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Parent–Child Agreement on Fatigue in Pediatric Otolaryngology Patients

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ABSTRACT

Objectives: To investigate parent–child agreement on fatigue reporting in pediatric otolaryngology patients and whether agreement might vary by diagnosis and other patient factors.

Study Design: Cross-sectional survey.

Methods: Patients ages 5–18 years old being evaluated for hearing loss (HL) or obstructive sleep apnea (OSA) were recruited from a pediatric otolaryngology clinic and sleep center. Children and parents completed the Pediatric Quality of Life Inventory Multidimensional Fatigue Scale (PedsQL MFS).

Results: Responses of 42 patients with HL, 49 with OSA, 10 with sleep-disordered breathing (SDB), and 34 controls were analyzed. Parent and child PedsQL MFS scores were strongly correlated (Pearson $r > 0.7$) across groups with few exceptions. Only the median child–parent score differences for general domain score in the SDB group (12.5; 95% CI 2.08 to 22.9), and total score (7.41; 95% CI −0.69 to 25.7) and general domain score (11.5; 95% CI 2.08 to 27.1) in the developmental delay group met clinical significance thresholds. Wide confidence intervals prevented definitive conclusions regarding clinical significance. A pattern of decreased parent–child score correlations was observed in children reported to have delays. Weak (±0.1 to ±0.4) to moderate (±0.4 to ±0.69) correlations were observed for total score, general domain score, and cognitive domain score for children with reported developmental/speech/language delay.

Conclusion: Overall, the parent-proxy PedsQL MFS demonstrates strong agreement with self-reports for pediatric otolaryngology patients being evaluated for HL and OSA. However, parent–child score discrepancies within specific patient groups, especially children whose parents reported speech/developmental/language delays, emphasize the importance of administering self-reports when possible.

Level of Evidence: 3

1 | Introduction

Hearing loss (HL) and obstructive sleep apnea (OSA) are some of the more common conditions for which children are seen in otolaryngology clinics. HL affects 1 to 2 of every 1000 children at birth [1] and nearly 20% of children in the United States by age 18 [2]. Pediatric OSA also has a relatively high prevalence, affecting up to 5.7% of children [3].

QOL in children with HL and OSA is decreased relative to children without these diagnoses. Children with HL report lower QOL compared to their normal hearing (NH) peers. School-aged

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children with HL also report higher levels of fatigue than children with NH, suggesting a possible link between increased fatigue and decreased QOL in children with HL [4–7]. Pediatric OSA is associated with excessive daytime sleepiness, cognitive deficits, academic difficulties, behavioral disorders, and decreased physical function/mobility [8, 9]. As increased fatigue is a possible consequence of both OSA and HL that may warrant intervention, understanding a child's fatigue level is important for clinical decision making. Often, clinicians rely on parent-reports of a child's fatigue level, especially when factors such as young age, illness, or disability status make self-reports challenging.

In general population samples, parent–child agreement on self- and parent-proxy QOL surveys is low to moderate, with parents reporting their child's QOL higher than the child themself [10, 11]. Parents of children with health conditions were found to report overall lower QOL for their child [11, 12]. However, agreement has varied by diagnosis, emphasizing the importance of investigating parent–child agreement in specific populations of interest.

Parent–child agreement on child fatigue has not been robustly studied in pediatric otolaryngology patients. In one study of children with HL, parents reported lower fatigue on the Pediatric Quality of Life Multidimensional Fatigue Scale (PedsQL MFS) than children themselves [4], indicating that parents of children with HL may underestimate their child's fatigue level. The degree of parent–child agreement on QOL metrics in children with OSA has yet to be reported.

Anecdotally, parent reports of child fatigue can vary widely in the pediatric otolaryngology setting. Parents of children with HL often report that their child is exhausted after a full day of school; however, this does not always align with the child's perception. Some parents of children with OSA report that their child does not experience any fatigue, while on visual examination the child appears excessively tired. While these subjective experiences demonstrate that parents may over- or underestimate their child's fatigue, it is not clear whether these differences demonstrate any pattern based on diagnosis or other patient factors within the pediatric otolaryngology clinic population.

