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Health Care Experiences and Perceived Financial Impact Among Families of Children With an Autism Spectrum Disorder

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Abstract

Objective—The authors compared the health care experiences of families raising a child with autism spectrum disorder (ASD), an intellectual disability disorder (IDD), or attention-deficit hyperactivity disorder (ADHD).

Methods—Children with a current diagnosis of ASD (N=3,005), ADHD (N=9,662), or IDD (N=949) were identified in the 2009–2010 National Survey of Children With Special Health Care Needs. Weighted structural equation modeling was used to determine the association between family satisfaction with medical care, timeliness of care, and medical insurance coverage and the impact of the child's condition on the family's financial situation.

Results—Families of children diagnosed as having ASD comorbid with either ADHD or IDD or comorbid with both conditions reported the highest levels of dissatisfaction across all health care quality variables and experienced the greatest impact on the family's financial situation.

Conclusions—The findings underscore the need for comprehensive and accessible health care services for children with ASD, particularly those with comorbid conditions.

Children with autism spectrum disorders (ASDs) often present with a complex set of behavioral symptoms that require extensive intervention from a variety of health care professionals (1). Unfortunately, the health care system has struggled to keep pace with the rising prevalence of ASD. As a result, families face multiple obstacles in accessing and receiving adequate care, with many experiencing financial hardships (2). Research on this topic is critical in substantiating the need for improving health care quality for these families.

Families of children with ASD frequently experience difficulty obtaining a timely initial diagnostic evaluation. The literature indicates families see an average of four to five different providers and wait over a year between initiating evaluation services and receiving an ASD diagnosis (3, 4). Unfortunately, most primary care clinicians lack specialized

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training in assessing and treating ASD (5), and clinicians who specialize in treating ASD have extensive wait times (6). As a result, parents may receive suboptimal treatments and referrals for their children by less qualified professionals or encounter professionals who do not fully appreciate the impact on the family of raising a child with ASD. Suboptimal treatment may leave parents feeling increasingly isolated, relying on their own resources to seek and coordinate care, which can be time consuming, financially draining, and emotionally and physically taxing.

In addition to navigating a complex health care system, families of children with special health care needs, particularly ASD, report significant financial adversity. Okumura and colleagues (7) reported that 24% of families with children with special health care needs reduced their work hours or completely stopped working because of factors related to their child's medical care. Kogan and colleagues (8) found that families of children with ASD incurred higher health-related costs compared with families of children with other special health care needs, with parents taking substantial time off work.

One explanation for this financial burden is the lack of insurance coverage for diagnosis and treatment of ASDs. Peele and colleagues (9) found that 36% of private health plans had complete exclusions for autism and intellectual disability. Poor coverage leads to high costs, as well as to delayed access to services, and approximately 55% of families of children with ASD report at least \$500 in annual out-of-pocket costs (10). Similarly, services of poorer quality have been associated with greater financial burdens and dissatisfaction with care (11).

This study is the first to examine the relationship between family satisfaction with doctors and other health care providers, timeliness of care, and insurance coverage and the financial impact of the child's health condition on the family. Families raising a child with an ASD were compared with families of children with an intellectual disability disorder (IDD) or attention-deficit hyperactivity disorder (ADHD). The latter two disorders are chronic neurodevelopmental conditions that are common among children with ASD and require substantial care. We hypothesized that compared with parents of children with IDD and ADHD, parents of children with ASD would report poorer quality of health care services, greater dissatisfaction with their health care experiences, and the largest impact on the family's financial situation.

Methods

Data were obtained from the 2009–2010 National Survey of Children With Special Health Care Needs, a cross-sectional, population-based study of health and well-being among children with special health care needs and their families. The survey was sponsored by the Maternal and Child Health Bureau and was conducted by the National Center for Health Statistics (12). Interviews were conducted with 40,242 parents or guardians with at least one resident child (#17 years) with special health care needs. The response rate for the survey was 25.5%, and the completion rate among responders was 80.8%. When weighted, the sample was representative of the population of children in the United States with special health care needs.

