Comparing Quality of Life in Families with Children with Down Syndrome, Autism Spectrum Disorder, or a DS+ASD Diagnosis

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BACKGROUND

Individuals with developmental disabilities, such as DS and ASD, may have challenges with behavioral regulation, communication, and social relatedness, which may impact family quality of life and functioning. Prior studies have focused on parental wellbeing in the Down syndrome (DS), Autism (ASD) and both ASD and DS (DS+ASD) populations 1, 2, 3, but few have compared overall quality of life (QoL) between these groups nor investigated factors that may impact QoL.

OBJECTIVES/AIMS

This retrospective study compares parent report of quality of life and overall family functioning among clinical populations of children who have (1) DS, (2) ASD, and (3) DS+ASD diagnoses.

DESIGN/METHODS

Measures:

- PedsQL Family Impact Module 2.0 (PedsQL FIM): 36-item parent-report measure of family quality of life. It includes:
  - Overall score
  - Parent functioning score
  - Family functioning score
  - Sub-scale scores
- Parent impression of Child’s Global Functioning (PGI): parent-reported, single-item measure as a proxy for overall impression of child functioning rated on a scale of 1-7. This is a modified version of the Clinical Global Impression – Severity (CGI-S) scale.

Participating Patients:

- Families of patients with ASD (N=610), DS (N=177), and DS+ASD (N=37) completed the PedsQL FIM.
- ASD cohort (N=177) was gender-matched to the DS cohort (N=177).
- ASD and DS cohorts were gender matched to DS+ASD (N=37) to remove gender bias.

Statistical Analysis:

- Scoring of data and t-tests to look for differences in participant characteristics among diagnosis groups.

RESULTS

![PedsQL FIM Sub-Scale Scores by Diagnosis](image)

Table 1. Participant Characteristics and PedsQL Scores for Children with DS or ASD (N=37 vs. N=177)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Age (SD)</th>
<th>Mood Disorder**</th>
<th>Social Communication*</th>
<th>Behavioral Disorder</th>
<th>Communication Disorder</th>
<th>DSM+ASD** vs. ASD**</th>
</tr>
</thead>
<tbody>
<tr>
<td>DS (N=177)</td>
<td>72.8 (17.3)</td>
<td>66.9 (20.1)</td>
<td>66.2 (17.3)</td>
<td>77 (99)</td>
<td>70.2 (21.4)</td>
<td>0.0</td>
</tr>
<tr>
<td>ASD (N=37)</td>
<td>72.8 (17.3)</td>
<td>66.9 (20.1)</td>
<td>66.2 (17.3)</td>
<td>77 (99)</td>
<td>70.2 (21.4)</td>
<td>0.0</td>
</tr>
</tbody>
</table>

CONCLUSIONS

This study demonstrates higher QoL and family functioning in families of patients with DS compared to those with ASD and a DS+ASD diagnosis.

REFERENCES