In this study, we evaluated parent–child agreement on the PedsQL MFS in pediatric otolaryngology patients with OSA and HL to better understand clinically relevant differences in fatigue reporting, and how these differences may vary between children with different diagnoses. We hypothesized that, similar to previous findings in children with chronic conditions, parents of children with HL and OSA would rate their child's fatigue higher on the PedsQL MFS than the child themselves.

2 | Materials and Methods

2.1 | Population

Institutional Review Board approval was obtained through the Washington University Human Research Protection Office (#202106151). Informed consent from parents was obtained prior to enrollment. Eligible children ages 5–18 years old and their parents were recruited from pediatric otolaryngology clinics and the sleep laboratory at a tertiary care center from September 2021 to March 2022. Children with HL or OSA were identified using ICD-10 diagnosis codes for sensorineural HL and OSA or sleep-disordered breathing (SDB), with confirmed diagnoses on audiogram or polysomnogram, respectively. Exclusion criteria included having both HL and OSA, fluctuating/conductive HL, central sleep apnea, unresolved OSA following surgery, medical problems associated with increased fatigue such as trisomy 21 [13] and epilepsy [14], not speaking English, and being in foster care.

Participants with HL or OSA were mailed packets including a demographic survey and the PedsQL MFS, with the option to complete forms by mail or online. Additionally, participants evaluated for OSA through otolaryngology referral were recruited at the sleep laboratory and had the option to complete forms on paper or online. Participants recruited at the sleep laboratory who were found to have SDB (obstructive apnea-hypopnea index [oAHI] <1.0) but not OSA were also included. The recruited control group consisted of pediatric otolaryngology clinic patients who did not have HL on audiogram or who had clinically resolved OSA following surgery, as defined by reported resolution of symptoms.

In analysis stratified by diagnosis severity, OSA severities were classified as mild (apnea hypopnea index [AHI] 1–4.9), moderate (AHI 5–9.9), or severe (AHI ≥ 10). HL severities were classified using American Speech-Language-Hearing Association guidelines as slight/mild to moderate (pure tone averages [PTA] 16–55 dB HL), moderately severe to severe (PTA 56–90 dB HL), or profound (PTA ≥ 90 dB HL) based on the worse ear severity between the right and left ears [15].

2.2 | Questionnaires

The PedsQL MFS Young Child (5–7 year-old), Child (8–12 year-old), and Teen (13–18 year-old) versions were used to evaluate fatigue. All utilized versions have a self- and parent-report. The measure consists of 18 items under the domains of general fatigue, sleep/rest fatigue, and cognitive fatigue (Supporting Information). Except for the Young Child self-report, each item is scored on a 5-point scale ranging from 0 (never) to 4 (almost always) and then transformed to a scale of 0 to 100, with lower scores indicating worse fatigue. For the Young Child self-report, each item is scored on a 3-point scale (0 = not at all, 2 = sometimes, 4 = a lot).

2.3 | Statistical Analysis

Participants' data were de-identified for analysis. Statistical analyses were performed using IBM SPSS Statistics Version 28 (IBM Corp., Armonk, NY, USA). Demographic data from participant groups was analyzed using Cramer's V for categorical variables and eta squared for continuous variables. Cramer's $V \geq 0.25$ and eta squared ≥ 0.06 was considered significant. Because data was non-parametric, agreement between parent- and self-reports was reported as self-parent median difference estimate with 95% confidence interval (CI). Spearman's rho was calculated as a correlation

measure between self- and parent-reports and classified according to the Dancey & Reidy guidelines for interpretation [16]. Correlation of ±1 was considered perfect, ±0.7 to ±0.99 strong, ±0.4 to ±0.69 moderate, ±0.1 to ±0.4 weak, and 0 to ±0.1 zero.

Minimally clinically important differences (MCID) were calculated as 1*standard error of measurement (SEm) for PedsQL MFS total score and each of the three domains. SEm is a commonly used distribution-based method for calculating MCID in quality of life instruments and has been used to calculate MCID for other variations of the PedsQL [17–19].

