

## Children with Autism: Quality of Life and Parental Concerns

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**Abstract** Past research has shown that children with autism and their families have compromised quality of life (QOL) in several domains. This study examined QOL and parental concerns in children with autism during early childhood, childhood, and adolescence compared to children with Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (ADD/ADHD) and to typical controls from a US national sample. Families with children diagnosed with autism reported more profound QOL effects than families of children with ADD/ADHD or unaffected controls. Children with autism were significantly less likely to attend religious services, more likely to miss school, and less likely to participate in organized

activities. Parental concerns over learning difficulty, being bullied, stress-coping, and achievement were overwhelming in the autism group relative to the comparison groups.

**Keywords** Autism · ADD · ADHD · Quality of life · Parental concern

Quality of life (QOL) is a measure of an individual's well-being that includes multiple domains of functioning and is being increasingly recognized as an important construct to use in the study of developmental disabilities. Important components of QOL conceptualization were first stated by the Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities (Schalock et al. 2002). Researchers in the field later refined the original statements and suggested that QOL may be conceptualized as a construct with principles stating that QOL (1) is multidimensional and influenced by personal and environmental actors and their interactions, (2) has the same basic composition for all people, (3) is both subjective and objective, (4) and is enhanced by self-determination, resources, purpose in life, and a sense of belonging (see review Cummins 2005). However, a consensus regarding principles that guide the measurement of QOL has not yet been attained across disciplines and substantial work remains to reach an agreement in measuring QOL (IASSID World Congress 2004; Verdugo et al. 2005).

The few studies that have examined QOL of children with autism and their families only involved small clinical samples, but have suggested that families of children with autism reported a higher level of family stress and more family problems than families of children with cognitive disabilities, such as Down's Syndrome (Donovan 1988;

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Holroyd and McArthur 1976), or other medical conditions such as cystic fibrosis (Bouma and Schweitzer 1990). This may reflect the difficult behavioral profile of many children with Autism Spectrum Disorders, involving for example, self-injury, tantruming, or complex rituals, which can be hard to manage and can interfere with the daily lives of their families. Disruptive behaviors, fixed schedules, and the demands of daily life may also make it difficult for families to participate in activities outside the home (Bouma and Schweitzer 1990; Fox et al. 2002; Howlin 1988). In a study conducted by Fox et al. (2002), parents indicated that they refrained from participating in activities outside the home because their attention was constantly on their child with autism and because they felt that others did not understand their child's behavior problems (Fox et al. 2002).

Having a child with special needs is associated with child-caring stress as well as less time for parents to meet their own needs (Bouma and Schweitzer 1990; Donenberg and Baker 1993; Escobar et al. 2005; Fombonne et al. 2001; Klassen et al. 2004; Seltzer et al. 2004). Compared to parents of typically developing children, parents of children with autism report greater family burden and are at a greater risk of experiencing physical and psychological distress (Allik et al. 2006; Bouma and Schweitzer 1990; Fombonne et al. 2001; Seltzer et al. 2004). Furthermore, it has been reported that the level of emotional distress in parents is positively associated with the level of challenging behavior in the child (Allik et al. 2006; Baker et al. 2002; Bromley et al. 2004; Fombonne et al. 2001; Klassen et al. 2004) and is negatively associated with the child's ability to communicate functionally (Ello and Donovan 2005). Financial challenges may also arise, as having a child with a developmental disability is associated with higher rates in work loss and medical costs than unaffected families (Hecimovic and Gregory 2005; Parish et al. 2004; Swensen et al. 2003). There is evidence that socioeconomic status, as assessed by using a modified Hollingshead four-factor index, is weakly associated with family stress and that there is greater family stress when the child with autism is an older adolescent or young adult (aged 15–21.9) compared to a younger adolescent (aged 10–14.9) (Donovan 1988). Evidence regarding effects on siblings is mixed in that there are findings both for and against an increase in their risk for externalizing and internalizing adjustment problems and a decreased level of social competence (Kaminsky and Dewey 2002).

Children with developmental disabilities tend to have learning problems and poorer academic achievement than their typically developing peers (Griswold et al. 2002; Spira and Fischel 2005). In addition, they experience difficulties in school functioning (Brereton et al. 2006), have poorer social and adaptive functioning (de Bildt et al. 2005; Liss et al. 2001), and are less independent than typically

developing children (Curran et al. 2001). Independence is a particularly important issue for children with autism as they are more likely to remain dependent on their family or services for support as they age compared to children with other disabilities or medical conditions (Ballaban-Gil et al. 1996; Howlin et al. 2004; Seltzer et al. 2004).

Though both autism and ADD/ADHD (Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder) are developmental neuropsychiatric disorders and are diagnosed during childhood, much research has been done on quality of life and parental concerns of children with ADD/ADHD (Bagwell et al. 2001; DuPaul et al. 2001; Escobar et al. 2005; Klassen et al. 2004; Spira and Fischel 2005; Strine et al. 2006; Swensen et al. 2003) while little has been done in autism or in directly comparing the two. To be able to measure autism's unique contribution to a child and his or her family's well-being, it is important to use a comparison group that has a developmental disability so the measured effect is that of autism and not developmental disability in general. Specifically, ADD/ADHD was included as a comparison group for the autism group because they are both childhood-onset neuropsychiatric disorders and have some overlap in behavior problems and symptoms. This study used national survey data to examine differences in quality of life reported by parents of children with autism, parents of children with ADD/ADHD, and parents of unaffected controls. Domains considered were social activity, family burden, family activities, schooling, independence, and parental concerns about their children's quality of life.

