception, data collection and data analysis, initial manuscript drafting; **Kaitlyn Cook**, study design, data analysis, manuscript revision for important intellectual content; **Jiayan Liu**, study design, data analysis, manuscript revision for important intellectual content; **Raouf S. Amin**, study supervision, data contribution and interpretation, manuscript revision for important intellectual content; **Craig Derkay**, study supervision, data contribution and interpretation, manuscript revision for important intellectual content; **Lisa M. Elden**, study supervision, data contribution and interpretation, manuscript revision for important intellectual content; **Susan L. Garetz**, study supervision, data contribution and interpretation, manuscript revision for important intellectual content; **Alisha S. George**, study supervision, data contribution and interpretation, manuscript revision for important intellectual content; **Sally Ibrahim**, study supervision, data contribution and interpretation, manuscript revision for important intellectual content; **Stacey L. Ishman**, study supervision, data contribution and interpretation, manuscript revision for important intellectual content; **Erin M. Kirkham**, study supervision, data contribution and interpretation, manuscript revision for important intellectual content; **S. Kamal Naqvi**, study supervision, data contribution and interpretation, manuscript revision for important intellectual content; **Jerilynn Radcliffe**, study design, data analysis and interpretation, manuscript revision for important intellectual content; **Kristie R. Ross**, study supervision, data contribution and interpretation, manuscript revision for important intellectual content; **Gopi B. Shah**, study supervision, data contribution and interpretation, manuscript revision for important intellectual content; **Ignacio E. Tapia**, study supervision, data contribution and interpretation, manuscript revision for important intellectual content; **H. Gerry Taylor**, study design, data analysis and interpretation, manuscript revision for important intellectual content; **David A. Zopf**, study supervision, data contribution and interpretation, manuscript revision for important intellectual content; **Susan Redline**, study supervision, data contribution and interpretation, manuscript revision for important intellectual content; **Cristina M. Baldassari**, study design, conception, and supervision; data contribution and interpretation; initial manuscript drafting.

Disclosures

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Supplemental Material

Additional supporting information is available in the online version of the article.

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