3 | Results

3.1 | Participants

Of 441 eligible patients contacted, 151 (34.2%) were consented for participation. Data was excluded from 7 participants across multiple groups due to incomplete surveys, 8 controls due to continued OSA symptoms after surgery, and 1 OSA group participant due to reported resolution of OSA symptoms without intervention. Data was ultimately analyzed from 42 patients with HL, 49 with OSA, 10 with SDB, and 34 controls. Participants with HL were older (mean age 11.7 years) than participants in the OSA (mean age 8.90 years), SDB (mean age 9.00 years), and control groups (mean age 8.24 years). A higher proportion of African American participants were in the OSA group (34.7% compared to 7.1%, 10.0%, and 17.6% respectively for the HL, SDB, and control groups). A higher proportion of children with HL had speech delay (42.9% compared to 12.2%, 10.0%, and 8.8% in the OSA, SDB, and control groups respectively). No significant differences were found between these cohorts in other baseline characteristics shown (Table 1).

3.2 | Calculation of MCIDs

The greater SEm between parent- and self-report was used as the MCID for total score and in each domain (Table S2). MCIDs were 6.03 for total score, 9.23 for general domain, 10.4 for sleep domain, and 7.80 for cognitive domain.

3.3 | Comparison of PedsQL MFS Parent- and Self-Reports Overall

In overall comparison of PedsQL MFS surveys, self- and parent-report scores were strongly correlated in all domains (rho ≥ 0.7). Self-parent score median difference estimates and 95% CIs all fell within the bounds of ±MCID (Figure 1A–D; Table 2).

3.4 | Comparison of PedsQL MFS Parent- and Self-Reports by Participant Group

PedsQL MFS parent- and self-reports were strongly correlated (rho ≥ 0.7) in all domains in the HL, OSA, and control groups, except for moderate correlations in the general domain of the OSA group (rho = 0.696) and in the sleep domain of the control group (rho = 0.623) (Table 3). All median parent–child difference estimates in these groups fell within the limits of ±MCID. 95%

TABLE 1 | Sample characteristics of HL (HL), obstructive sleep apnea (OSA), sleep disordered breathing (SDB), and control children and families reported by parent participants.

	HL ($n = 42$)	OSA ($n = 49$)	SDB ($n = 10$)	Control ($n = 34$)	Effect size[a]
Age, mean (standard deviation)	11.7 (3.49)	8.90 (3.59)	9.00 (3.77)	8.24 (3.80)	0.500[c]
Sex, *n* (%)					0.085
Female	20 (47.6%)	21 (42.9%)	6 (60.0%)	17 (50%)	—
Male	22 (52.4%)	27 (55.1%)	4 (40.0%)	17 (50%)	—
Other/no response	0 (0%)	1 (2.0%)	0 (0%)	0 (0%)	—
Race/ethnicity, *n* (%)[b]					—
White	36 (85.7%)	33 (67.3%)	8 (80.0%)	28 (83.4%)	0.194
African American	3 (7.1%)	17 (34.7%)	1 (10.0%)	6 (17.6%)	0.294
Native American	1 (2.4%)	1 (2%)	1 (10.0%)	0 (0%)	0.163
Asian or Pacific Islander	2 (4.8%)	0 (0%)	0 (0%)	1 (2.9%)	0.141
Latino or Hispanic	1 (2.4%)	2 (4.1%)	0 (0%)	3 (8.8%)	0.131
Other/no response	0 (0%)	1 (2.0%)	0 (0%)	1 (2.9%)	0.101
Developmental delay, *n* (%)	6 (14.3%)	4 (8.2%)	1 (10.0%)	1 (2.9%)	0.150
Speech delay, *n* (%)	18 (42.9%)	6 (12.2%)	1 (10.0%)	3 (8.8%)	0.368[c]
Language Delay, *n* (%)	8 (19.0%)	6 (12.2%)	1 (10.0%)	0 (0%)	0.228

[a]Effect sizes were calculated using Cramer's V for categorical variables and eta squared for continuous variables.
[b]Race/ethnicity questions allowed participants to select multiple options; thus, percentages do not total 100%.
[c]Significant effect size (defined as Cramer's V ≥ 0.25 or eta squared ≥ 0.06).