## Methods

### Study Design

This study analyzed cross-sectional parent-reported data from the National Survey of Children's Health (NSCH), 2003. The NSCH contains data for 102,353 children aged 0–17 years, however, questions regarding quality of life and parental concerns were asked only of families with children aged 3–17. The NSCH was sponsored by the Maternal and Child Health Bureau, the US Health Resources and Services Administration, and the Centers for Disease Control and Prevention's National Center for Health Statistics. Random-digit dialing was used to sample households with children 0–17 years of age from all 50 states and the District of Columbia in the US. The household member who is most knowledgeable about a sampled child's health, had received the consent information, and agreed to participate in the study was the survey respondent. Specifically, 78.5% were mothers, 17.3% were fathers, and 4.2% were others. Detailed information on the development, plan, sampling,

and operation of the NSCH is described elsewhere (Blumberg et al. 2005). The NCHS study was reviewed and approved by the NCHS Research Ethics Review Board and the Abt Associates Institutional Review Board.

### Study Groups

The present study compared data from NSCH families with children between the ages of 3 to 17 years in three mutually exclusive groups: autism, ADD/ADHD, and unaffected controls. The criteria for each are described below.

1. **Autism:** Children were included in the autism group when parents responded positively to the question “Has a doctor or health professional ever told you that [CHILD] has autism?” Parents of children in this group may also have responded positively to questions about other diagnoses such as ADD/ADHD, learning disability, asthma, hearing or vision problems, depression or anxiety problems, behavioral or conduct problems, bone/joint/muscle problems, diabetes, or any developmental delay or physical impairment. As a result, this group included a total of 483 children with autism. Of these children, 82 were ages 3–5 (early childhood), 228 were ages 6–11 (childhood), and 173 were ages 12–17 (adolescence). Of the 483, parents of 177 (36.6%) reported an ADD/ADHD diagnosis as well.
2. **ADD/ADHD:** Children were included in this group when parents responded positively to the question “Has a doctor or health professional ever told you that [CHILD] has Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder, that is, ADD or ADHD?” and negatively to the question on an autism diagnosis. Children in this group may also have other diagnoses such as learning disability, asthma, hearing or vision problems, depression or anxiety problems, behavioral or conduct problems, bone/joint/muscle problems, diabetes, or any developmental delay or physical impairment. There were a total of 6319 children in this group, of which 191 were ages 3–5, 2366 were ages 6–11, and 3762 were ages 12–17.
3. **Unaffected controls:** This comparison group comprised children without parent-reported disabilities or medical conditions (i.e. autism, ADD/ADHD, learning disability, asthma, hearing or vision problems, depression or anxiety problems, behavioral or conduct problems, bone/joint/muscle problems, diabetes, or any developmental delay or physical impairment). The number of children included in each stratum was 13,398 for ages 3–5, 21,787 for ages 6–11, and 23,768 for ages 12–17.

### Outcome Measures

#### *Quality of Life*

The NSCH includes a number of items related to quality of life. Unfortunately, not all questions of interest were asked for all children in the 3–17 age range and, therefore, some items were limited to children in narrower age groups. The QOL items are described below and, for each item, the ages of children for which data were available are indicated. In the statistical analyses, each question was treated as a separate outcome variable.

1. **Caring burden:** This variable was constructed by summing scores from three questions that asked parents: how often, during the past month, they felt that (1) their child is much harder to care for than most children [his/her] age; (2) their child does things that really bother them a lot; and (3) they are giving up more of their life to meet their child’s needs than they ever expected. Coding for each of the three items was 1 = never, 2 = sometimes, 3 = usually, and 4 = always. This resulted in a continuous summary score ranging from 3 to 12 with a higher score indicating more caring burden. This question was asked for children aged 3–17.
2. **Family outing:** This variable was measured by asking parents, “During the past week, how many times did you or any family member take [CHILD] on any kind of outing, such as to the park, library, zoo, shopping, church, restaurants, or family gatherings?” This variable was treated as continuous with a range from 0 to 20 and was only asked for children aged 3–5.
3. **Family meals:** This variable recorded the number of days during the past week that household family members ate a meal together and was asked for children aged 3–17.
4. **Religious service attendance:** The question asked, “About how often does [CHILD] attend a religious service?” The frequency of attendance was categorized as 0 = none, 1 = once/per year to less than once/per week, and 2 = once/per week or more. Data on this variable were available for children aged 3–17.
5. **Quit a job:** This dichotomous variable (yes/no) asked parents whether any family member had to quit a job, or greatly change their job, because of problems with child care for the child during the past 12 months. This question was only asked for children aged 3–5.
6. **Days of missing school:** The number of days the child missed school during the past 12 months because of illness or injury was coded as 0 = none, 1 = 1–7 days, 2 = 8–14 days, 3 = 15 days or more and was only asked for children aged 6–17.

7. Activity participation: This variable asked whether the child participated in after school or weekend clubs or organizations (e.g. Scouts, a religious group, or boy/girl's club), or any other organized events or activities, during the past 12 months. It was coded as a dichotomous variable (yes/no) and was only asked in children aged 6–17.
8. Repeated a grade: This question asked parents whether their child ever repeated any grade since kindergarten. The variable was coded as a dichotomous variable (yes/no) and was only asked in children aged 6–17.
9. Independence: This question asked, "During the past week, did [CHILD] spend time caring for himself/herself for even a small amount of time?" This dichotomous variable (yes/no) was only asked for ages 6–11.
10. Community service: This question asked, "During the past 12 months, has [CHILD] been involved in any type of community service or volunteer work at school, church, or in the community?" This variable was coded as dichotomous (yes/no) and was only asked for ages 12–17.

