The Perception of Otolaryngology-Related Diseases Among Parents of Children with Down Syndrome in Saudi Arabia

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Disclosure

The authors have no actual or potential conflict of interest.
Down syndrome (trisomy 21) is the most common chromosomal abnormality in humans. ¹

The incidence in Saudi Arabia: 1 /554 births. ²

It is well known that Otolaryngology-problems are more common in children with Down syndrome. ³

Care of children with Down syndrome has improved significantly.

Objectives

- To assess the perception of Otolaryngology-related diseases among parents of children with Down syndrome.

- To assess the care of children with Down syndrome in terms of regular follow up.
Method

- **Study design:** Cross-sectional survey.

- **Setting:** World Down Syndrome Day event on the 21\textsuperscript{st} March, 2013.
  
  Organized by Princess Al-Jawhara Center of Excellence in Research of Hereditary Disorders.

- **Subjects:** Parents of children with Down syndrome attending the event.

- **Method:** Convenience sampling approach, distributing questionnaires to parents who attended the event and those who visited the Otolaryngology booth.
Questionnaire measured perception about:

- Ear wax
- Otitis media
- Hearing loss
- Difficulty understanding words
- Delayed speech
- Difficulty in learning
- Difficulty in interacting with others
- Snoring
- Obstructive sleep apnea
- Allergic rhinosinusitis
Results

- 78 questionnaires were filled.
- Data analysis completed using SPSS
Results

Visited an Otolaryngologist

- Yes: 78%
- No: 22%

Regular follow up

- Yes: 70%
- No: 30%
Results

Perception

- Delayed speech: 16%
- Ear wax: 15%
- Snoring: 12%
- Allergic rhinosinusitis: 10%
- Hearing loss: 10%
- Difficulty in learning: 9%
- Otitis media: 7%
- Difficulty in interacting with others: 7%
- Obstructive sleep apnea: 6%
- Difficulty understanding words: 5%
## Results

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Perceived</th>
<th>Experienced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ear wax</td>
<td>35 (14.6%)</td>
<td>21 (14.4%)</td>
</tr>
<tr>
<td>Otitis media</td>
<td>18 (7.5%)</td>
<td>10 (6.8%)</td>
</tr>
<tr>
<td>Hearing loss</td>
<td>23 (9.6%)</td>
<td>18 (12.3%)</td>
</tr>
<tr>
<td>Difficulty understanding words</td>
<td>15 (6.3%)</td>
<td>9 (6.2%)</td>
</tr>
<tr>
<td>Delayed speech</td>
<td>38 (15.9%)</td>
<td>32 (21.9%)</td>
</tr>
<tr>
<td>Difficulty in learning</td>
<td>22 (9.2%)</td>
<td>12 (8.2%)</td>
</tr>
<tr>
<td>Difficulty in interacting with others</td>
<td>18 (7.5%)</td>
<td>9 (6.2%)</td>
</tr>
<tr>
<td>Snoring</td>
<td>29 (12.1%)</td>
<td>16 (11%)</td>
</tr>
<tr>
<td>Obstructive sleep apnea</td>
<td>17 (7.1%)</td>
<td>11 (7.5%)</td>
</tr>
<tr>
<td>Allergic rhinosinusitis</td>
<td>24 (10%)</td>
<td>8 (5.5%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>239</strong></td>
<td><strong>146</strong></td>
</tr>
<tr>
<td>Frequencies on perception</td>
<td>Does your child have any of those condition?</td>
<td>Total (perceived)</td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td>---------------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td></td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Ear wax</td>
<td>31</td>
<td>4</td>
</tr>
<tr>
<td>Otitis media</td>
<td>18</td>
<td>0</td>
</tr>
<tr>
<td>Hearing loss</td>
<td>21</td>
<td>2</td>
</tr>
<tr>
<td>Difficulty understanding words</td>
<td>14</td>
<td>1</td>
</tr>
<tr>
<td>Delayed speech</td>
<td>34</td>
<td>4</td>
</tr>
<tr>
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<td>19</td>
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<td>3</td>
</tr>
</tbody>
</table>
Discussion
Speech Delay (P: 48%, E: 41%)

- Multiple factors.
- Cognitive deficits in 80%.  
- Hearing loss in 78%.  
  (P: 29%, E: 23%).

Factors influencing hearing:

increased incidence of OME and a high rate of under-diagnosis and under-treatment.  

P: 23%, E:12%.


40-50% of the newborns with DS have stenotic ear canals. 

P: 44%, E: 26%.

Snoring (P: 37%, E: 20%)

- A symptom of OSA.
- Incidence estimated at 31-63%\(^8,9\).
- OSA, P: 21%, E: 14%.


Discussion

- The marked difference between the incidence of ORL issues in our study and other studies could be attributed to the use of parental reporting to determine the experienced conditions.

- Underestimation of the presence of these conditions among the children.
Limitations

- Parents and children demographics were not included in the survey.
Parents are not familiar with these ORL-related diseases.

Perception of parents is highly influenced by their child’s experience with the condition.

Many of the children did not have regular follow up and some did not visit an otolaryngologist before.
Recommendations

- Spread awareness among 1ry and 2ry health care physicians about the importance of educating parents about common ORL-related diseases affecting children with DS.

- Raise awareness regarding the need for regular follow up visits for children with DS.

Future studies:

Include parents and children demographics to better reach the most misinformed segment of the population.
Thank you ...