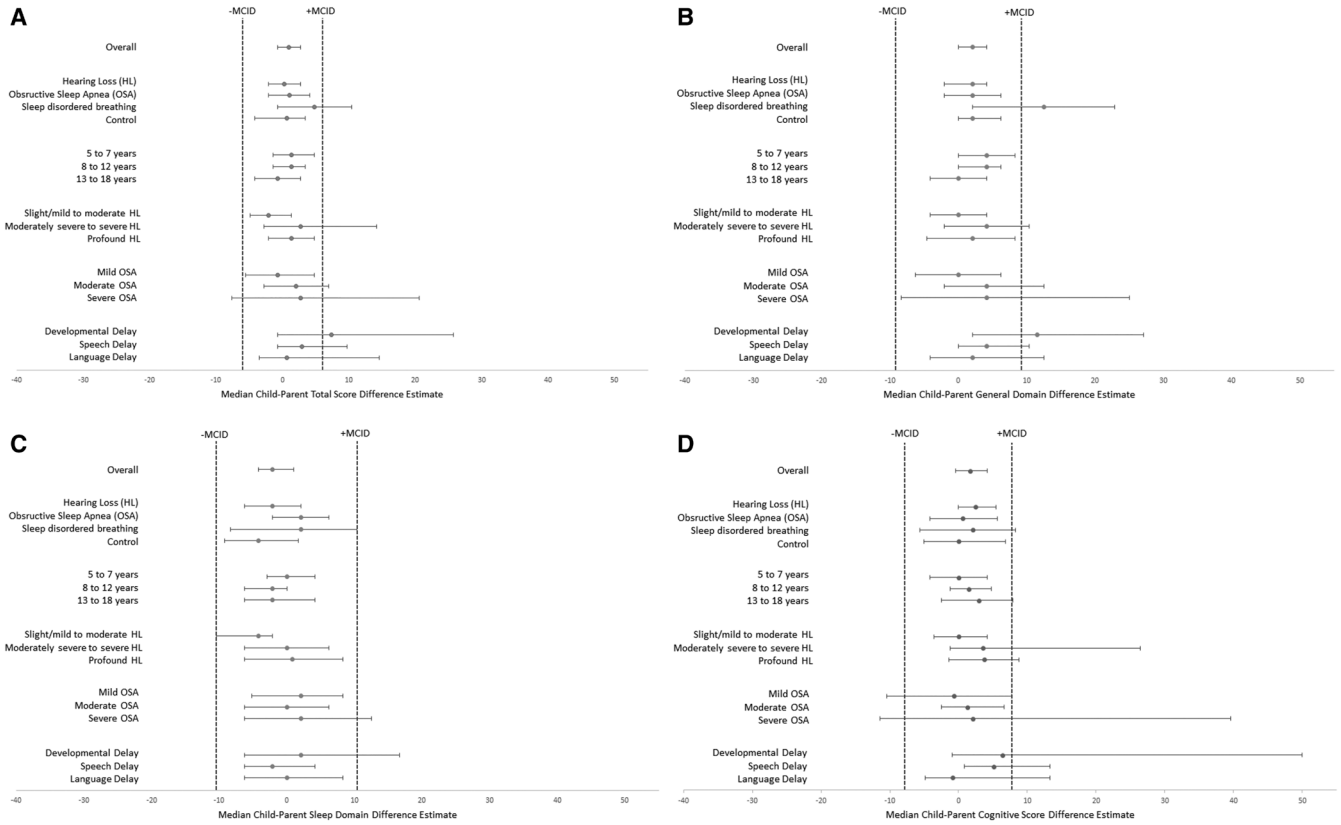

FIGURE 1 | Median child–parent* score difference estimates and 95% confidence intervals. (A) total score; (B) general domain; (C) sleep domain; (D) cognitive domain. *Calculated as child score minus parent score.