### Parental Concerns

A total of five questions asked parents, "Are you currently concerned a lot, a little, or not at all about the [CHILD]'s: (a) achievement, (b) self-esteem, (c) stress-coping, (d) learning difficulties, and (e) being bullied by classmates?" These questions were only asked for ages 6–17. Each question was treated as a separate outcome variable.

### Statistical Analysis

Bivariate (unadjusted) and multivariate (adjusted) regression analyses were performed to compare outcome measures in children with autism to children with ADD/ADHD, and unaffected controls. Methods of variance estimation accounted for the complex sample design (i.e. multi-stage sampling) with weighting. In order to produce population-based estimates for the US population of children, each respondent who completed the data was assigned a sampling weight. These sampling weights account for non-response and numbers of household phone lines. Detailed procedures and calculations of NSCH sampling weights are described in the Design and Operation of the NSCH (Blumberg et al. 2005). Standard errors were obtained using the Taylor-series approximation method in both bivariate and multivariate analyses. Three regression modeling approaches were adopted depending

on the type of outcome variable. Logistic regression was used for dichotomous outcome measures (such as community service), multinomial regression for ordinal outcome measures (such as measures of parental concern), and linear regression for continuous outcome measures (such as caring burden). Multinomial regression modeling was used instead of ordinal logistic regression for ordinal dependent variables because bivariate analyses suggested that the relative increase in odds associated with group membership (i.e., either autism versus ADD/ADHD or autism versus typical controls) was not similar for different levels of the outcome (i.e., for different levels of parental concern)—a necessary assumption in the ordinal logistic regression approach. Effects of group membership (i.e., either autism versus ADD/ADHD or autism versus typical controls) on outcomes in logistic and multinomial regressions are odds ratios (ORs) which indicate the relative increase in the odds of the outcome being reported for the autism children versus comparison group children. For continuous outcomes, beta coefficients are displayed. These are estimates of the mean difference in the outcome for autism versus comparison group children. For each OR and beta coefficient estimate, 95% confidence intervals (CIs) were provided. Demographic characteristics, such as child sex, child birth order, number of children in the household, child race, and family poverty level were included as confounding variables and adjusted for in the multivariate regression models.

### Results

Demographic characteristics of the study groups are shown in Table 1. Consistent with literature (Fombonne 2005), a male preponderance was observed in children with autism and ADD/ADHD, with a male to female ratio of 4:1, whereas it is approximately 1:1 in the unaffected controls. Study groups are predominately white (ranging from 75.8% to 84.5%) in the study sample across the three age strata.

Bivariate associations between study groups in the quality of life and parental concern measures by age stratum are shown in Table 2. Parent-reported caring burden was significantly higher in the autism group than the two comparison groups. Children aged 6–11 with autism were reported to be more likely to repeat a grade, to miss more than a week of school, and less likely to participate in activities/events than the two comparison groups. Compared with unaffected control children, parental concerns in all five domains (achievement, self-esteem, stress-coping, learning difficulty, and being bullied) were significantly higher in the children with autism. Results in Tables 2 (bivariate analyses) and 3 (multivariate analyses) are shown separately for age groups; 3–5, 6–11, and 12–17 and are

**Table 1** Distribution of demographic characteristics in the study groups by age strata<sup>A,B</sup>

	Ages 3–5		
	Autism ( <i>n</i> = 82)	ADD/ADHD ( <i>n</i> = 191)	Unaffected control ( <i>n</i> = 13,398)
Child sex			
Male	63 (76.8%) <sup>b</sup>	151 (79.1%) <sup>c</sup>	6,544 (48.9%)
Female (ref)	19 (23.2%)	40 (20.9%)	6,847 (51.1%)
Child birth order			
1st (ref)	36 (44.4%)	65 (35.1%)	4,585 (35.5%)
2nd	15 (18.5%)	42 (22.7%)	2,782 (21.6%)
3rd or above	30 (37.0%)	78 (42.2%)	5,537 (42.9%)
Number of children in the household			
1 (ref)	36 (43.9%)	65 (34.0%)	4,585 (34.2%)
2	34 (41.5%)	89 (46.6%)	5,737 (42.8%)
3 or more	12 (14.6%)	37 (19.4%)	3,076 (23.0%)
Race			
White (ref)	65 (83.3%)	138 (75.8%)	9,892 (80.3%)
Other	13 (16.7%)	44 (24.2%)	2,428 (19.7%)
Family poverty level			
< 100%	11 (13.4%)	43 (22.5%) <sup>c</sup>	1,510 (11.3%)
100–184%	17 (20.7%)	38 (19.9%)	2,115 (15.8%)
185–299%	13 (15.9%)	39 (20.4%)	2,899 (21.6%)
300% or above (ref)	35 (42.7%)	53 (27.7%)	5,647 (42.1%)
Missing	6 (7.3%)	18 (9.4%)	1,227 (9.2%)
	Ages 6–11		
	Autism ( <i>n</i> = 228)	ADD/ADHD ( <i>n</i> = 2,366)	Unaffected control ( <i>n</i> = 21,787)
Child sex			
Male	184 (80.7%) <sup>a,b</sup>	1,691 (71.5%) <sup>c</sup>	10,163 (46.7%)
Female (ref)	44 (19.3%)	675 (28.5%)	11,600 (53.3%)
Child birth order			
1st (ref)	65 (29.4%)	819 (35.1%)	5,931 (27.8%)
2nd	68 (30.8%)	662 (28.4%) <sup>c</sup>	6,286 (29.5%)
3rd or above	88 (39.8%)	850 (36.5%) <sup>c</sup>	9,084 (42.6%)
Number of children in the household			
1 (ref)	65 (28.5%)	819 (34.6%)	5,931 (27.2%)
2	105 (46.1%)	963 (40.7%) <sup>c</sup>	9,718 (44.6%)
3 or more	58 (25.4%)	584 (24.7%) <sup>c</sup>	6,138 (28.2%)
Race			
White (ref)	177 (81.9%)	1,793 (79.0%)	16,349 (80.8%)
Other	39 (18.1%)	477 (21.0%)	3,884 (19.2%)
Family poverty level			
< 100%	27 (11.8%)	378 (16.0%) <sup>c</sup>	2,037 (9.3%)
100–184%	37 (16.2%)	425 (18.0%) <sup>c</sup>	3,178 (14.6%)
185–299%	46 (20.2%) <sup>b</sup>	544 (23.0%) <sup>c</sup>	4,759 (21.8%)

