Family Impacts Among Children With Autism Spectrum Disorder: The Role of Health Care Quality

*Katharine E. Zuckerman, MD, MPH; Olivia J. Lindly, MPH;
Christina D. Bethell, PhD, MPH, MBA; Karen Kuhlthau, PhD*

From the Child and Adolescent Health Measurement Initiative (Drs Zuckerman and Bethell, and Ms Lindly), Division of General Pediatrics (Dr Zuckerman), Oregon Health & Science University, Portland, Ore; Department of Public Health, Oregon State University, Corvallis, Ore (Ms Lindly); Center for Child and Adolescent Health Research and Policy, Massachusetts General Hospital for Children, Boston, Mass (Dr Kuhlthau); and Division of General Pediatrics, Department of Pediatrics, Harvard Medical School, Cambridge, Mass (Dr Kuhlthau)

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Address correspondence to Katharine E. Zuckerman, MD, MPH, Oregon Health & Science University, Mail Code CDRC-P 707 SW Gaines Rd, Portland, OR 97239 (e-mail: zuckerma@ohsu.edu).

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ABSTRACT

OBJECTIVE: To compare health care quality and family employment and financial impacts among children with special health care needs (CSHCN) with autism spectrum disorder (CSHCN + ASD), CSHCN with functional limitations (CSHCN + FL), and CSHCN lacking these conditions (other CSHCN); to test whether high health care quality was associated with reduced family impacts among CSHCN + ASD.

METHODS: Data from the 2009–2010 National Survey of CSHCN were used to compare 3025 CSHCN + ASD, 6505 CSHCN + FL, and 28,296 other CSHCN. Weighted multivariate logistic regression analyses examined 6 age-relevant, federally defined health care quality indicators and 5 family financial and employment impact indicators. Two composite measures were additionally used: 1) receipt of care that met all age-relevant quality indicators; and 2) had ≥2 of the 5 adverse family impacts.

RESULTS: Across all health care quality indicators, CSHCN + ASD fared poorly, with only 7.4% meeting all age-relevant indicators. CSHCN + ASD had worse health care quality than other CSHCN, including CSHCN + FL. CSHCN + ASD also had high rates of adverse family impact, with over half experiencing ≥2 adverse impacts. Rates of adverse family impact were higher in CSHCN + ASD than other CSHCN, including CSHCN + FL. Among CSHCN + ASD, those whose health care that met federal quality standards were less likely to have multiple adverse family impacts than CSHCN + ASD whose health care did not meet federal quality standards.

CONCLUSIONS: CSHCN + ASD are more prone to experience poor health care quality and family impacts than other CSHCN, even CSHCN + FL. Receipt of care meeting federal quality standards may potentially lessen adverse family impacts for CSHCN + ASD.

KEYWORDS: autism spectrum disorder; children with special health care needs; delivery of health care; integrated; disabled children; family burden; family health; financial burden; quality of health care

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WHAT'S NEW

Children with autism spectrum disorder (ASD) experienced more adverse family impacts and lower health care quality than other children with special health care needs, including those with functional limitations. Quality health care was associated with reduced family impact among children with ASD.

AUTISM SPECTRUM DISORDER (ASD) affects up to 1 in 50 US school-aged children,[1] and recent evidence suggests that the diagnosis is becoming more prevalent.[1,2] ASD involves problems with social communication and behavior, and the condition, along with its comorbidities, have been associated with impaired child and family functioning.[3,4] Many children with ASD require intensive educational, behavioral, and health care services, which require significant financial, time, and care coordination investments for families.[5,6]

In general, parents of children with special health care needs (CSHCN) are at increased risk of under- or unemployment,[7,8] financial stress,[9] family burden,[10] poor health-related quality of life,[11] worse physical and mental health, and poorer psychological well-being.[12,13] For CSHCN with ASD in particular, data from the 2005–2006 National Survey of Children With Special Health Care Needs (NS-CSHCN) demonstrate that the families have higher risk for financial and employment burden than families of other CSHCN, including CSHCN with other emotional, developmental, or behavioral problems. However, medical home care was associated with lower family financial impact.[14] In another national data set, Montes and Halterman[15] found that 39% of children with ASD had parents reporting that child care problems

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affected their employment decisions, compared to 9% of typically developing children.