TABLE 2 | Overall comparison of parent- and self-report Pediatric Quality of Life Inventory Multidimensional Fatigue Scale (Peds QL MFS) surveys ($n = 135$).

Domain	Mean Score (standard deviation)	Self-Parent Score Median Difference Estimate (95% confidence interval)[a]	Spearman's rho[b]
Total score self	62.5 (20.8)	1.02 (−0.69 to 2.78)	0.843
Total score parent	61.2 (21.1)		
General domain self	66.7 (22.1)	2.08 (0 to 4.17)	0.800
General domain parent	63.7 (22.1)		
Sleep domain self	63.6 (21.8)	−2.08 (−4.17 to 1.04)	0.797
Sleep domain parent	64.7 (22.4)		
Cognitive domain self	57.4 (28.9)	1.67 (−0.42 to 4.17)	0.789
Cognitive domain parent	55.2 (27.1)		

[a]Minimally clinically important difference (MCID) for each domain is: 6.03 (total score), 9.23 (general domain), 10.4 (sleep domain), 7.80 (cognitive domain).
[b]Correlation of ±1 is considered perfect, ±0.7 to ±0.99 is strong, ±0.4 to ±0.69 is moderate, ±0.1 to ±0.4 is weak, and 0 to ±0.1 is zero according to the Dancey & Reidy guidelines for interpretation [16].

CIs for median difference estimates fell within the ±MCID interval (Figure 1A–D).

Parent- and self-reports in the SDB group were strongly correlated in total score (rho = 0.733) and cognitive domain (rho = 0.902) but moderately correlated in general (rho = 0.500) and sleep (rho = 0.610) domains. The total score, sleep domain, and cognitive domain median difference estimates did not meet thresholds for clinical significance (Table 3). The median child–parent difference estimates for general domain score of 10.42 exceeded the MCID; however, the lack of precision (95% CI −4.17 to 29.2) prevents definitive conclusions about whether the general domain child–parent difference is clinically significant (Figure 1B).

TABLE 3 | Comparison of parent- and self-report Pediatric Quality of Life Inventory Multidimensional Fatigue Scale (Peds QL MFS) surveys by participant group.

Group	Domain	Mean Score (standard deviation)	Self-Parent Score Median Difference Estimate (95% confidence interval)[b]	Spearman's rho[c]
Hearing loss ($n=42$)	Total score self	64.7 (16.1)	0.33 (−2.08 to 2.78)	0.826
	Total score parent	63.2 (16.1)		
	General domain self	68.5 (17.1)	2.08 (−2.08 to 4.17)	0.868
	General domain parent	66.9 (17.4)		
	Sleep domain self	67.3 (17.6)	−2.08 (−6.25 to 2.08)	0.795
	Sleep domain parent	68.8 (18.2)		
	Cognitive domain self	59.1 (24.7)	2.50 (0 to 5.42)	0.754
	Cognitive domain parent	53.9 (23.1)		
Obstructive sleep apnea ($n=49$)	Total score self	54.6 (22.1)	1.10 (−2.08 to 4.17)	0.789
	Total score parent	52.7 (22.1)		
	General domain self	58.7 (23.7)	2.08 (−2.08 to 6.25)	0.696
	General domain parent	55.6 (23.1)		
	Sleep domain self	56.0 (24.6)	2.08 (−2.08 to 6.25)	0.768
	Sleep domain parent	54.4 (24.0)		
	Cognitive domain self	49.4 (30.1)	0.60 (−4.17 to 5.66)	0.717
	Cognitive domain parent	47.9 (27.7)		
Sleep disordered breathing ($n=10$)	Total score self	57.8 (13.0)	4.86 (−0.69 to 10.4)	0.733
	Total score parent	53.1 (12.5)		
	General domain self	66.7 (12.9)	12.5[a] (2.08 to 22.9)	0.500
	General domain parent	54.2 (14.8)		
	Sleep domain self	50.0 (15.1)	2.08 (−8.33 to 10.4)	0.610
	Sleep domain parent	50.0 (14.3)		
	Cognitive domain self	56.4 (26.1)	2.08 (−5.66 to 8.33)	0.902
	Cognitive domain parent	55.0 (22.0)		
Control ($n=34$)	Total score self	72.4 (21.3)	0.69 (−4.17 to 3.47)	0.842
	Total score parent	73.6 (20.8)		
	General domain self	76.0 (23.9)	2.08 (0 to 6.25)	0.850
	General domain parent	74.4 (22.6)		
	Sleep domain self	74.0 (18.5)	−4.17 (−9.17 to 1.67)	0.623
	Sleep domain parent	78.8 (16.8)		
	Cognitive domain self	66.9 (30.6)	0 (−5.06 to 6.85)	0.824
	Cognitive domain parent	67.3 (28.8)		