**Table 1** continued

	Ages 6–11		
	Autism ( <i>n</i> = 228)	ADD/ADHD ( <i>n</i> = 2,366)	Unaffected control ( <i>n</i> = 21,787)
300% or above (ref)	98 (43.0%)	867 (36.6%) <sup>c</sup>	9,910 (45.5%)
Missing	20 (8.8%)	152 (6.4%) <sup>c</sup>	1,903 (8.7%)
	Ages 12–17		
	Autism ( <i>n</i> = 173)	ADD/ADHD ( <i>n</i> = 3,762)	Unaffected control ( <i>n</i> = 23,768)
Child sex			
Male	125 (72.3%) <sup>b</sup>	2,707 (72.0%) <sup>c</sup>	11,557 (48.7%)
Female (ref)	48 (27.7%)	1,054 (28.0%)	12,185 (51.3%)
Child birth order			
1 <sup>st</sup> (ref)	84 (48.8%)	1,918 (51.2%)	10,881 (45.8%)
2nd	50 (29.1%) <sup>b</sup>	1,193 (31.9%) <sup>c</sup>	8,297 (35.0%)
3rd or above	38 (22.1%)	634 (16.9%) <sup>c</sup>	4,554 (19.2%)
Number of children in the household			
1 (ref)	84 (48.6%)	1,918 (51.0%)	10,881 (45.8%)
2	69 (39.9%)	1,195 (31.8%) <sup>c</sup>	8,354 (35.1%)
3 or more	20 (11.6%) <sup>b</sup>	649 (17.3%) <sup>c</sup>	4,533 (19.1%)
Race			
White (ref)	142 (84.5%)	3,054 (83.8%)	18,241 (81.7%)
Other	26 (15.5%)	589 (16.2%) <sup>c</sup>	4,077 (18.3%)
Family poverty level			
<100%	15 (8.7%) <sup>a,b</sup>	412 (11.0%) <sup>c</sup>	1,868 (7.9%)
100–184%	20 (11.6%)	554 (14.7%)	3,019 (12.7%)
185–299%	37 (21.4%)	793 (21.1%)	4,901 (20.6%)
300% or above (ref)	84 (48.6%)	1,695 (45.1%)	11,638 (49.0%)
Missing	17 (9.8%)	308 (8.2%)	2,342 (9.9%)

<sup>A</sup> Numbers in cells might not add up to the total number due to missing values

<sup>B</sup> Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children's Health, 2003

<sup>a</sup> Significant difference between Autism and ADD/ADHD groups at  $p \leq 0.05$  (two-tailed)

<sup>b</sup> Significant difference between Autism and Unaffected Control groups at  $p \leq 0.05$  (two-tailed)

<sup>c</sup> Significant difference between ADD/ADHD and Unaffected Control groups at  $p \leq 0.05$  (two-tailed)

discussed separately below. Recall that not all outcomes are available for all age groups because not all questions were asked of parents of children of all ages (Table 3).

#### Early Childhood (Ages 3–5)

The autism group families reported significantly higher child caring burden than ADD/ADHD and unaffected controls even after taking into account the effect of demographic characteristics. Children with autism were 70% less likely (OR = 0.30) to attend a religious service once per week or more than children in the two comparison groups.

Furthermore, family members of children with an autism diagnosis were about seven times more likely (OR = 6.66, 95% confidence interval (CI): 3.22–13.76) to leave a job because of child care issues than control family members.

#### Childhood (Ages 6–11)

As was observed in the stratum of younger children (ages 3–5), families of the autism group reported significantly greater child caring burden than the ADD/ADHD and unaffected control groups with coefficients of 1.29 and 2.58, respectively. In addition, children with autism

**Table 2** Descriptive statistics and unadjusted associations between study groups in quality of life and parental concerns by age strata<sup>A,B</sup>

