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Psychological Functioning and Coping Among Mothers of Children With Autism: A Population-Based Study

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ABSTRACT

OBJECTIVES. Studies suggest that having a child with autism has a negative impact on maternal psychological functioning, but no large-scale, population-based studies are available. The objectives of this study were to (1) describe the psychological functioning, physical and mental health, family communication, and parenting support of mothers of a child with autism compared with other mothers on a population basis and (2) assess the independent relationship between having a child with autism and these outcomes, controlling for the child's social skills and demographic background.

METHODS. Mothers of 61 772 children who were 4 to 17 years of age were surveyed by the National Survey of Children's Health, 2003. Autism was measured from an affirmative maternal response to the question, "Has a doctor or health professional ever told you your child has autism?" There were 364 children with autism in the sample.

RESULTS. Mothers of a child with autism were highly stressed and more likely to report poor or fair mental health than mothers in the general population, even after adjustment for the child's social skills and demographic background. However, mothers of a child with autism were more likely to report a close relationship and better coping with parenting tasks and less likely to report being angry with their child after adjustment for the child's social skills and demographic background. Having a child with autism was not associated with lower social support for parenting, an altered manner in which serious disagreements were discussed in the household, or increased violence in the household.

CONCLUSION. Mothers of children with autism showed remarkable strengths in the parent-child relationship, social support, and stability of the household in the context of high stress and poorer mental health.

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Dr Montes had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Key Words

autism, psychological functioning, health survey, National Survey of Children's Health, resilience, United States

Abbreviations

ASD—autism spectrum disorder
NSCH—National Survey of Children's Health

CI—confidence interval

OR—odds ratio

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SEVERAL STUDIES RECENTLY considered the impact of having a child with an autism spectrum disorder (ASD) on parental psychological functioning.¹⁻⁵ Uniformly, the literature finds that parenting a child with ASD is associated with higher levels of stress.^{1,6-8} Comparing parents of children with autism with parents of children without autism, one study found that parents of children with autism had much higher levels of family strain and lower social support.⁶ Another recent study² showed that having a child with ASD was the primary contributor to maternal stress, even in the presence of other maternal mental health problems. Perceived social support has been identified as an important stress buffer that influences the parenting of mothers with a child with autism.⁹

Having a child with autism also influences marital and family functioning. Parents of children with autism are more likely to use avoidant coping strategies that may have a negative impact on the marital relationship.^{6,7} Several studies reported lower marital satisfaction, and at least 1 study¹⁰ showed that mothers of children with autism had lower marital satisfaction than mothers of children with Down syndrome.

Research on the impact of having a child with autism on the probability of divorce is inconclusive.^{1,11,12} Although not focused on psychological functioning, one population-based study¹³ found that children with autism in the United States were equally represented in 2-parent families compared with children without autism.

The main weakness of the previous literature on psychological functioning in parents of a child with autism is the potential for sampling bias. Many studies have drawn from clinic- or referral-based samples or autism societies for their data collection. As previous studies have noted,^{1,7} parents who belong to autism societies, are known to local organizations that serve children with ASD, or received care in specialty clinics likely are not representative of the general population of parents of children with autism. Because there are no population studies, it is not clear whether mothers of a child with autism perceive that they have lower parenting support than other parents, whether they are psychologically distanced from their child, or whether they rate their parenting as poor on a population basis. Moreover, little is known about which aspects of autism have a negative impact on maternal psychological functioning. One study¹⁴ found that the child's behavior problems were more predictive of maternal stress than the severity of the child's autistic symptoms. Other studies suggested that the stress of caring for a child with autism cannot fully explain psychological impairments in the mothers of children with autism.¹⁵ No studies have attempted to compare mothers of children with autism with mothers of other children with similar levels of social skills but who do not have a diagnosis of autism. We hypothesized

that compared with mothers of other children with similarly poor social skills, the psychological functioning of mothers of children with autism will not be significantly impaired.

Recently, researchers used nationally representative telephone surveys to estimate the prevalence of autism in the United States on the basis of parental responses to a single question. All studies reported prevalence estimates within the generally accepted range of 6 per 1000, thereby supporting the validity of parent-reported information about autism.^{13,16} Using the National Survey of Children's Health, 2003 (NSCH), we conducted the first population-based study of psychological and family functioning of mothers of children with autism. Our objectives were to (1) describe the psychological functioning, physical and mental health, family communication, and parenting support of mothers of a child with autism compared with other mothers on a population basis and (2) assess the independent relationship between having a child with autism and these outcomes, controlling for the child's social skills and demographic background.