This analysis compared responses among families with children aged three and older who were diagnosed as having an ASD (N=3,005), ADHD only (N=9,662), or ID Only (N=949). Many children in the ASD group had a comorbid diagnosis of ADHD (33.2%), IDD (12.2%), or both (8.7%).

Parents were asked if their child had received a current diagnosis of “autism, Asperger’s disorder, pervasive developmental disorder, or other autism spectrum disorder” (labeled ASD); “intellectual disability or mental retardation or Down syndrome” (labeled IDD); or “attention deficit disorder or attention-deficit hyperactivity disorder (ADD or ADHD)” (labeled ADHD) from “a doctor or other health care provider.” Parents were also asked whether their child was currently diagnosed as having specific internalizing or externalizing disorders as well as “migraines or frequent headaches,” “diabetes,” and “asthma.”

Information was also collected about the children’s demographic characteristics, including age, race (Caucasian, African American, and other), ethnicity (Hispanic or non-Hispanic), and gender. Demographic information was also collected about the family, including the number of household children (one, two, and three or more), family structure (household with two biological or adoptive parents and all other types), highest educated household member (less than high school, high school, and college degree or higher), and income relative to the federal poverty level (FPL) (<100%, 100%–199%, 200%–399%, and \$400%).

Doctor satisfaction was assessed by asking families nine questions about how frequently (never, sometimes, usually, or always) doctors and health care providers “spent enough time with their child,” “listened carefully,” “were sensitive to the family’s value and customs,” “[provided] specific information [the parent] needed,” “felt like a partner in the child’s care,” “discussed the range of options for health care or treatment,” “encouraged [the parent] to ask questions or raise concerns,” “made it easy to ask questions or raise concerns,” and “considered and respected what health care treatment choices [the parent] thought would work best.”

Timeliness of care was assessed through five questions about how quickly families were able to obtain the services they needed to address their child’s special health care needs. Parents were asked “During the past 12 months, did you have any difficulties or delays getting services for your child because [he or she] was not eligible for services,” “[the] services needed were not available in your area,” “there were waiting lists, backlogs, or other problems getting appointments,” “[there were] issues related to cost,” and “[you] had trouble getting the information needed [for acquiring care]?”

Insurance coverage was assessed through three questions asking about the scope of the child’s health care insurance, including “Does your child’s health insurance offer benefits or cover services that meet his or her needs?” “Are the costs not covered by your child’s health insurance reasonable?” and “Does your child’s health insurance allow him or her to see the health care providers he or she needs?”

Finally, impact on financial situation was assessed through four questions about the perceived impact of the child’s special health care needs on the family’s financial situation,

including “Has your child’s health condition(s) caused financial problems for your family?” “Have you or other family members stopped working because of your child’s health condition(s)?” “Have you or other family members cut down on the hours you work because of your child’s health condition(s)?” and “Have you or other family members avoided changing jobs because of concerns about maintaining health insurance for your child?”

Demographic differences among children with ASD, ADHD, and IDD were compared by using weighted analyses of variance (ANOVAs) and chi square tests. Weighted confirmatory factor analysis generated latent variables measuring doctor satisfaction ($\alpha=.91$), timeliness of care ($\alpha=.71$), insurance coverage ($\alpha=.74$), and the financial impact of raising a child with special health care needs ($\alpha=.60$). Weighted structural equation modeling (SEM) examined the relationship between the three health care variables and the financial impact for each diagnostic group. All factors within the SEM were adjusted for demographic (age, gender, race, ethnicity, family structure, educational level, and poverty level) and clinical characteristics (general medical or psychiatric conditions). Additional analyses determined whether there were differences between the health care experiences of children diagnosed as having only ASD versus ASD with ADHD, IDD, or both. To ease interpretation, standardized path coefficients are reported, which can be interpreted as correlation coefficients.

A series of fit indices included a root mean square error of approximation (RMSEA), a comparative fit index (CFI), the Tucker-Lewis Index (TLI), and a chi square test of model fit. Factor score means, with higher scores indicating better care or increased satisfaction, were compared by using weighted ANOVAs with post hoc Tukey’s honestly significant difference tests to adjust for multiple comparisons (significance was indicated by $p<.017$). Analyses were performed with Stata 10.0 or Mplus 6.0.