	Ages 3–5		
	Autism (n = 82)	ADD/ADHD (n = 191)	Unaffected control (n = 13,398)
<i>Quality of life</i>			
Caring burden during the past month (mean ± SD)	7.29 ± 2.28 <sup>a,b</sup>	6.26 ± 2.35 <sup>c</sup>	4.50 ± 1.42
Family outing in the past week (mean ± SD)	4.62 ± 2.34	4.28 ± 2.66	4.51 ± 2.63
Family meal together in the past week in days (mean ± SD)	4.80 ± 2.38 <sup>b</sup>	5.06 ± 2.34	5.48 ± 2.05
Religious service attendance			
None (ref)	32 (39.5%)	66 (35.1%)	3,270 (24.5%)
1 per year to less than 1 per week	20 (24.7%)	41 (21.8%)	3,073 (23.0%)
1 per week or more	29 (35.8%) <sup>b</sup>	81 (43.1%)	6,991 (52.4%)
Quit a job			
Yes	26 (31.7%) <sup>b</sup>	47 (24.6%) <sup>c</sup>	1,054 (7.9%)
No (ref)	56 (68.3%)	144 (75.4%)	12,331 (92.1%)
<hr/>			
	Ages 6–11		
	Autism (n = 228)	ADD/ADHD (n = 2,366)	Unaffected control (n = 21,787)
<i>Quality of life</i>			
Caring burden during the past month (mean ± SD)	6.72 ± 2.31 <sup>a,b</sup>	5.69 ± 2.01 <sup>c</sup>	4.36 ± 1.34
Family meal together in the past week in days (mean ± SD)	5.22 ± 2.30	5.23 ± 2.14	5.34 ± 1.97
Religious service attendance			
None (ref)	78 (34.2%)	497 (21.1%)	3,407 (15.7%)
1 per year to less than 1 per week	37 (16.2%) <sup>b</sup>	561 (23.8%) <sup>c</sup>	5,051 (23.3%)
1 per week or above	113 (49.6%) <sup>a,b</sup>	1,295 (55.0%) <sup>c</sup>	13,231 (61.0%)
Missed school during the past 12 months in days			
None (ref)	28 (12.4%)	406 (17.4%)	4,521 (20.9%)
1 – 7 days	132 (58.4%)	1,535 (65.6%)	15,413 (71.4%)
8 days or more	66 (29.2%) <sup>a,b</sup>	398 (17.0%) <sup>c</sup>	1,663 (7.7%)
Repeat a grade			
Yes	44 (19.8%) <sup>a,b</sup>	495 (21.0%) <sup>c</sup>	1,034 (4.7%)
No (ref)	178 (80.2%)	1,865 (79.0%)	20,742 (95.3%)
Activity participation during the past 12 months			
Yes	118 (60.2%) <sup>a,b</sup>	1,408 (76.0%) <sup>c</sup>	13,438 (81.3%)
No (ref)	78 (39.8%)	444 (24.0%)	3,083 (18.7%)
Taking care of self			
Yes	38 (16.8%)	572 (24.2%) <sup>c</sup>	3,738 (17.2%)
No (ref)	188 (83.2%)	1,788 (75.8%)	18,001 (82.8%)
<i>Parental Concerns</i>			
Achievement			
A lot	141 (62.1%) <sup>a,b</sup>	1,140 (48.3%) <sup>c</sup>	6,103 (28.1%)
A little	56 (24.7%) <sup>b</sup>	657 (27.9%) <sup>c</sup>	3,446 (15.9%)
Not at all (ref)	30 (13.2%)	562 (23.8%)	12,153 (56.0%)
Self-esteem			
A lot	90 (39.8%) <sup>b</sup>	950 (40.2%) <sup>c</sup>	5,234 (24.1%)
A little	85 (37.6%) <sup>b</sup>	862 (36.5%) <sup>c</sup>	5,371 (24.7%)
Not at all (ref)	51 (22.6%)	550 (23.3%)	11,119 (51.2%)

**Table 2** continued

	Ages 6–11		
	Autism ( <i>n</i> = 228)	ADD/ADHD ( <i>n</i> = 2,366)	Unaffected control ( <i>n</i> = 21,787)
<b>Stress-coping</b>			
A lot	146 (64.9%) <sup>a,b</sup>	1,113 (47.1%) <sup>c</sup>	5,089 (23.5%)
A little	66 (29.3%) <sup>b</sup>	961 (40.7%) <sup>c</sup>	8,866 (40.9%)
Not at all (ref)	13 (5.8%)	289 (12.2%)	7,728 (35.6%)
<b>Learning difficulty</b>			
A lot	154 (67.8%) <sup>a,b</sup>	1,087 (46.0%) <sup>c</sup>	3,205 (14.7%)
A little	52 (22.9%) <sup>b</sup>	725 (30.7%) <sup>c</sup>	3,549 (16.3%)
Not at all (ref)	21 (9.3%)	552 (23.4%)	14,983 (68.9%)
<b>Being bullied</b>			
A lot	63 (27.9%) <sup>b</sup>	413 (17.5%) <sup>c</sup>	2,590 (11.9%)
A little	90 (39.8%) <sup>b</sup>	839 (35.5%) <sup>c</sup>	5,508 (25.3%)
Not at all (ref)	73 (32.3%)	1,111 (47.0%)	13,633 (62.7%)
<b>Ages 12–17</b>			
	Autism ( <i>n</i> = 173)	ADD/ADHD ( <i>n</i> = 3,762)	Unaffected control ( <i>n</i> = 23,768)
<i>Quality of life</i>			
Caring burden during the past month (mean ± SD)	7.36 ± 2.43 <sup>a,b</sup>	5.60 ± 2.06 <sup>c</sup>	4.48 ± 1.43
Family meal together in the past week in days (mean ± SD)	4.92 ± 2.15	4.53 ± 2.29 <sup>c</sup>	4.65 ± 2.19
<b>Religious service attendance</b>			
None (ref)	63 (36.4%)	958 (25.6%)	4,389 (18.6%)
1 per year to less than 1 per week	38 (22.0%) <sup>b</sup>	1,006 (26.8%) <sup>c</sup>	6,008 (25.4%)
1 per week or more	72 (41.6%) <sup>b</sup>	1,783 (47.6%) <sup>c</sup>	13,249 (56.0%)
<b>Missed school during the past 12 months in days</b>			
None (ref)	33 (19.4%)	700 (19.1%)	5,834 (24.9%)
1–7 days	101 (59.4%) <sup>b</sup>	2,233 (60.9%) <sup>c</sup>	15,660 (66.8%)
8 days or more	36 (21.2%) <sup>b</sup>	734 (20.0%) <sup>c</sup>	1,943 (8.3%)
<b>Repeat a grade</b>			
Yes	46 (26.7%) <sup>b</sup>	972 (25.9%) <sup>c</sup>	1,710 (7.2%)
No (ref)	126 (73.3%)	2,774 (74.1%)	22,025 (92.8%)
<b>Activity participation during the 12 months past</b>			
Yes	89 (58.6%) <sup>b</sup>	2,170 (73.5%) <sup>c</sup>	15,208 (83.5%)
No (ref)	63 (41.4%)	782 (26.5%)	3,007 (16.5%)
<b>Community service/ volunteer work</b>			
Yes	70 (41.2%) <sup>b</sup>	2,204 (58.7%) <sup>c</sup>	15,704 (66.4%)
No (ref)	100 (58.8%)	1,550 (41.3%)	7,949 (33.6%)
<i>Parental concerns</i>			
<b>Achievement</b>			
A lot	117 (68.0%) <sup>b</sup>	2,076 (55.3%) <sup>c</sup>	7,607 (32.1%)
A little	28 (16.3%)	1,045 (27.8%) <sup>c</sup>	5,111 (21.6%)
Not at all (ref)	27 (15.7%)	633 (16.9%)	10,964 (46.3%)
<b>Self-esteem</b>			
A lot	85 (49.4%) <sup>b</sup>	1,478 (39.4%) <sup>c</sup>	5,556 (23.5%)
A little	62 (36.0%) <sup>b</sup>	1,366 (36.4%) <sup>c</sup>	6,580 (27.8%)
Not at all (ref)	25 (14.5%)	911 (24.3%)	11,549 (48.8%)

