

# A Comparison of Parent Proxy & Self-Reports of Fatigue in Children with Hearing Loss

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## INTRODUCTION

Fatigue is a common complaint in children with chronic health conditions (e.g., cancer, diabetes, rheumatic diseases).<sup>1</sup> The Pediatric Quality of Life Inventory Multidimensional Fatigue Scale (PedsQL MFS) is a popular, standardized questionnaire for measuring subjective self-reports and parent proxy reports of fatigue.<sup>2</sup>

Parents and teachers have long believed that children with hearing loss (CHL) may be at increased risk for hearing-related fatigue. To date, research on fatigue in CHL is underexplored. In 2014, Hornsby and colleagues reported significantly higher levels of fatigue in CHL (n=10) compared to children with normal hearing (CNH) using the PedsQL MFS.<sup>3</sup>

Measuring fatigue in children who do not have the language or cognitive skills to self-report may necessitate relying on parent proxy report. There is moderate- to good agreement between parent proxy and child reports for general health-related quality of life, with higher agreement for observable, physical function and lower agreement for internal domains.<sup>4</sup> Instruments specifically measuring fatigue in chronic health populations yield poor- to fair parent proxy-child agreement.<sup>5,6</sup> Subjective child and parent proxy reports of fatigue have yet to be explored in CHL and this study aims to investigate whether parents of CHL accurately estimate their child's subjective experience of fatigue.

## PURPOSE

The purposes of this study were to quantify fatigue in CHL using a validated measure (PedsQL MFS) and to examine agreement between child and parent proxy reports of fatigue.

## METHODS

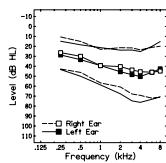
### Participants

Children ages 6-12 years were recruited as part of a larger, ongoing study examining listening effort and fatigue in school-age CHL. All children were monolingual English speakers and spent at least two hours per day in a general education classroom. Children with a diagnosis of cognitive impairment, autism, or other developmental disorders were excluded.

CNH had normal hearing sensitivity, bilaterally ( $\leq 15$  dB HL from 250-8000 Hz). CHL had mild- to moderate sensorineural hearing loss, bilaterally.

\*Mild hearing loss was defined as pure tone average (PTA, 0.5, 1.0, 2.0 kHz) of 20-40 dB HL or PTA > 25 dB HL at two or more frequencies above 2.0 kHz.

Figure 1. Mean (symbols) and  $\pm 1$  SD (dashed/solid lines) thresholds for CHL.



### PedsQL MFS

- 18 questions assess the perception of fatigue in children
- Assesses three subscales of fatigue:
  - General, Sleep/Rest, Cognitive
  - Provides a "Total Fatigue Score" by averaging across subscales
- Includes a child self-report and a parent proxy version
- Standardized, strong internal validity for children 5-18 years of age<sup>2</sup>
- Easy and fast (<5 minutes) to administer

Intraclass Correlation Coefficient (ICC) can be used as an index of absolute agreement between parent-proxy and child reports.

- <0.40: poor- to fair agreement
- 0.41 to 0.60: moderate agreement
- 0.61 to 0.80: good agreement
- > 0.81: excellent agreement<sup>6</sup>

In the past ONE month, how much of a problem has this been for you...

	Never	Almost Never	Sometimes	Often	Almost Always	Fatigue Subscale
I feel tired	0	1	2	3	4	General
I sleep a lot	0	1	2	3	4	Sleep/Rest
It is hard for me to keep my attention on things	0	1	2	3	4	Cognitive

Table 1: Sample questions from the child version of the PedsQL MFS

## RESULTS

	CHL	CNH
Number of child participants	33	33
Mean (SD) age in years	10.5 (1.8)	9.0 (2.29)
Mean (SD) age of identification of hearing loss in years	5.4 (3.2)	N/A
Number of males	15	21
Mothers who completed high school	27	31
Mean (SD) left ear PTA dB HL	40.0 (16)	$\leq 15$
Mean (SD) right ear PTA dB HL	37.2 (14)	$\leq 15$
Mean (SD) CELF score	85.5 (23.9)	109.2 (10.3)
Mean (SD) PPVT score	90.8 (17.8)	109.7 (12.0)
Mean (SD) TONI score	101.5 (13.7)	109.3 (9.6)

CELF: Clinical Evaluation of Language Fundamentals – 4<sup>th</sup> Edition; TONI: Test of Non-Verbal Intelligence – 4<sup>th</sup> Edition; Peabody Picture Vocabulary Test – 4<sup>th</sup> Edition.