Results

Children with ASD were more likely to be male and younger than children in other diagnostic groups. Children diagnosed as having IDD were more likely to be Hispanic compared with children in the other groups. Children with ASD were least likely to live in a household with income below 100% of the FPL and were most likely to have a parent with a college degree or higher. Children with ASD or IDD were more likely than children with ADHD to live in households with two biological or adoptive parents. [A summary of the demographic characteristics of the sample is available online as a data supplement to this report.]

A comparison of mean factor scores across diagnostic groups found notable differences in doctor satisfaction ($F=63.66$, $df=2$ and $13,564$, $p<.001$), timeliness of care ($F=187.19$, $df=2$ and $13,564$, $p<.001$), insurance coverage ($F=113.77$, $df=2$ and $13,564$, $p<.001$), and impact on the family’s financial situation ($F=285.30$, $df=2$ and $13,564$, $p<.001$). Tukey’s post hoc comparisons revealed that parents of children with an ASD reported lower doctor satisfaction, greater delays in care, lower scope of insurance coverage, and a greater financial impact resulting from the child’s condition compared with parents of children with ADHD ($p<.01$ for all). Scores among families of children with ASD were comparable to

those among families of children with IDD, except scores for insurance quality, which were significantly lower among parents of children with ASD ($p < .01$). Families of children with an IDD had lower factor scores than families of children with ADHD on all indices except insurance quality ($p < .01$ for all).

Families of children with ASD and a comorbid condition reported lower doctor satisfaction ($t = -2.75$, $df = 2,928$, $p = .006$), longer delays in care ($t = 6.50$, $df = 2,928$, $p < .001$), poorer insurance coverage ($t = -2.28$, $df = 2,928$, $p = .02$), and a greater financial impact resulting from the child's condition ($t = 7.22$, $df = 2,928$, $p < .001$) compared with families whose child was diagnosed as having only ASD.

As Figure 1 shows, the SEM found an excellent fit between the three health care variables and financial impact on the family for each diagnostic group ($\chi^2 = 1,924.47$, $df = 1,347$, $p < .001$; CFI = .98; TLI = .98; RMSEA = .01). A significant inverse relationship was found between insurance coverage, doctor satisfaction, and timelessness of care and financial impact among all diagnostic groups, after adjustment for all covariates, with the exception of the relationship between doctor satisfaction and financial impact among families of a child with IDD.

Discussion

Over the past decade, a growing body of literature indicates that families raising a child with an ASD report problems with access to and quality of health care services (8, 13). Specific challenges include lack of providers trained to treat children with ASD (14), lack of a medical home (8), extended wait times for diagnosis and clinical services (3), inadequate insurance coverage (9), poor service or poor coordination among professionals, and inordinately expensive treatments (15). Families who experience financial strain associated with their child's condition may be forced to seek less optimal yet more readily accessible and financially feasible care. Alternatively, attempts to seek optimal care may result in greater financial stressors, given that the time and effort required to see more specialists may result in more time off from work.

This study used a national data set to reinforce previous findings that parents of children with ASD face a variety of health care obstacles. These parents experienced greater dissatisfaction with their health care provider and perceived suboptimal clinical care, less timely care, and more limited insurance coverage compared with parents of children with ADHD. They also reported poorer insurance coverage compared with parents of children with IDD. Parents of children with ASD with comorbid conditions reported the greatest perceived financial impact resulting from their child's condition and the lowest perceived quality of health care. The results of this study also highlight that families of children with intellectual disabilities have similarly challenging health care experiences.

Although we are unable to draw causal conclusions because of the nature of the data, the significance of the associations between health care variables and perceived financial impact highlights the potential for reducing financial burdens among families with children with an ASD by improving health care quality and infrastructure. Specific efforts, such as increasing

the number of providers with specialized training, reducing wait times to obtain an appointment, enhancing doctor-patient communication, supporting parental decision-making processes, increasing coordination of care, and improving the scope of health care coverage, can potentially reduce financial strain by improving continuity of care. These efforts may help parents to better navigate the health care system and avoid seeking out less qualified professionals, sometimes due to a lack of or to poor insurance. Initiatives to improve the health care infrastructure for children with special health care needs at all stages of development are clearly needed to improve their families' overall health care experiences.