**Table 2** continued

	Ages 12–17		
	Autism ( <i>n</i> = 173)	ADD/ADHD ( <i>n</i> = 3,762)	Unaffected control ( <i>n</i> = 23,768)
<b>Stress-coping</b>			
A lot	111 (64.5%) <sup>b</sup>	1,652 (44.0%) <sup>c</sup>	5,381 (22.7%)
A little	48 (27.9%)	1,538 (41.0%) <sup>c</sup>	9,788 (41.4%)
Not at all (ref)	13 (7.6%)	563 (15.0%)	8,489 (35.9%)
<b>Learning difficulty</b>			
A lot	119 (69.2%) <sup>a,b</sup>	1,678 (44.6%) <sup>c</sup>	3,078 (13.0%)
A little	36 (20.9%) <sup>a,b</sup>	1,280 (34.0%) <sup>c</sup>	3,894 (16.4%)
Not at all (ref)	17 (9.9%)	802 (21.3%)	16,729 (70.6%)
<b>Being bullied</b>			
A lot	50 (28.9%) <sup>a,b</sup>	543 (14.5%) <sup>c</sup>	2,262 (9.5%)
A little	63 (36.4%) <sup>a,b</sup>	999 (26.6%) <sup>c</sup>	3,955 (16.7%)
Not at all (ref)	60 (34.7%)	2,213 (58.9%)	17,486 (73.8%)

<sup>A</sup> Numbers in cells might not add up to the total number due to missing values

<sup>B</sup> Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children's Health, 2003

<sup>a</sup> Indicates a significant difference between Autism and ADD/ADHD groups at  $p \leq 0.05$  (two-tailed)

<sup>b</sup> indicates a significant difference between Autism and Unaffected Control groups at  $p \leq 0.05$  (two-tailed)

<sup>c</sup> indicates a significant difference between ADD/ADHD and Unaffected Control groups at  $p \leq 0.05$  (two-tailed)

attended religious services at a significantly lower frequency (OR = 0.51 compared to ADD/ADHD and OR = 0.38 compared to unaffected controls) and were more likely to miss eight or more days of school due to illness or injury than the ADD/ADHD children (OR = 3.76) and unaffected children (OR = 10.80).

Compared with parents of unaffected children, parents of children with autism reported significantly more concerns ("a lot") about their children's achievement, self-esteem, stress-coping, learning difficulties, and being bullied by classmates (OR ranged from 4.53 to 41.69). Parental concerns ("a lot") over their children's achievement, stress-coping, learning difficulties and being bullied were also significantly greater in the autism group than in the ADD/ADHD group (OR ranged from 2.47 to 4.84).

#### Adolescence (Ages 12–17)

Consistent with findings in younger children, parents of adolescents with autism reported significantly more child caring burden than the comparison groups (coefficient = 1.65 compared to ADD/ADHD, and 2.86 compared to unaffected controls). Compared to the unaffected group, the autism group attended a religious service about 50% less frequently (OR = 0.48 and 0.51), was about twice as likely to miss school for 1–7 days (OR = 1.78) and was five times as likely to miss 8 days or more (OR = 5.29).

They were 3.35 times more likely to repeat a grade, much less likely to participate in activities/events (OR = 0.27), and significantly less likely to take part in community service (OR = 0.58). Notably, compared to the ADD/ADHD group, parents of the autism group reported significantly greater concerns over their children's learning difficulty (OR = 4.83) and being bullied (OR = 4.00). Parental concerns reported by parents of the autism group were all significantly greater than the unaffected controls.

