Factors Affecting the Global Health Status of Children with ASD: An Analysis of PROMIS Pediatric Global Health Parent-Proxy Data from the Interactive Autism Network

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**Background**

The overall well-being or "global health" of children with autism is important. Identifying specific factors associated with poor global health may lead to improved treatment and care.

**Objectives**

- To determine factors associated with global health as measured by the Patient-Reported Outcomes Measurement Information System (PROMIS) Pediatric Global Health measure (PGH-7) parent-proxy report.

**Methods**

- Parent participants in the Interactive Autism Network (IAN)—a large, internet-mediated, parent-report research registry—completed the PGH-7 about their children age 5-17 with ASD.
- All children had a professional diagnosis of ASD, with a confirmatory score on the Social Communication Questionnaire (SCQ) screener ≥12 and a Social Responsiveness Scale (SRS) T-score ≥60. Parent report of ASD in IAN has been validated (Lee et al., Marvin et al.) and verified (Daniels et al.).
- Demographic data was collected during IAN registration.
- PGH-7 is a validated 7-item measure that assesses a parent’s overall evaluations of the physical, mental, and social health of his or her child. Responses to each question range from 1 (worst) to 5 (best). Raw total scores (the sum of the 7 question scores; min=7, max=35) are converted to standardized T-scores (Mean=50; SD=10).
- Parents also completed IAN’s Birth and Diagnosis Questionnaire (BDQ), which: (i) collects baseline data on birth, ASD diagnosis, and development; (ii) asks about the degree to which the child has experienced 15 common conditions/difficulties associated with ASD during the past 30 days; (iii) includes questions on parental marital status and household income. Proxy for intellectual disability (ID): rating of “significantly below age level” on cognitive functioning question and/or IQ score < 70. Normal verbal ability: rating of “meaningful, fluent speech”.
- Analysis was limited to children who resided in the US and who had the BDQ at age 5 or older due to complications relating to assigning verbal ability status to younger children.

**Results**

- **Demographics:** n=1,052; 79% male; 86% white; 10% Hispanic; mean (SD) age at completion of PGH-7 12.3 (3.36) years.
- **Household information:** 80% of parents married or in committed relationship; median income $60,000-$69,999.
- **PGH-7 T-Scores:** Mean (SD) for IAN = 40.3 (7.6); thus, IAN mean T-Scores are approximately 1 SD below the norm. 52.7% scored >1SD below mean, with 8.3%-2SD below mean. See Figure 1 for IAN PGH-7 T-Score distribution compared to standardized normal distribution.
- **Multiple linear regression** was performed on the PGH-7 raw total score. The number predictors reduced to six, with global health inversely related to (i) age and (ii) SRS raw score, the presence of (iii) irritability/aggression and (iv) depression, and difficulties with (v) feeding and (vi) bowel movements, with no multicollinearity. \( R^2 = 0.21, F(6, 889) = 38.56, p < 0.001. \)
- **Ordered logistic regression** was performed on each of the PGH-7 items. The greatest areas of concern are socialization (Item 6), mental health (Item 4), and “sadness” (Item 6). See Table 1.
- Variables included in regression analyses are listed in Table 1.

<table>
<thead>
<tr>
<th>Item</th>
<th>Very Good/ Excellent</th>
<th>Good</th>
<th>Fair/Poor</th>
<th>Variables Associated with PGH-7 Score at p&lt;0.04</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. In general, would you say your child's health is:</td>
<td>729 (69.3)</td>
<td>256 (24.5)</td>
<td>65 (6.2)</td>
<td>3.9 (0.7)</td>
</tr>
<tr>
<td>2. In general, would you say your child's quality of life is:</td>
<td>707 (69.4)</td>
<td>265 (26.2)</td>
<td>78 (7.4)</td>
<td>3.8 (0.9)</td>
</tr>
<tr>
<td>3. In general, how would you rate your child's physical health?</td>
<td>716 (68.1)</td>
<td>250 (23.8)</td>
<td>86 (8.2)</td>
<td>3.8 (0.9)</td>
</tr>
<tr>
<td>4. In general, how would you rate your child's mental health, including your mood and your ability to think?</td>
<td>252 (24.9)</td>
<td>432 (41.1)</td>
<td>388 (35.0)</td>
<td>2.9 (0.5)</td>
</tr>
<tr>
<td>5. How often does your child feel your child is really sad?</td>
<td>365 (34.7)</td>
<td>541 (51.4)</td>
<td>146 (13.9)</td>
<td>3.2 (0.74)</td>
</tr>
<tr>
<td>6. How often does your child feel your child are fun with friends?</td>
<td>228 (21.7)</td>
<td>383 (36.4)</td>
<td>441 (41.9)</td>
<td>7.2 (1.56)</td>
</tr>
<tr>
<td>7. How often does your child feel that you listen to his or her ideas?</td>
<td>712 (67.7)</td>
<td>274 (26.0)</td>
<td>66 (6.3)</td>
<td>4.0 (0.78)</td>
</tr>
</tbody>
</table>

**Conclusions**

- Children with ASD in IAN have significantly lower well-being than the general child population.
- Depression is the main condition associated with poor global health in children with ASD.
- Other potentially treatable conditions associated with poor global health in children with ASD include: feeding problems, difficulty with bowel movements, difficulty with movement/coordinating, and challenging behaviors (e.g., irritability/aggression, difficulty controlling emotions, self-injurious behavior).
- Treatment of a few key conditions has the potential to significantly increase well-being in children with ASD.

**Support and Acknowledgements**

IAN is a partnership project of the Kennedy Krieger Institute and the Simons Foundation. IAN is also partially funded through a Patient-Centered Outcomes Research Institute (PCORI) Award for development of the National Patient-Centered Clinical Research Network, known as PCORnet. A special thank you to IAN Families for making this study possible.