The limitations of the study included the cross-sectional design; the absence of other potential explanatory variables, such as parental stress, parental coping, and per capita family income; the low survey response rate (due to inclusion of cell phones); the lower loadings on the financial impact factor; and an overall lack of diagnostic validation. The strengths included the large, national sample; the inclusion of numerous covariates and control populations, and the use of a latent variable modeling strategy that allowed for estimation of simultaneous relationships while correcting for biases due to random error.

Conclusions

This study underscores the urgent need for improving health care services for families raising children with special health care needs. Although the causal implications of the study are limited by its design, it is clear that improving health care quality among these populations may also enhance the family's financial situation. As such, future longitudinal studies that examine the temporal relationship between health care quality and family income, as well as additional research that tracks the needs of children as their medical and educational needs evolve, are highly warranted.

References

1. Myers SM, Johnson CP, et al. Management of children with autism spectrum disorders. *Pediatrics*. 2007; 120:1162–1182. [PubMed: 17967921]
2. Sharpe DL, Baker DL. Financial issues associated with having a child with autism. *Journal of Family and Economic Issues*. 2007; 28:247–264.
3. Wiggins LD, Baio J, Rice C. Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample. *Journal of Developmental and Behavioral Pediatrics*. 2006; 27(suppl):S79–S87. [PubMed: 16685189]
4. Goin-Kochel RP, Mackintosh VH, Myers BJ. How many doctors does it take to make an autism spectrum diagnosis? *Autism*. 2006; 10:439–451. [PubMed: 16940311]
5. Heidgerken AD, Geffken G, Modi A, et al. A survey of autism knowledge in a health care setting. *Journal of Autism and Developmental Disorders*. 2005; 35:323–330. [PubMed: 16119473]
6. Kalb LG, Freedman B, Foster C, et al. Determinants of appointment absenteeism at an outpatient pediatric autism clinic. *Journal of Developmental and Behavioral Pediatrics*. 2012; 33:685–697. [PubMed: 23095496]
7. Okumura MJ, Van Cleave J, Gnanasekaran S, et al. Understanding factors associated with work loss for families caring for CSHCN. *Pediatrics*. 2009; 124(suppl 4):S392–S398. [PubMed: 19948604]
8. Kogan MD, Strickland BB, Blumberg SJ, et al. A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics*. 2008; 122:e1149–e1158. [PubMed: 19047216]

9. Peele PB, Lave JR, Kelleher KJ. Exclusions and limitations in children's behavioral health care coverage. *Psychiatric Services*. 2002; 53:591–594. [PubMed: 11986509]
10. Parish S, Thomas K, Rose R, et al. State insurance parity legislation for autism services and family financial burden. *Intellectual and Developmental Disabilities*. 2012; 50:190–198. [PubMed: 22731968]
11. Looman WS, O'Conner-Von SK, Ferski GJ, et al. Financial and employment problems in families of children with special health care needs: implications for research and practice. *Journal of Pediatric Health Care*. 2009; 23:117–125. [PubMed: 19232928]
12. The National Survey of Children With Special Health Care Needs Chartbook 2009–2010. Rockville, Md: US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau; 2013. Available at mchb.hrsa.gov/cshcn0910/more/downloads.html
13. Kalb LG, Stuart EA, Freedman B, et al. Psychiatric-related emergency department visits among children with an autism spectrum disorder. *Pediatric Emergency Care*. 2012; 28:1269–1276. [PubMed: 23187983]
14. Dosreis S, Weiner CL, Johnson L, et al. Autism spectrum disorder screening and management practices among general pediatric providers. *Journal of Developmental and Behavioral Pediatrics*. 2006; 27(suppl):S88–S94. [PubMed: 16685190]
15. Bromley J, Hare DJ, Davison K, et al. Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services. *Autism*. 2004; 8:409–423. [PubMed: 15556959]