[a]Exceeds minimally clinically important difference (MCID).
[b]MCIDs for each domain are: 6.03 (total score), 9.23 (general domain), 10.4 (sleep domain), 7.80 (cognitive domain).
[c]Correlation of ±1 is considered perfect, ±0.7 to ±0.99 is strong, ±0.4 to ±0.69 is moderate, ±0.1 to ±0.4 is weak, and 0 to ±0.1 is zero according to the Dancey & Reidy guidelines for interpretation [16].

3.5 | Comparison of PedsQL MFS Parent- and Self-Reports by Age Group

Across age groups, PedsQL MFS parent- and self-reports were strongly correlated in all domains apart from a moderate correlation (rho = 0.691) in the cognitive domain of the 13–18-year-old age group (Table S3). All child–parent median difference estimates fell within the limits of ±MCID (Figure 1).

3.6 | Comparison of PedsQL MFS Parent- and Self-Reports by Diagnosis Severity

Correlation between PedsQL MFS parent –and self-report scores was strong or moderate across HL and OSA severities, with only two exceptions (Tables S4 and S5). Correlation between parent –and self-report cognitive domain scores was weak in children with moderately severe to severe HL (rho = 0.382) and in children with severe OSA (rho = 0.327). There was no clear pattern of correlation based on diagnosis severity. No median differences between parent –and self-report scores in HL or OSA severity groups met clinical significance thresholds. Wide confidence intervals in several comparisons prevent definitive conclusions about the clinical significance of parent–child score differences (Figure 1; Tables S4 and S5).

3.7 | Comparison of PedsQL MFS Parent- and Self-Reports in Children With Delays and Other Comorbidities

In participants with parent-reported developmental delay, parent- and self-reports were strongly correlated in the sleep domain (rho = 0.788), weakly correlated in total score (rho = 0.272) and general domain (rho = 0.295), and not correlated in the cognitive domain (rho = 0.050). In participants with reported speech delay, parent- and self-reports were strongly correlated in the sleep domain (rho = 0.707), and moderately correlated in total score (rho = 0.585), general domain (rho = 0.674), and cognitive domain (rho = 0.454). In participants with reported language delay, parent- and self-reports were moderately correlated in total score (rho = 0.570), general domain (rho = 0.687), and sleep domain (rho = 0.686), and weakly correlated in the cognitive domain (rho = 0.360) (Table 4).

No median parent–child differences met clinical significance thresholds apart from the developmental delay group total score (median difference = 7.41; 95% CI −0.69 to 25.7) and general domain (median difference = 11.5; 95% CI 2.08 to 27.1) (Figure 1A–D; Table 4). Wide CIs prevent definitive conclusions regarding the clinical significance of these findings.

Of note, significant outliers were found in all delay groups ($n = 2$ in the developmental delay and speech delay groups, $n = 1$ in the language delay group) for which the child–parent score difference in the cognitive domain was 100 points. As responses in other domains did not maintain this pattern, these participants appear to be true outliers rather than a result of incorrect instrument usage. Thus, they were included in theanalysis.

No notable parent-self score differences were found in the analysis of other comorbidities.