METHODS

Sample

The NSCH is part of the State and Local Area Integrated Telephone Survey program conducted by the National Center for Health Statistics. The survey interviewed 102 353 parents of children who were aged 0 to 17 between January 2003 and July 2004 (87% of the interviews were completed in 2003). The survey interviewed the adult in the household who was most knowledgeable about the sampled child's health, typically the mother. The response rate was 68.8%. Weights were provided to adjust for the complex survey design and for nonresponse rates. Therefore, the estimates that are presented in this article are nationally representative estimates.

Analytic Sample

We restricted the sample to 61 772 school-aged children (4-17 years) for whom the respondent was the mother of the child sampled.

Measures

Autism Measure

Autism was measured with the following yes/no question: "Has a doctor or health professional ever told you that [child] has any of the following conditions? Autism?"

Physical and Mental Health

Maternal overall health was measured by the question, "Would you say that in general your health is excellent, very good, good, fair, or poor?" Mothers who responded

fair or poor were coded as having poor health. Similarly, mothers who responded fair or poor to the question, "Would you say that in general your mental and emotional health is excellent, very good, good, fair, or poor?" were coded as having poor mental health.

Parenting Stress and Parent–Child Relationship

We used items from the parent aggravation scale used in the National Survey of America's Families studies^{17,18} to measure parent stress and aspects of the parent–child relationship. The scale was derived from the Parental Stress Index and Parental Attitudes About Childrearing scale.¹⁹ It contains 4 items: (1) how often in the last month the parent believed the child was much harder to care for than most, (2) how often the child did things that really bothered the parent, (3) how often the parent was giving up more of his or her life to meet the child's needs than expected, and (4) how often the parent felt angry with the child. Items 1 and 3 are regarded as maternal stress items, whereas items 2 and 4 are categorized as parent–child relationship items in this study. All items were dichotomized as "never" versus "sometimes," "usually," and "always." Closeness of the parent–child relationship was measured by a dichotomous variable that grouped parents who reported "very close" relationships versus those who reported relationships as "somewhat close," "not very close," and "not close at all."

Coping With Parenting

Coping was measured by the following item: "In general, how well do you feel you are coping with the day-to-day demands of parenthood? Would you say that you are coping very well, somewhat well, not very well, or not well at all?" Parents who answered "very well" were coded as coping very well, whereas all other answers were coded as not coping very well.

Parent Support

Parent support was measured by a yes/no question that asked, "Is there someone that you can turn to for day-to-day emotional help with parenting?"

Family Communication and Domestic Violence

Two questions that were adopted from the National Survey of Families and Households and the Early Childhood Longitudinal Survey measured increasingly violent approaches to domestic disagreement. Parents were asked, "When you have serious disagreements with your household members, how often do you end up hitting or throwing things?" Those who responded with "never" were coded as having no domestic violence. Those who responded with any answer other than never were coded as having domestic violence, following the usage of the question in the literature on marital violence.²⁰ Similarly, those who responded with any answer other than never to 2 similar questions ("When you have

serious disagreements with your household members, how often do you argue heatedly or shout?" and, "How often do you just keep your opinions to yourself?") were coded as having "heated arguments" and "keeping opinions to oneself," respectively.

For the remaining disagreement style question, "When you have serious disagreements with your household members, how often do you discuss your disagreements calmly?" a different coding approach was used, because only 2 mothers of a child with autism responded with "never." Therefore, we coded a mother who responded with "usually" or "always" as "discusses calmly."

Child Prosocial Skills

We measured child prosocial skills by the sum of 4 items, some of which were adapted from the Positive Behaviors Scale. These items comprise a scale that is currently being validated by the Centers for Disease Control and Prevention. The 4 items were (1) "[he/she] shows respect for teachers and neighbors"; (2) "[he/she] gets along well with other children"; (3) "[he/she] tries to understand other people's feelings"; and (4) "[he/she] tries to resolve conflicts with classmates, family, or friends." Each item was scored on a 4-point scale (1 = never to 4 = always). Cronbach's α reliability in the analytic sample was .649. The α reliability for the autistic subsample was .650.