#### Discussion

Findings of the present study indicate that parents of children with autism more frequently report indicators that their children have diminished quality of life and have higher levels of concerns about their child's well-being than do parents of children with ADD/ADHD or unaffected children. Overall, families of children with autism reported a greater level of child caring burden, less frequent attendance of religious services, a greater likelihood to quit a job because of child care problems, more school days missed, more repeated grades, less participation in activities/events, and less involvement in community services, compared to families of children with ADD/ADHD or unaffected children. The lesser participation in activities/events and involvement in community service reported by families of children with autism may result from the

**Table 3** Adjusted associations between study groups in quality of life and parental concerns by age strata<sup>a, b, c, d</sup>

	Ages 3–5			
	Autism versus ADD/ADHD		Autism versus unaffected control	
	Coef	95%CI	Coef	95%CI
<i>Quality of life</i>				
Caring burden	<b>1.51</b>	<b>0.65, 2.38</b>	<b>2.86</b>	<b>2.12, 3.59</b>
Family outing	−0.21	−1.07, 0.65	−0.16	−0.73, 0.41
Family meals	−0.21	−1.13, 0.71	−0.63	−1.41, 0.15
	OR	95%CI	OR	95%CI
Religious service attendance				
1 per year to less than 1 per week	0.63	0.22, 1.79	0.77	0.34, 1.72
1 per week or more	<b>0.30</b>	<b>0.12, 0.77</b>	<b>0.30</b>	<b>0.14, 0.65</b>
Quit a job (yes)	2.08	0.93, 4.61	<b>6.66</b>	<b>3.22, 13.76</b>
<i>Ages 6–11</i>				
	Autism versus ADD/ADHD		Autism versus Unaffected Control	
	Coef	95%CI	Coef	95%CI
<i>Quality of life</i>				
Caring burden	<b>1.29</b>	<b>0.78, 1.79</b>	<b>2.58</b>	<b>2.11, 3.05</b>
Family meals	0.13	−0.36, 0.63	−0.06	−0.53, 0.41
	OR	95%CI	OR	95%CI
Religious service attendance				
1 per year to less than 1 per week	0.59	0.25, 1.38	0.44	0.19, 1.02
1 per week or more	<b>0.51</b>	<b>0.30, 0.87</b>	<b>0.38</b>	<b>0.23, 0.63</b>
Missed school				
1–7 days	1.43	0.73, 2.79	1.53	0.79, 2.98
8 days or more	<b>3.76</b>	<b>1.67, 8.46</b>	<b>10.80</b>	<b>4.66, 25.06</b>
Repeat a grade (yes)	0.55	0.30, 1.00	2.32	<b>1.20, 4.49</b>
Activity participation (yes)	0.56	0.31, 1.01	<b>0.45</b>	<b>0.26, 0.79</b>
Taking care of self (yes)	<b>0.53</b>	<b>0.30, 0.95</b>	0.71	0.41, 1.24
<i>Parental concerns</i>	OR	95%CI	OR	95%CI
Achievement				
A lot	<b>2.74</b>	<b>1.52, 4.94</b>	<b>10.33</b>	<b>5.77, 18.48</b>
A little	1.34	0.70, 2.55	5.02	<b>2.67, 9.45</b>
Self-esteem				
A lot	1.28	0.72, 2.29	<b>4.58</b>	<b>2.63, 7.96</b>
A little	0.94	0.54, 1.64	<b>3.17</b>	<b>1.87, 5.38</b>
Stress-coping				
A lot	<b>3.27</b>	<b>1.43, 7.49</b>	<b>18.54</b>	<b>8.58, 40.06</b>
A little	1.37	0.58, 3.21	<b>3.68</b>	<b>1.63, 8.33</b>
Learning difficulty				
A lot	<b>4.84</b>	<b>2.45, 9.58</b>	<b>41.69</b>	<b>21.34, 81.48</b>
A little	<b>2.29</b>	<b>1.08, 4.88</b>	<b>11.92</b>	<b>5.70, 24.92</b>

**Table 3** continued

	Ages 6–11			
	Autism versus ADD/ADHD		Autism versus Unaffected Control	
	Coef	95%CI	Coef	95%CI
<b>Being bullied</b>				
A lot	<b>2.47</b>	<b>1.29, 4.75</b>	<b>4.53</b>	<b>2.41, 8.52</b>
A little	1.59	0.93, 2.71	<b>2.76</b>	<b>1.65, 4.63</b>
	Ages 12–17			
	Autism versus ADD/ADHD		Autism versus unaffected control	
	Coef	95%CI	Coef	95%CI
<i>Quality of life</i>				
Caring burden	<b>1.65</b>	<b>1.17, 2.13</b>	<b>2.86</b>	<b>2.39, 3.34</b>
Family meals	<b>0.62</b>	<b>0.18, 1.06</b>	0.32	−0.11, 0.75
	OR	95%CI	OR	95%CI
<i>Religious service attendance</i>				
1 per year to less than 1 per week	0.58	0.32, 1.04	<b>0.48</b>	<b>0.27, 0.85</b>
1 per week or more	0.65	0.39, 1.09	<b>0.51</b>	<b>0.31, 0.86</b>
<i>Missed school</i>				
1–7 days	1.45	0.82, 2.58	<b>1.78</b>	<b>1.01, 3.14</b>
8 days or more	1.60	0.71, 3.60	<b>5.29</b>	<b>2.28, 12.26</b>
Repeat a grade (yes)	0.80	0.49, 1.32	<b>3.35</b>	<b>2.08, 5.40</b>
Activity participation (yes)	<b>0.47</b>	<b>0.26, 0.85</b>	<b>0.27</b>	<b>0.15, 0.48</b>
Community service (yes)	0.73	0.45, 1.20	<b>0.58</b>	<b>0.35, 0.94</b>
<i>Parental concerns</i>				
	OR	95%CI	OR	95%CI
<i>Achievement</i>				
A lot	1.27	0.66, 2.46	<b>6.04</b>	<b>3.20, 11.40</b>
A little	0.49	0.22, 1.09	1.65	0.75, 3.62
<i>Self-esteem</i>				
A lot	2.08	0.89, 4.87	<b>6.96</b>	<b>2.94, 16.50</b>
A little	1.78	0.77, 4.12	<b>4.36</b>	<b>1.86, 10.18</b>
<i>Stress-coping</i>				
A lot	2.29	0.73, 7.22	<b>10.66</b>	<b>3.33, 34.15</b>
A little	0.84	0.26, 2.73	1.83	0.56, 5.99
<i>Learning difficulty</i>				
A lot	<b>4.83</b>	<b>2.35, 9.93</b>	<b>54.93</b>	<b>26.69, 113.08</b>
A little	<b>2.57</b>	<b>1.06, 6.20</b>	<b>14.70</b>	<b>6.26, 34.54</b>
<i>Being bullied</i>				
A lot	<b>4.00</b>	<b>2.08, 7.66</b>	<b>7.30</b>	<b>3.71, 14.36</b>
A little	<b>2.08</b>	<b>1.22, 3.55</b>	<b>3.74</b>	<b>2.18, 6.41</b>