4 | Discussion

Increased fatigue in children with chronic conditions such as HL and OSA is clinically relevant when assessing management strategies. The objective of our study was to investigate parent–child agreement on the PedsQL MFS in pediatric otolaryngology patients with HL and OSA. We hypothesized that parents of children with HL or OSA would rate their child's fatigue as worse than the children themselves. We found that, overall, parents of children with HL or OSA rate their child's fatigue similarly on the parent-report PedsQL MFS to children on self-report, with median differences falling below clinical significance thresholds. This demonstrates the overall reliability of the parent-proxy PedsQL MFS survey for approximating fatigue levels in pediatric otolaryngology patients. Additionally, this reliability does not appear to differ based on the diagnosis of OSA or HL. However, a pattern of decreased correlation between parent- and self-report scores was observed in children with reported delays, suggesting that parents of these children may have less understanding of their child's subjective experience of fatigue.

While we did not observe clinically significant differences in parent- and self-reports of fatigue for children with HL and OSA, this finding conflicts with other studies in the existing literature. Hornsby et al. found that in children ages 6–12 years with HL, parents tend to underestimate their child's sleep/rest and cognitive fatigue [4]. Another investigation utilizing the PedsQL MFS found that in children ages 6–16 years with HL, self- and parent-report scores were significantly different in the sleep and cognitive domains [20]. There is limited literature available on parent–child agreement on QOL in children with OSA. However, one recent study found that in patients aged 5–12 years with SDB (defined as oAHI < 3), the parent-report PedsQL score was significantly higher than the self-report [21].

Resolving the source of these differences is difficult given that the other studies did not define MCIDs. Thus, differentiating statistical significance from clinical significance is challenging. Additionally, although we did not find any significant impact of age on parent–child agreement, it is possible that differences in participant age between studies could have impacted agreement. Previous reports have described conflicting impacts of age on parent–child agreement, with some studies reporting lower concordance for parents and older children [22], others describing worse agreement between parents and younger children [21, 23, 24], and some finding that age does not impact parent–child agreement [11, 25]. Cultural differences have also been found to moderate agreement between PedsQL parent- and child-reports and may contribute to differences between studies [26]. While differences could have stemmed from varied diagnosis severities, the lack of clear differences in agreement based on OSA or HL severity makes this less likely. Furthermore, previous studies have found that QOL itself is not strongly associated with OSA or HL severity in children [27–33].

TABLE 4 | Pediatric Quality of Life Inventory Multidimensional Fatigue Scale (Peds QL MFS) parent- and self-reports in children with delays or prematurity.

Group	Domain	Mean Score (standard deviation)	Self-Parent Score Median Difference Estimate (95% confidence interval)[b]	Spearman's rho[c]
Developmental delay ($n=12$)	Total score self	55.8 (17.2)	7.41[a] (−0.69 to 25.7)	0.272
	Total score parent	43.4 (18.1)		
	General domain self	59.4 (14.2)	11.5[a] (2.08 to 27.1)	0.295
	General domain parent	45.8 (19.9)		
	Sleep domain self	60.4 (22.7)	2.08 (−6.25 to 16.7)	0.788
	Sleep domain parent	56.4 (24.2)		
	Cognitive domain self	48.4 (29.1)	6.40 (−0.89 to 50.0)	0.050
	Cognitive domain parent	28.1 (17.1)		
Speech delay ($n=28$)	Total score self	62.9 (14.8)	2.92 (−0.69 to 9.72)	0.585
	Total score parent	56.3 (17.6)		
	General domain self	66.1 (15.2)	4.17 (0 to 10.4)	0.674
	General domain parent	59.3 (20.7)		
	Sleep domain self	65.9 (20.0)	−2.08 (−6.25 to 4.17)	0.707
	Sleep domain parent	64.9 (21.1)		
	Cognitive domain self	57.1 (24.2)	5.15 (0.83 to 13.3)	0.454
	Cognitive domain parent	44.6 (22.0)		
Language delay ($n=15$)	Total score self	51.1 (19.7)	0.69 (−3.47 to 14.6)	0.570
	Total score parent	46.8 (16.8)		
	General domain self	55.0 (17.5)	2.08 (−4.17 to 12.5)	0.687
	General domain parent	50.6 (16.6)		
	Sleep domain self	58.1 (25.9)	0 (−6.25 to 8.33)	0.686
	Sleep domain parent	55.3 (21.9)		
	Cognitive domain self	39.6 (26.1)	−0.89 (−4.88 to 13.3)	0.360
	Cognitive domain parent	34.4 (20.2)		

