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 disease). The Pediatric Quality of Life Inventory Multidimensional Fatigue Scale (PedsQL MFS) is a popular standardized questionnaire for measuring subjectively reported parent and child reports of fatigue.[1] Parents and teachers have long believed that children with hearing loss (CHL) may be at increased risk for fatigue.[2] To date, no research on fatigue in CHL is available. In 2014, Hornsby and colleagues reported significantly higher levels of fatigue in CHL (n=50) compared to children with normal hearing (CHN) using the PedsQL MFS.[3]

Measuring fatigue in children who do not have the language or cognitive skills to self-report may necessitate relying on parent 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.[4] Instruments specifically measuring fatigue in children with hearing loss are useful in the pediatric hearing loss population to help parents provide effective fatigue management for children with CHL, and the study aims to investigate whether parents of CHL accurately estimate their child’s subjective experience of fatigue.

PURPOSE

The purpose of this study was 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 age 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 (≤15 dB). Mean baseline fatigue was assessed at age 5-18 years (PedsQL MFS version 5-18, Intraclass Correlation Coefficient, ICC = 0.80). Children with sensorineural hearing loss, bilaterally.

PedsQL MFS

• To help assess the perception of fatigue in children
• Includes three sub-scales of fatigue: General Sleep/Rest Cognitive
• Provides a “Total Fatigue Score” by averaging scores across sub-scales
• Includes a child self-report and a parent proxy report
• Standardized, strong internal validity for children 4-18 years
• Easy to read (<5 minutes to administer)

Pediatric Fatigue Scale (PedsQL MFS) can be used as an index of agreement between parent-proxy and child reports:

- Over 0.5-1.0: Fair Agreement
- 0.41 to 0.60: Moderate agreement
- 0.61 to 0.80: Good agreement
- 0.81-1.0: Excellent agreement

In the past ONE month, if any of the problem has been this bad for you:

Felt too tired to do things
1 2 3 4
Felt too tired to keep up
1 2 3 4
Felt not as good as other kids
1 2 3 4
Fatigue Subscale

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

RESULTS

Table 2: Summary of CHL and CNH demographic information and test scores. Bolded values indicate a significant group difference (p<.05).

<table>
<thead>
<tr>
<th></th>
<th>CHL</th>
<th>CNH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of child participants</td>
<td>33</td>
<td>50</td>
</tr>
<tr>
<td>Mean (SD) age in years</td>
<td>10.5 (1.8)</td>
<td>9.0 (2.2)</td>
</tr>
<tr>
<td>Mean (SD) of identification of hearing loss in years</td>
<td>5.4 (3.2)</td>
<td>N/A</td>
</tr>
<tr>
<td>Number of males</td>
<td>15</td>
<td>21</td>
</tr>
<tr>
<td>Mothers who completed high school</td>
<td>27</td>
<td>31</td>
</tr>
<tr>
<td>Mean (SD) left ear PT/AHI</td>
<td>40.0 (16)</td>
<td>37.2 (14)</td>
</tr>
<tr>
<td>Mean (SD) right ear PT/AHI</td>
<td>40.0 (16)</td>
<td>37.2 (14)</td>
</tr>
<tr>
<td>Mean (SD) CELF score</td>
<td>80.2 (20)</td>
<td>109.2 (19.2)</td>
</tr>
<tr>
<td>Mean (SD) PPVT score</td>
<td>96.8 (17.6)</td>
<td>105.8 (12.0)</td>
</tr>
</tbody>
</table>

Fatigue in CHL vs. Parent Proxy Report

- 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<.001).

- Similar, but non-significant trends of parent proxy overestimation were seen in the cognitive domain (p>.05).

- No such trend was apparent for the general fatigue domain.

- A similar pattern of parent-proxy child differences was seen in a control group of CHL (data not shown).

- 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 -40 (underestimation by parents).

- Agreement between parent-proxy child differences for Overall Fatigue scores displayed as a function of the child’s language for CHL (dashed line) and CHL (open squares). Solid line represents what would be expected if there was no child-parent proxy difference.

- Overall Fatigue scores for CHL (filled squares) and CNH (open squares). The dotted line shows the linear regression for child- and parent-proxy scores.

- Mean data on Overall Fatigue scores displayed as a function of the child’s language for CHL (dashed line) and CHL (open squares). Solid line represents what would be expected if there was no child-parent proxy difference.

- Consistent with prior work in other chronic conditions, mean data for CHL (filled squares) and CNH (open squares) shows that agreement between parent proxy and child reports of fatigue are consistent with these findings.

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 CHL show decreased agreement rate. The parental underestimation of child-reported fatigue found in this study is consistent with previous findings in other children with chronic disease.[1-3]

Several studies suggest that proxy reports do not provide adequate estimates of a child’s self-report on internal, less visible domains such as fatigue.[4,5] Our results of poor to fair agreement between parent proxy and child-reported 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-good agreement between parent proxy and child reports across all subscales of this burden. This fair-to-good 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 overall fatigue, it is important to note that the findings from the current study 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 test 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 established tools to quantify hearing-related fatigue in children with CHL. Future research efforts should be directed to developing such a tool that is validated and clinically feasible.

KEY REFERENCES


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