This study sought to address several gaps in existing literature addressing health care quality and adverse family impacts in ASD. First, accelerating ASD diagnosis rates over the past 5 years, including a near doubling of prevalence in national parent-reported surveys,[2] have led to demographic changes in children considered to have ASD. With diagnoses occurring among younger children,[16,17] children with less severe[1] or more variable[17] phenotypes, and children with psychiatric or developmental comorbidities,[17,18] family burdens may have changed since previous studies were conducted. For instance, family impacts may have lessened as younger and relatively healthier children are diagnosed with ASD, or they may have increased as children with ASD have become more medically complex or as health care benefits have become less generous.[19] Likewise, health care quality may have changed: quality may have improved as providers become more familiar with ASD or deteriorated as health and educational systems become overburdened by children with ASD.

Previous studies additionally did not consider that ASD is associated with increased functional deficits compared to other emotional, behavioral, and developmental conditions.[20] Consequently, some of the family burden associated with ASD may be due to higher prevalence of functional deficits in this population rather than factors unique to ASD.[21] Finally, previous studies only assessed medical home as a correlate of family burden, although other quality measures, such as insurance adequacy, have strong associations with family burden overall[22,23] and may be important modifiers of family burden for ASD.

This study therefore further investigated the relationship of health care quality with family burden among children with ASD. The study used a national data set with more recent data, a broader array of family impacts, and a federal quality measurement framework, the Maternal Child Health Bureau's (MCHB) System of Care Core Outcomes. The study additionally accounts for differences between ASD versus other special health care needs that limit functioning.

We hypothesized that adverse family impacts would be prevalent among children with ASD, would be worse than other CSHCN (who experience substantial adverse impacts), and would be particularly worse than CSHCN with functional limitations (FL; considered the highest-risk group of CSHCN).[24] We also hypothesized that although health care quality would be worse in ASD compared to other CSHCN, high-quality care would be associated with fewer adverse impacts among CSHCN with ASD.

METHODS

DATA SOURCE

The 2009–2010 NS-CSHCN is a random-digit dial survey designed and sponsored by the MCHB and administered by the Centers for Disease Control's National Center for Health Statistics.[25] A household is included in the sample if it contains ≥1 CSHCN aged <18 years. The MCHB defines CSHCN as those who "have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related service of a type or amount beyond that required by children generally."[26] Special health care needs status is assessed using the CSHCN Screener, a non-condition-specific, consequences-based measure.[27] In the survey, a parent or guardian (herein called "parent") is interviewed about 1 CSHCN per household. Prevalence for all variables can be weighted to represent noninstitutionalized populations of US children and CSHCN. The combined landline and cell phone response rate in the 2009–2010 NS-CSHCN was 25.5%; completed interview response rate was 80.8%.[25] The National Center for Health Statistics institutional review board approved the survey protocol.

SAMPLE

In this analysis, CSHCN with ASD (CSHCN + ASD) were compared to CSHCN without ASD who had FL (CSHCN + FL) and CSHCN who had neither ASD nor FL (other CSHCN). CSHCN + ASD were defined as those CSHCN aged 3 to 17 whose parent answered "yes" to the question, "Has a doctor or other health care provider ever told you that your child had autism, Asperger disorder, pervasive developmental disorder, or other autism spectrum disorder?" and "yes" to the question, "Does your child currently have autism or an autism spectrum disorder?"

We compared CSHCN + ASD to CSHCN + FL because CSHCN + FL are generally considered as the highest-acuity group of CSHCN—only about 24% of CSHCN have FL, but this group uses more health care resources than other CSHCN.[28] In the survey, CSHCN + FL were defined as CSHCN aged 3 to 17 whose parents gave affirmative responses to the items, "Is your child limited or prevented in any way in his/her ability to do the things most children of the same age can do?" and "Is your child's limitation in abilities because of any medical, behavioral, or other health condition?," and who did not have ASD as defined above. Children with current ASD and FL were classified as CSHCN + ASD, although sensitivity analyses examined this group separately. We also compared CSHCN + ASD to other CSHCN. "Other CSHCN" were defined as CSHCN aged 3 to 17 with neither ASD nor FL.

MEASURES

Health care quality was measured using the MCHB's Six Core Outcomes, which were designed to promote the community-based system of services mandated for CSHCN under Title V and Healthy People 2020.[29] Outcomes include shared decision making between families and health care providers; receipt of medical home care; consistent, adequate health insurance coverage over the past 12 months; receipt of preventive medical and dental care; access to community-based services; and receipt of health care transition services for youth with special health care needs. Each measure had multiple subcomponents (Table 1). We also constructed a composite measure of CSHCN meeting all age-relevant quality measures.

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