



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)⁴: 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)⁵: 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.
 • 1 = Needs 24 hour professional care
 • 7 = Excellent functioning
Participants:
 • 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:
 • Chi-square and 2-sample t-tests to look for differences in participant characteristics among diagnosis groups.

RESULTS

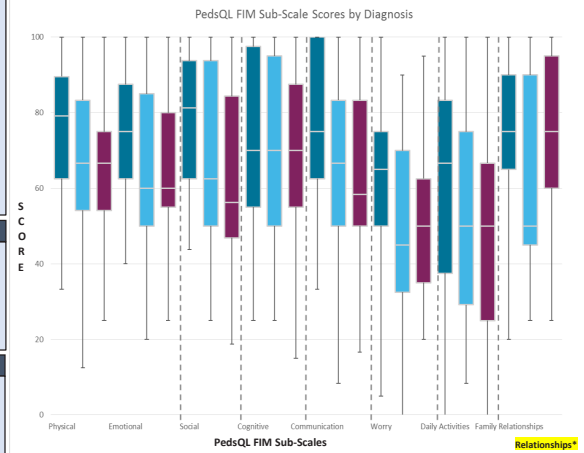


Figure 1: PedsQL FIM Sub-Scale Scores by Diagnosis ($p < 0.05 = *$; $p < 0.01 = **$)
 ■ = DS ■ = ASD ■ = DS+ASD

PedsQL FIM Questions

PedsQL FIM Instructions to Caregivers:
 Families of children sometimes have special concerns or difficulties because of the child's health. Please tell us **how much of a problem** each one has been for you during the **past 7 days** by circling:
 0 if it is **never** a problem
 1 if it is **almost never** a problem
 2 if it is **sometimes** a problem
 3 if it is **often** a problem;
 4 if it is **almost always** a problem.
 Items are reversed scored and linearly transformed to a 0-100 scale as follows:
 0=100=GREAT functioning, 1=75, 2=50, 3=25, 4=0=POOR functioning

Sample PedsQL Family Impact Module 2.0

I worry about how others will react to my child's condition.

I worry about how my child's illness is affecting other family members.

Conflicts between family members.

Stress or tension between family members.

I have trouble getting support from others.

It is hard to find time for social activities.

I feel helpless or hopeless.

I feel frustrated.

RESULTS (Continued)

Table 1. Participant Characteristics and PedsQL Scores for Children with DS or ASD ($p < 0.05 = *$; $p < 0.01 = **$)

	DS (N=177)	ASD (N=177)
Co-Occurring Diagnoses (% yes)		
Medically Complex**	24%	7%
Mood Disorder**	8%	25%
ADHD**	8%	52%
Behavioral Disorder	10%	8%
Communication Disorder	20%	15%
PedsQL Summary and Sub-Scale Scores [Mean (SD)] – Higher is Better		
Overall**	70.5 (17.2)	67.2 (19.9)
Parent Functioning	71.9 (17.8)	69.1 (19.9)
Family Functioning*	70.5 (21.5)	64.4 (23.1)
Physical Functioning*	71.3 (20.2)	70.7 (21.7)
Emotional Functioning*	70.9 (18.7)	66.2 (21.9)
Social Functioning*	73.3 (23.3)	68.3 (24.7)
Cognitive Functioning*	73.3 (22.0)	70.2 (23.9)
Communication*	76.4 (21.4)	70.2 (21.4)
Worry**	61.5 (21.7)	61.2 (19.3)
Daily Activity**	69.3 (26.8)	66.3 (27.9)
Family Relationship**	77.8 (21.1)	68.6 (24.0)
PGI (1-7 Higher is Better)	4.2 (1.4)	4.5 (1.1)

Table 2. Participant Characteristics and PedsQL Scores for Children with DS, ASD, or DS+ASD Diagnosis ($p < 0.05 = *$; $p < 0.01 = **$)

	DS (N= 37)	ASD (N= 37)	DS+ASD (N= 37)
Age (SD)*	7.8 (5.7)	9.6 (3.9)	10.6 (4.0)
Co-Occurring Diagnoses (% yes)			
Medically Complex	19%	8%	24%
Mood Disorder**	3%	16%	3%
ADHD**	5%	27%	11%
Behavioral Disorder	11%	8%	24%
Communication Disorder	27%	11%	32%
PedsQL Summary and Sub-Scale Scores [Mean (SD)] – Higher is Better			
Overall*	72.2 (16.5)	62.9 (19.6)	63.6 (17.4)
Parent Functioning	72.8 (17.3)	66.8 (20.1)	66.2 (17.3)
Family Functioning*	73.5 (20.8)	59.1 (21.8)	65.0 (21.9)
Physical Functioning	75.2 (19.5)	67.9 (21.6)	64.8 (22.7)
Emotional Functioning*	74.5 (16.0)	62.8 (22.0)	65.7 (19.8)
Social Communication*	78.5 (17.5)	66.7 (25.3)	63.2 (25.2)
Physical Functioning	71.4 (22.8)	69.3 (24.8)	70.4 (22.7)
Cognitive Functioning*	77.9 (19.5)	67.8 (22.1)	64.4 (23.3)
Communication*	61.9 (26.8)	50.7 (24.9)	50.8 (19.7)
Worry*	61.9 (26.8)	53.2 (26.6)	48.6 (27.3)
Daily Activity*	61.9 (26.8)	62.7 (23.9)	74.7 (21.7)
Family Relationship*	76.2 (20.2)	67.2 (23.9)	74.7 (21.7)
PGI (1-7 Higher is Better)**	4.6 (1.4)	4.4 (1.3)	4.2 (1.1)

SUMMARY

- DS vs. ASD:**
- Families in DS group reported higher overall QoL compared to those in the ASD group with fewer problems reported in:
 - Emotional
 - Social
 - Communication
 - Worry
 - Family Relationships
- DS vs. ASD vs. DS+ASD:**
- Families in DS group reported higher overall QoL and family functioning compared to both ASD and DS+ASD groups.
 - Overall impression of child functioning (PGI) was better for the DS and ASD groups than the DS+ASD group.
 - Problems with family relationships were significantly higher in ASD group vs. DS and DS+ASD groups.

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.

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