Demographic Variables

Family structure was measured with a dichotomous 2-parent family indicator (2-parent households with biological, adoptive, or step parents versus single-parent families and all other family structures). Family poverty was coded using the derived NSCH variable that used income and family size information to classify the household's income as above or below 200% of the 2003 federal poverty level, based on Department of Health and Human Services guidelines. Age, gender, race, and Hispanic ethnicity were measured by using direct questions from the survey. All participants consented to the study. Additional information on the survey and informed consent procedures are available.¹⁹

Statistical Analysis

Stata (Stata Corp, College Station, TX) was used to adjust for the complex sample design using Taylor approximations that provide the correct standard errors, following NSCH guidelines.¹⁹ Demographic characteristics were analyzed using univariate descriptive and χ^2 statistics. We conducted multivariate logistic regressions on the outcomes after controlling for demographic variables (age, gender, race, Hispanic ethnicity, education, and family structure) and the child's prosocial skill score. Because children with autism have a range of social

skills, the prosocial skill score was entered as a continuous variable.

RESULTS

Description of the Sample

Table 1 shows the demographic characteristics for the samples of children with autism and children without autism. There were 364 children with autism in the analytic sample. As previously reported,¹⁶ the prevalence rate for autism in the United States on the basis of the NSCH 2003 sample is 6 per 1000 (95% confidence interval [CI]: 4.7–6.8) with male individuals having a rate of 9 per 1000 (95% CI: 7.2–11.2) and female individuals a rate of 2 per 1000 (95% CI: 1.5–2.8). Parental report of autism probably includes diagnoses throughout the autism spectrum. Aside from a greater prevalence of autism among boys, children with autism were equally represented in the US population by race of the child, Hispanic ethnicity (any race), household education, and household poverty. There were no statistical differences between families with and without a child with autism by family structure (2-parent families). The average age of the children with autism (10.07 years; 95% CI: 9.50–10.64) was comparable to the average age of children without autism (10.44 years; 95% CI: 10.38–10.49).

Parent–Child Relationship and Psychological Functioning: Univariate Results

Table 2 compares mothers of a child with autism with other mothers on the maternal health and psychological functioning variables. Mothers of a child with autism rated their overall health as poor or fair at similar rates as the general population. However, mothers with a child with autism were more likely to report poor or fair mental and emotional health (17.3% vs 7.1%; $P < .01$).

A significantly higher percentage of mothers with a child with autism reported that their child was much

TABLE 2 Bivariate Comparisons of Maternal Functioning Among Families With and Without a Child With Autism

Parameter	Family Has a Child With Autism		Family Does Not Have a Child With Autism	
	<i>n</i>	%	<i>n</i>	%
Maternal health				
Overall health (poor/fair)	47	14.3	5963	11.4
Mental and emotional health (poor/fair)	51	17.3 ^a	3541	7.1
Maternal stress				
Child is harder to care for than most children	301	85.6 ^b	17 370	30.8
Parent gives up her life to meet child's needs	246	68.3 ^b	23 332	40.9
Parent–child relationship				
Relationship is very close	288	89.3	46 255	86.8
Talk about important things with child	157	47.0 ^b	40 685	76.8
Angry at child	279	81.7	48 129	79.3
Child bothers mother a lot	295	80.6 ^a	39 644	64.8
Coping and support				
Coping very well with parenting	163	51.1	33 752	54.3
Has someone to talk about parenting	327	89.9	55 074	86.3
Disagreement style				
Keeps opinions to oneself	259	71.6	41 455	67.4
Discusses calmly	260	70.2	44 367	69.7
Argues heatedly	271	73.9	46 396	77.5
Hits or throws things	43	12.3	5982	11.8

^a $P < .01$.

^b $P < .001$.

harder to care for than most children his or her age compared with mothers without a child with autism (85.6% vs 30.8%; $P < .001$). Similarly, more mothers of children with autism reported that they had given up more of their life than expected during the previous month to meet the child's needs (68.3% vs 40.9%; $P < .001$).

Mothers of a child with autism reported having close relationships with the child at the same rate as the rest of the population (89.3% vs 86.8%; $P > .05$). Similarly, there were no significant differences regarding the frequency of being angry with the child (81.7% vs 79.3%; $P > .05$). Conversely, mothers of a child with autism reported that they were not able to share ideas or talk about the things that really mattered with the child as well as other mothers (47.0% vs 76.8%; $P < .001$). They also reported that their child “bothered them a lot” more frequently than other mothers (80.6% vs 64.8%; $P < .01$).