[a]Exceeds minimally clinically important difference (MCID).
[b]MCIDs for each domain are: 6.03 (total score), 9.23 (general domain), 10.4 (sleep domain), 7.80 (cognitive domain).
[c]Correlation of ±1 is considered perfect, ±0.7 to ±0.99 is strong, ±0.4 to ±0.69 is moderate, ±0.1 to ±0.4 is weak, and 0 to ±0.1 is zero according to the Dancey & Reidy guidelines for interpretation [16].

In children with parent-reported delays, weaker parent–child report correlations in the total score, general domain, and cognitive domain may reflect communication challenges between parents and children, leading to less accurate parental perceptions of child fatigue. While this finding is limited by the fact that the classification of delay was based on parent report rather than medical diagnosis, it is possible that the parent's perception of the delay alone is what biases their report. Parents who perceive their child to be delayed may be more likely to project their own feelings in the parent-proxy measure; they may not ask the child or discount the child's report of their own fatigue. Furthermore, in children with true delays, the child may experience difficulties verbalizing their experiences to a parent. This may be especially true for internal, subjective experiences such as those assessed in the general and cognitive fatigue domains. In our analysis, extreme outliers, especially in the cognitive domain, negatively impacted correlations in these domains. While these outliers limit the generalizability of our findings, they suggest that when parents and their children with delays do disagree on QOL, differences may be more extreme.

In contrast, correlations between parent- and self-reports in the sleep domain remained overall strong in children with delays, likely reflecting the more observable nature of items in this domain (e.g., sleeping/resting a lot, difficulty sleeping through the night). This aligns with previous research indicating that parent–child agreement is stronger on external symptoms than on non-observable symptoms [34–37] and indicates that this effect may be stronger in children with delays.

Small sample sizes in developmental/speech/language delay groups indicate a need for further investigation into how these diagnosed delays impact parent–child agreement on QOL and fatigue. Additionally, the increased prevalence of speech delay in children with HL in our sample prevents us from fully discriminating between speech delay and HL diagnosis in the analysis. Nevertheless, our findings emphasize the importance of considering how a child's diagnoses (and perceived diagnoses) can impact how a parent views their fatigue and QOL. Parent-proxy reports should be interpreted carefully, with the knowledge that parents of children with perceived delays may report lower child QOL compared to self-reports. Thus, children who have the capacity to give reports on their own fatigue and quality of life should be given the opportunity to do so.

In general, this study is limited by the small sample size that may not be representative of children with OSA, HL, or SDB. Because our control group was made up of patients recruited from an otolaryngology clinic, they may not be representative of a general population control sample. Given the participant yield of 34.2%, it is possible that self-selection bias may have impacted results. However, we believe that this yield is acceptable given that studies utilizing targeted mail invitation generally have response rates anywhere from 6% to 37% [38–41]. The PedsQL MFS does not have published MCIDs for each of its domains. While we calculated MCIDs for our sample, these clinical significance thresholds are only applicable for a pediatric otolaryngology clinic sample and cannot be further generalized. Finally, we cannot confirm that self- and parent-reports were completed independently as requested for responses completed remotely. This may have impacted results, as self-reports completed with significant parent input may more closely agree with parent-reports.

5 | Conclusion

The parent-proxy PedsQL MFS demonstrates overall strong agreement with self-reports for pediatric otolaryngology clinic patients being evaluated for both HL and OSA, supporting its validity in assessing pediatric fatigue. However, parent–child score discrepancies within specific patient groups, especially those with reported speech, developmental, or language delays, emphasize the importance of administering self-reports when possible. Further studies can investigate the role of comorbidities such as developmental/speech/language delay on parent–child agreement on QOL measurement instruments.

Acknowledgments

The authors have nothing to report.

Conflicts of Interest

The authors declare no conflicts of interest.

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