

Research Paper

Factors associated with parental ratings of condition severity for children with autism spectrum disorder

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Abstract

Background: There is currently little consensus on how the severity of a child's autism spectrum disorder (ASD) should be measured, and yet despite the lack of a standardized definition, parents were readily able to answer a question asking them to describe the severity of his/her child's ASD in a national survey.

Objective: The current study examined factors associated with a parent's judgment of ASD severity, by identifying child and household characteristics that were associated with a parent's severity rating of his/her child's ASD, including child ASD symptomatology, child impact, and family impact.

Methods: Data came from the 2011 Survey of Pathways to Diagnosis and Services ("Pathways"). A total of 967 parents in households with a child diagnosed with ASD between the ages of 6–17 were eligible for the current study. A measurement model was used to create latent factors of child symptoms, child impact, and family impact; multivariate logistic regression models examined the relationship between these latent factors and the parent's severity rating of their child's ASD.

Results: Children with higher family impact factor scores were more likely to have parents who rated their child's ASD as the most severe. Surprisingly, symptomatology and impact on the child were less predictive of severe ratings.

Conclusions: A parent's conceptualization of their child's ASD severity may vary more as a function of the impact of the child's condition on the family and less as a function of the symptoms exhibited by the child or the impact directly felt by the child. Published by Elsevier Inc.

Keywords: Autism spectrum disorders; Parents; Severity; National survey; Developmental disability

Autism spectrum disorder (ASD) is a neurodevelopmental disability that affects approximately 1 in 50 school-aged children (6–17 years old) in the United States according to a recent national survey.¹ Children diagnosed with ASD are characterized by their social and communication deficits along with stereotyped and repetitive behaviors.² Co-occurring psychiatric conditions as well as intellectual disabilities are common in children diagnosed with ASD, with a substantial percentage of children also being diagnosed with attention deficit/hyperactivity disorder.^{3–5}

Children diagnosed with what is considered severe ASD are more likely to have received an earlier diagnosis than those less impaired,^{6,7} but definitions of severity fluctuate between studies, with little consensus on how severity should

be measured.⁸ To date, some definitions of severity have included the number and intensity of core symptoms, the overall level of functional impairment displayed by the child, and the child's ASD diagnosis subtype (e.g., Asperger's Disorder, Autistic Disorder). Additional definitions have focused on the presence of secondary diagnoses, including intellectual disabilities, behavioral problems, and learning disabilities. The notable variety in the definitions of severity is evidenced by the substantial number of rating scales that are currently available,^{9–12} with researchers defining higher scores as greater severity.^{13–16} Although these scales have considerable overlap in content, they can vary by their intended rater (teacher, clinician, or parent) and may be administered in multiple locations, thereby providing multiple contexts. As a result, severity as a construct has the potential to be conceptualized differentially by different types of raters with varying interpretations of the same symptoms.

There is the additional possibility that a reporter's assessment of a child's ASD severity may be influenced by subjective experiences. Previous research utilizing data from the National Survey of Children's Health has found that a parent's rating of the severity of his/her child's

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ASD is associated with various family characteristics. Children whose parents reported poor mental health, high stress levels, and greater burdens requiring higher levels of personal sacrifice were more likely to be described as having moderate to severe ASD.^{17–19} In addition, children who were not receiving family-centered care or effective care coordination were more likely to be described as having moderate to severe ASD than mild ASD.²⁰ Severity, however, was not found to be a significant correlate of educational services, with children with severe ASD being no more likely to have an Individualized Education Program (IEP) than children with mild ASD.²¹

A recent National Center for Health Statistics (NCHS) National Health Statistics Report examined parent-reported data from the 2011–2012 National Survey of Children's Health (NSCH), which included a question about whether the parent would "describe their child's autism or ASD as mild, moderate, or severe." Blumberg and colleagues¹ found that school-aged children who were diagnosed with an ASD in or after 2008 were more likely to be described as having a milder ASD (and less likely to have a severe ASD) when compared to children diagnosed with an ASD in or before 2007. This result led to the conclusion that much of the recent observed increase in prevalence of ASD was due to improved awareness and ascertainment of ASD by doctors and other health care professionals when the symptoms are mild.¹ The conclusion rested on the assumption that parents are reliable reporters of ASD severity, yet it is largely unknown how parents of children with ASD conceptualize the severity of his/her child's condition, especially when asked a simple survey question with limited response options.