### Fatigue in CHL vs. Parent Proxy Report

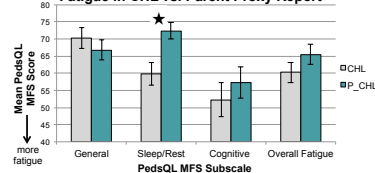


Figure 2. Parent proxy vs. CHL PedsQL MFS mean ( $\pm 1$  SD) fatigue scores.

- Consistent with prior work in other chronic conditions, mean data suggest that parents of CHL underestimate their child's fatigue, particularly in the sleep/rest domain (p=0.002).
- Similar, but non-significant, trends of parent proxy overestimation were seen in the cognitive (p=0.403) domain and for overall fatigue (p=0.100).
  - No such trend was apparent for the general fatigue domain
- A similar pattern of parent proxy-child differences was seen in our control group of CNH (data not shown).

Table 2. Summary of CHL and CNH demographic information and test scores. Bolded values indicate a significant group difference (p<0.05).

- As expected, CHL showed poorer language skills compared to CNH.
- Despite the significant difference in non-verbal intelligence, CHL scored within the average range for their age.

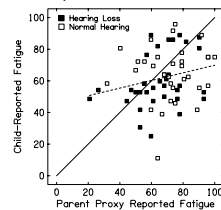


Figure 3. Comparison of child- and parent proxy reported fatigue using Overall Fatigue scores for CHL (filled squares) and CNH (open squares). Solid line represents what would be a perfect (1:1) correlation of reported fatigue. The dotted line shows the linear regression for child- and parent-proxy reported fatigue collapsed across groups. Similar patterns were observed across all fatigue domains.

- Agreement between parent proxy and child reports of fatigue was poor- to fair (ICC < 0.40) across all fatigue domains for CHL and CNH.
- Although mean differences were small, individual variability was large, with parent proxy-child differences ranging from -40 (overestimation by parents) to +50 (underestimation by parents).

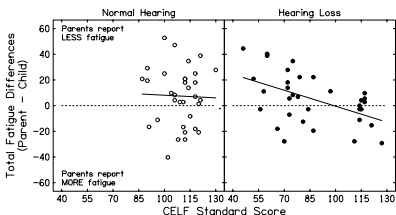


Figure 4. Difference between parent proxy- and child-reported fatigue based on Overall Fatigue scores displayed as a function of the child's language for CNH (left panel) and CHL (right panel). Parent proxy-child difference scores demonstrate whether parents tend to underestimate (positive difference) or overestimate (negative difference) their child's reported level of fatigue.

- Correlation analyses between parent proxy-child difference scores and the child's CELF scores revealed a moderate, negative relationship for CHL (r = -.503, p<0.05).
- No significant relationship was found for CNH (r = 0.31).

- Parents of CHL with lower language abilities underestimate their child's level of fatigue more than parents of CHL with higher language abilities.

## SUMMARY OF FINDINGS

Mean and individual fatigue scores with the PedsQL MFS indicate that parents of CHL tend to underestimate the levels of fatigue reported by their children, particularly in the sleep/rest domain. Parents of CNH show this same trend. The parental underestimation of child-reported fatigue found in this study is consistent with previous findings in other children with chronic illnesses.<sup>1,2,4,8</sup>

Several studies suggest that parent proxy reports do not provide adequate estimates of a child's self-report on internal, less visible domains such as fatigue.<sup>4,5</sup> Our results of poor to fair agreement between parent proxy and child reports of fatigue are consistent with these findings.

Parents of CHL with lower language abilities were more likely to underestimate their child's overall fatigue than were parents of CHL with higher language abilities. This suggests that a child's language level might affect the agreement of parent proxy and child reports on the PedsQL MFS.

## CONCLUSIONS

Fatigue is a common and complex phenomenon. The PedsQL MFS is a well-established, validated measure of subjective fatigue in children. However, our results suggest that there is generally fair- to-poor agreement between parent proxy and child scores in all subscales of fatigue. This fair- to-poor agreement was found between parents and school-age children with normal hearing and with mild- to moderate hearing loss. Because parents are likely to underestimate their child's own perception of fatigue, the parent proxy of the PedsQL MFS should not substitute a child's self-reported fatigue in clinical applications.

Notably, questions on the PedsQL MFS do not address fatigue directly related to hearing loss. This tool may lack the sensitivity to characterize fatigue associated with listening effort and speech processing – consequently misrepresenting the impact of hearing loss on fatigue in school-age children. At present, there are no evidence-based tools to quantify hearing-related fatigue in children. Future research efforts should be directed to developing such a tool that is validated and clinically feasible.

## KEY REFERENCES

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