On coping with parenting and parenting support, mothers with a child with autism were indistinguishable from other mothers. Approximately half of the mothers reported coping well with the demands of parenting (51.1% vs 54.3%; $P > .05$), and almost 9 of 10 reported having someone they “could turn to for day-to-day emotional help with parenting” (89.9% vs 86.3%; $P > .05$). Last, there were no detectable differences in the manner

TABLE 1 Demographic Characteristics

Characteristic	Family Has a Child With Autism		Family Does Not Have a Child With Autism	
	<i>n</i>	%	<i>n</i>	%
All	364	0.6	61 408	99.4
Female	79	18.4 ^a	30 104	49.3
Race/ethnicity				
White	294	78.6	46 651	75.8
Black	31	16.5	6070	16.1
Multiracial	14	2.0	2339	3.3
Other	10	2.9	2345	4.8
Hispanic (any race)	28	10.8	7527	17.4
High school education or less	74	28.7	15 702	34.8
Below federal poverty level	108	43.3	18 155	40.9
2-parent family	259	66.1	44 587	70.8

^a $P < .001$.

in which serious disagreements were discussed in the household.

Parent–Child Relationship and Psychological Functioning: Multivariate Results

Table 3 shows the unadjusted and adjusted odds ratios (ORs) and 95% CIs of the association of having a child with autism on parent–child relationship and psychological functioning outcomes. Adjusted ORs resulted from models that controlled for demographic variables (age, gender, race, Hispanic ethnicity, household education, poverty, and family structure) and the child’s prosocial skills scale score. We specifically adjusted for the child’s social skills to determine whether maternal psychological functioning was different for mothers of children with autism compared with mothers of children with similarly low social skills.

As expected, the majority (61%) of children with autism scored >1 SD below the mean in the child’s prosocial skill scale. Children with low social skills and no diagnosis of autism were a large group (8450) of whom the majority (72%) had no behavioral diagnoses (8% had attention-deficit/hyperactivity disorder, 8% had behavior or conduct problems, and 11% had both).

In the adjusted model, mothers of a child with autism were more than twice as likely as mothers in the general population to report poor or fair mental and emotional

health (OR: 2.42; 95% CI: 1.31–4.45). Similarly, more mothers of children with autism reported that they were giving up their life to care for their child beyond their expectations (OR: 3.77; 95% CI: 2.43–5.87).

Despite these challenges to their parenting and mental health, mothers with a child with autism showed some remarkable strengths. After adjustment for demographic background and the child’s prosocial skills, mothers of a child with autism were 5.2 times more likely to report a close relationship with their child (OR: 5.20; 95% CI: 2.05–13.20). In addition, mothers of a child with autism were 1.8 times less likely to report that they were angry at their child (OR: 0.54; 95% CI: 0.34–0.85).

Even after adjustment for demographic background and social skills, mothers of a child with autism reported that they were less likely to be able to talk to their child with autism about things that really matter (OR: 0.44; 95% CI: 0.29–0.67). It is interesting that mothers with a child with autism were no longer more likely than other mothers to report that their child bothers them more frequently (OR: 1.18; 95% CI: 0.73–1.93) in the adjusted analysis.

In terms of coping and support, mothers with a child with autism were more likely to report that they were coping well with the day-to-day challenges of parenting than mothers of children with similar demographic and social skills profiles (OR: 1.84; 95% CI: 1.28–2.65). Mothers with a child with autism were equally likely to have someone to whom they can talk about parenting on a day-to-day basis. Last, consistent with our findings in the univariate analysis, mothers with a child with autism dealt with disagreements about serious matters in the household just as other mothers did.

DISCUSSION

To our knowledge, this is the first population-based study of psychological functioning in mothers with a child with autism in the United States. Mothers of a child with autism had high levels of parenting stress and were more likely to report poor or fair mental and emotional health than mothers in the general population, even after adjustment for the child’s social skills and demographic background. This finding is consistent with the literature^{1,6–8} and suggests that other child⁵ or maternal¹⁵ factors, in addition to the child’s social skills and demographic background, may play a role in explaining the poorer mental health and increased stress of these mothers. However, we also found that mothers of a child with autism were indistinguishable from mothers in the general population with respect to having a close relationship, being angry with their child, or coping with parenting tasks. After adjustment for the child’s social skills and demographic background, mothers of a child with autism scored significantly better in all 3 areas. These results are in contrast to many negative findings in the