The current study represents a population-based effort to explore a parent's conceptualization of his/her child's ASD severity by investigating related factors of child symptoms, child impact, and family impact on a parent's rating of ASD severity. It is hypothesized that all factors will independently be associated with severity ratings. Family impact is expected to have a stronger association than other factors in a combined model because stressors that directly impact the rater are likely to be more readily recalled and accessible when forming judgments.²²

Methods

Sample

Data are drawn from two national surveys conducted by the National Center for Health Statistics (NCHS): the 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) and the 2011 Survey of Pathways to Diagnosis and Services ("Pathways"). Both surveys were modules of NCHS' State and Local Area Integrated Telephone Survey (SLAITS). The 2009–2010 NS-CSHCN was sponsored by the Maternal and Child Health Bureau of the U.S. Department of Health and Human Services' Health Resources and Services Administration, and

the Pathways survey was sponsored by the National Institutes of Health's National Institute of Mental Health. All consent and data collection procedures for the 2009–2010 NS-CSHCN and Pathways were previously approved by the NCHS Research Ethics Review Board, with participants giving informed consent prior to inclusion in the study. More information about Pathways and 2009–2010 NS-CSHCN may be found at: <http://www.cdc.gov/nchs/slaits/spds.htm> or by referring to the associated documentation published by the SLAITS program.^{23,24}

The 2009–2010 NS-CSHCN was a cross-sectional telephone survey that interviewed 40,242 households with children with special health care needs (CSHCN) throughout the 50 states and the District of Columbia. Households eligible for the 2009–2010 NS-CSHCN had one or more CSHCN up to 17 years of age. CSHCN include children who have one or more chronic physical, developmental, or emotional conditions which require health and related services of a type or amount beyond that generally required by children.²⁵ Only one child with special needs was sampled from each eligible household; if more than one child was eligible, one was randomly selected to be the subject of the 2009–2010 NS-CSHCN interview.

Pathways was a follow-back survey to the 2009–2010 NS-CSHCN for CSHCN aged 6–17 years who had ever been diagnosed with a developmental delay, autism spectrum disorder, or intellectual disability ($n = 4032$). Initial follow-back interviews were conducted via telephone with the same parent or guardian who responded to the 2009–2010 NS-CSHCN. Then, an additional supplemental questionnaire was either mailed to the household or administered over the telephone. The 2009–2010 NS-CSHCN had a 26% response rate, while Pathways had a 62% completion rate for the general survey and a 44% completion rate for the supplemental questionnaire.

The current study analyzed 2009–2010 NS-CSHCN and Pathways data for CSHCN who had a current ASD diagnosis at the time of the Pathway survey and who had a completed and returned supplemental questionnaire ($n = 967$) (see Fig. 1 for sampling plan). Given that children diagnosed with ASD are almost exclusively identified as CSHCN as a result of their need for routine health and related services,²⁶ and 95% of children with a current ASD diagnosis were identified as having a special health care need in the 2011–2012 National Survey of Children's Health,²⁷ hereafter we will simply identify them as children with ASD rather than CSHCN with ASD.

Measures

Children's Social Behavioral Questionnaire (CSBQ)

The CSBQ is a 49 item instrument that was developed to determine the presence and severity of social or behavior problems within the autism spectrum.²⁸ Parents were asked how frequently during the past month his/her child had engaged in specific behaviors, with the possible responses

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