<sup>a</sup> “Not at all” is the reference for parental concern variables

<sup>b</sup> Autism is the indicator group compared against ADD/ADHD, and Unaffected control

<sup>c</sup> Bold numbers indicate the differences are statistically significant

<sup>d</sup> Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children’s Health, 2003

challenges that accompany separating a child with autism from the home environment. This reasoning can also hold true for the reports of less frequent attendance of religious services and higher child care burden. Taking care of a child with a disability can be emotionally, physically, and financially exhausting. The fact that an excess number of parents of children with autism reported that they had to either quit a job or greatly change a job in order to provide child care for their child hints to a more stressful financial situation for these families.

Parents of children with autism in all three age groups had serious concerns about their children's well-being. Parental concerns in families of children with autism were common across early childhood, childhood, and adolescence, especially worries over their children's learning difficulties and being bullied. As expected, parents of children with ADD/ADHD also reported considerable concerns and potential indicators of diminished QOL; however, the magnitude was not as great as in families of children with autism.

One principal limitation of the study is that diagnoses of children (i.e. autism, ADD/ADHD) were obtained from parent report and were not validated by clinicians. There could be some misreporting of diagnoses and, further, it is impossible to stratify into more specific diagnostic categories in autism (i.e., autistic disorder versus Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS) versus Asperger's disorder). In addition, a measure of child cognitive functioning (e.g., IQ) was not available for this study. Autism spectrum disorders are known to have diverse clinical manifestations, behavioral phenotypes, and symptom severities, all of which are linked to cognitive functioning. Furthermore, cognitive ability is one of the most significant correlates of developmental outcome and prognosis. The lack of this information prevents us from distinguishing effects from autism versus effects due to low functioning level that children with autism commonly have. A second major limitation relates to the lack of richness in the available QOL data. Rather than incorporating an instrument with a full range of QOL questions into the survey, only a limited set of QOL questions were included in the NSCH. For example, only one question was asked with regard to a child's independence. As there is much variability in independence and self-help skills for children at different cognitive functioning level, a single item reported by parents may not be sufficient to provide a comprehensive measure of a child's independence.

Another concern is potential selection bias that would be introduced if families of children with autism were more likely to screen their phone calls or decide to skip the phone interview. However, because an advance letter was mailed prior to any telephone calls (Blumberg et al. 2005), we do not expect the potential selection bias to be substantial.

Information bias is also possible if parents of children with autism systematically report quality of life variables differently than other parents. Parents of children with autism have a higher prevalence of autism-related traits and other psychopathologies than the general population (Dawson et al. 2006; Piven and Palmer 1999; Sung et al. 2005). These traits and symptoms could influence parents' observations or elevate their concerns over their children's behavior and life. It has, however, been shown that the presence of psychopathologies among parents of children with autism does not exceed that reported in parents of children with other genetically determined behavioral disorders (Yirmiya and Shaked 2005)—however, comparative data with parents of children with ADD/ADHD have not been reported. Although some findings were observed in all age ranges, the continuity of effects of an autism diagnosis on quality of life and parental concerns cannot be assessed given the cross-sectional study design. Future studies would be advised to study the longitudinal course of quality of life outcomes. Nevertheless, this study utilized data from a nationally representative sample with large numbers in the study groups which provides sufficient statistical power to estimate effects precisely across three developmental stages – early childhood, childhood, and adolescence.

QOL domains may provide a framework for gauging the impact of autism in a way that may not be apparent when examining symptoms alone. By improving our understanding of how QOL is affected by autism, the needs of children with autism and their families will be better recognized and the necessary services and supports can be put into place. Our study provides initial information about domains of QOL and parental concerns most affected in families of children with autism in different developmental stages. More detailed work with comprehensive and multi-dimensional measures of QOL and parental concerns are needed so that educators and clinicians can design intervention plans and expand the outcome measures monitored in a manner most responsive to families' needs.

Measures of health and treatment outcomes of children with autism should not be limited to symptom severity and behavioral disturbance. Recent reviews of methodologies used in formal evaluations of autism interventions have noted a need for incorporation of expanded outcome measures (Matson 2006; Wolery and Garfinkle 2002). This study adds to the body of evidence documenting marked QOL decrements in families of children with autism when compared to families of typically developing children and families of children with ADD/ADHD, supporting the notion that QOL issues are of potentially great importance when considering the social, as well as medical, significance of treatment effects. Health care professionals who provide pharmacological treatments for children with autism may also want to consider including QOL and parental

concerns as monitored treatment outcomes in addition to a reduction in symptoms and behavioral problems. Development of optimal approaches for measuring these factors in the context of formal intervention research and in clinical practice is a considerable challenge (Bertelli and Brown 2006), but one that needs to be faced.

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