TABLE 3 Multivariate Analyses of Maternal Functioning

Parameter	Unadjusted OR (95% CI)	Adjusted OR (95% CI) ^a
Maternal health		
Overall health (poor/fair)	1.29 (0.65–2.57)	1.60 (0.80–3.21)
Mental and emotional health (poor/fair)	2.74 (1.45–5.18) ^b	2.42 (1.31–4.45) ^b
Maternal Stress		
Child is harder to care for than most children	13.33 (8.64–20.59) ^c	7.57 (4.47–12.82) ^c
Parent gives up her life to meet child’s needs	3.11 (2.03–4.77) ^c	3.77 (2.43–5.87) ^c
Parent–child relationship		
Relationship is very close	1.27 (0.62–2.56)	5.20 (2.05–13.20) ^b
Talk about important things with child	0.27 (0.18–0.40) ^c	0.44 (0.29–0.67) ^c
Angry at child	1.17 (0.80–1.71)	0.54 (0.34–0.85) ^b
Child bothers mother a lot	2.26 (1.33–3.84) ^b	1.18 (0.73–1.93)
Coping and support		
Coping very well with parenting	0.88 (0.61–1.27)	1.84 (1.28–2.65) ^b
Has someone to talk about parenting	1.40 (0.84–2.35)	1.14 (.55–2.38)
Disagreement style		
Keeps opinions to oneself	1.22 (0.79–1.89)	1.34 (0.83–2.14)
Discusses calmly	1.02 (0.66–1.57)	1.43 (0.93–2.20)
Argues heatedly	0.82 (0.48–1.39)	0.52 (0.27–1.01)
Hits or throws things	1.04 (0.63–1.73)	0.63 (0.30–1.34)

^a OR for families with a child with autism compared with families with a child without autism, adjusted for demographic variables and child’s social skills. Demographic variables include age, gender, race, Hispanic ethnicity, poverty, education, and 2-parent family.

^b $P < .01$.

^c $P < .001$.

previous literature that compared mothers of children with autism with mothers of normally developing children. Furthermore, these findings raise questions regarding previous research that was based on referral-based samples that found that mothers of children with autism pursue psychological distancing as a coping strategy.^{6,7}

Although mothers of a child with autism reported being bothered a lot by their child's behavior with greater frequency than mothers in the general population in the univariate analysis, the association disappeared after controlling for demographic characteristics and the child's social skills. This is consistent with previous research on a small number of preschool-aged children with autism that showed that maternal stress is influenced by the child's behavior problems¹⁴ and suggests that the child's poor social skills are an important reason for why mothers report the child as being bothersome.

Mothers with a child with autism reported that they were less likely to be able to talk to their child about things that really matter, even when compared with mothers of children with similar social skills. This result is not surprising given the communication impairments that are characteristic of autism. Consistent with this explanation, the level of the child's social skills was positively associated with mothers' being able to communicate with their child with autism (data not shown).

In the literature, the question of whether mothers of a child with autism had an "impaired capacity to believe that there are resources (parental support) available or that one has control of one's parental skills"² has been raised. In this study, we found that (1) mothers with a child with autism reported that they had someone with whom they can discuss the challenges of parenting on a day-to-day basis at comparable rates as the rest of the population and (2) mothers with a child with autism were more likely to report coping well with the challenges of parenting than mothers of children with similar demographics and social skills. Both of these findings contradict previous findings from less representative samples that mothers of children with autism have low parenting support and cope worse with parenting than other mothers.^{6,7,11}

In this large, nationally representative sample of the United States, we also found no evidence that children with autism are less likely to live in 2-parent families. This result replicates previous research on a different nationally representative sample.¹³ Therefore, on a population basis, having a child with autism does not seem to increase the probability of the child living in a single-parent home. In addition, despite mothers' having higher levels of stress and poor mental health, having a child with autism did not influence the way in which major disagreements were discussed in the household.

In summary, we found many strengths in the parent-

child relationship, coping with parenting, and parenting support for mothers of a child with autism, in contrast to previous studies that used nonrepresentative samples. This suggests that some of the negative findings that were reported in the previous literature might stem from sampling bias.

Limitations

There are a few potential limitations in this study. First, all data were based on maternal report. Although parent report of autism is viewed as fairly reliable,^{13,16} it is possible that mothers with a child with autism report domains of psychological functioning differently than other mothers because mental health problems and a diagnosis of autism may influence recall bias. We did not have access to medical charts or diagnostic reports, and we were limited by the questions that were asked in the survey. In addition, some children in the sample may be undiagnosed or improperly diagnosed. Finally, information on personality characteristics that were shown to be related to our outcomes in another population was not available.²¹

Implications

Although mothers of a child with autism experience high levels of stress and mental health problems, these mothers show remarkable strengths in coping, parent-child relationship, and psychological functioning. Given the challenges of parenting a child with autism, this suggests that families use compensatory strategies to maintain family stability in the context of poorer mental health and higher stress. A greater understanding of these potential strategies as well as the paths to resilient psychological functioning in the context of autism, stress, and poorer mental health problems is needed.

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