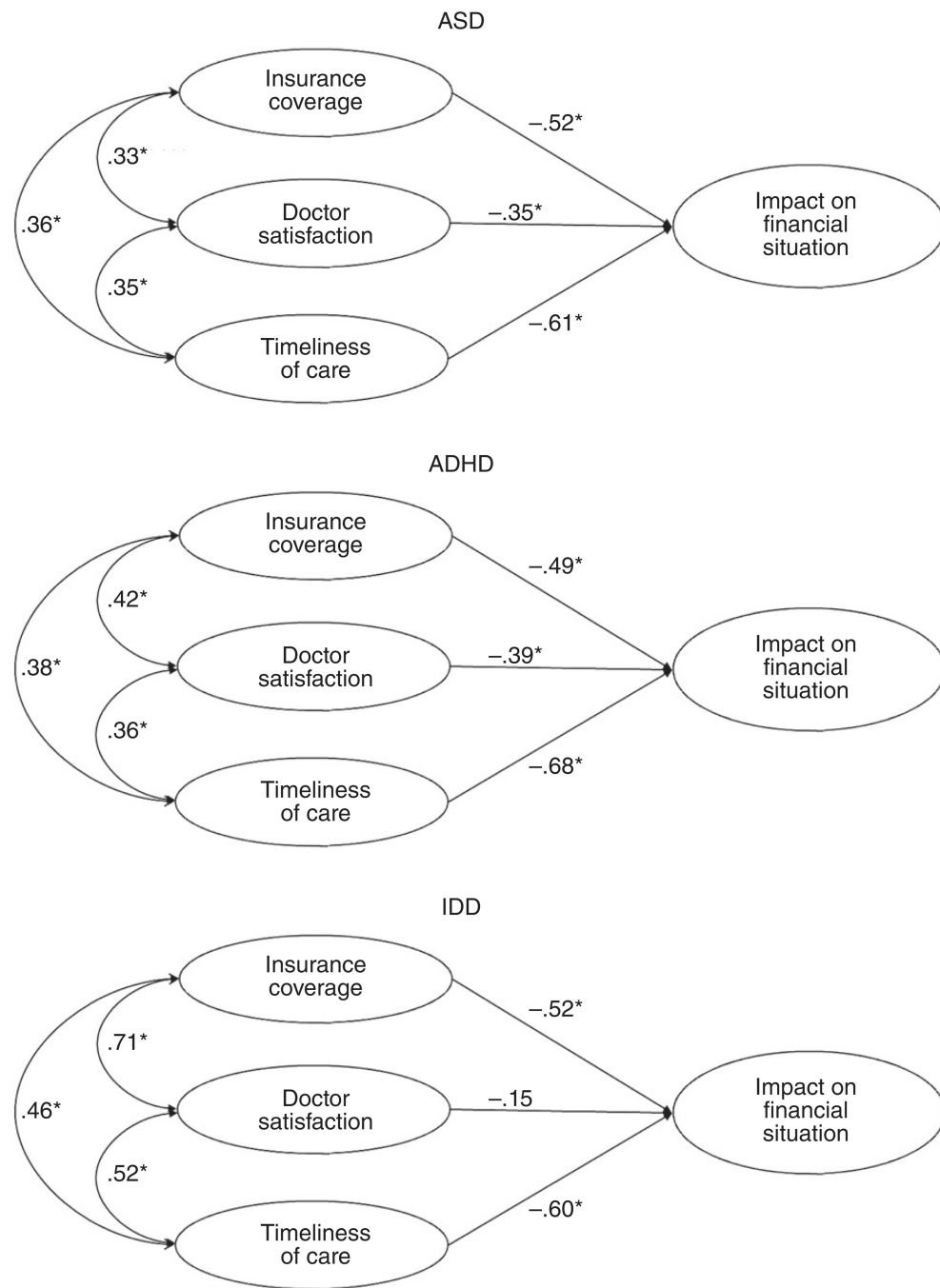


Figure 1.

Structural equation model of the relationship between health care variables and impact on financial situation of parents of children with ASD, ADHD, or IDDa

^a Children with autism spectrum disorder (ASD) also may have had a diagnosis of attention-deficit hyperactivity disorder (ADHD), intellectual disability disorder (IDD), or both.

*p,.001