Quality of Life and Parental Concerns in Children with Autism

Center for Autism and Developmental Disabilities Epidemiology, Department of Epidemiology, Johns Hopkins University Bloomberg School of Public Health, Baltimore, MD

Background

Past research has shown that children with autism, and ADD/ADHD, and their families have compromised quality of life (QOL) in several domains compared to typically developing children and their families. This is especially true for families of children with autism because these children may require additional attention that can interfere with the daily lives of their families. Taking care of children with special needs is associated with child-caring stress, and negative physical and emotional health in parents. 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. This study examined differences in QOL by comparing children with autism to children with ADD/ADHD and to typical controls in the domains of social activity, family burden, family activities, schooling, independence, and parental concerns about their children’s.

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 over 100,000 children ages 0-17 years, however, QOL questions were asked only of families with children ages 3-17. Specifically, this study explores QOL in children and their families by three age strata: preschool (3-5 years), childhood (6-11 years), and adolescence (12-17 years).

Study groups:

• Autism: age 3-5 (n=82), age 6-11 (n=228), age 12-17 (n=173)
• ADD/ADHD: age 3-5 (n=191), age 6-11 (n=2,366), age 12-17 (n=3,762)
• Typical controls: children without known disabilities, behaviors problems, anxiety/depression, or other medical conditions (e.g. asthma, hearing/ vision problems, bone/joint/muscle problems, and diabetes). age 3-5 (n=13,398), age 6-11 (n=21,787), age 12-17 (n=23,768)

Outcome measures:

• Caring burden during the past month: a higher score indicated more burden (range 3-12)
• Family outing: number of times family members took the child out - past week (range 0-20)
• Family meals: number of days household family members ate a meal together - past week (range 0-7)
• Religious services: frequency that child attended a religious service (0=none, 1=1/per year to less than 1/per month, 2=1/per month to less than 1/per week, 3=1/per week to less than daily, 4=daily)
• School absence: days child missed school during the past 12 months (0=none, 1=1-7 days, 2=8-14 days, 3=15 days or more)
• Quit a job: family member had to quit a job because of a child-care problem – since childbirth (YN, ages 3-5)
• Activity participation: child participated in organized activities during the past 12 months (YN, ages 6-17)
• Repeat a grade: child ever repeated any grade since kindergarten (YN, ages 6-17)
• Independence: child spent time caring for him/herself - past week (YN, ages 6-11)
• Community service: child involvement in any community service or volunteer work during the past 12 months (YN, ages 12-17)
• Parental concerns: current concerns over the child’s achievement, self-esteem, stress coping, learning difficulties, and being bullied by classmates (A lot, A little, Not at all, ages 6-17)

Statistical analysis:

• Multivariate regression analysis was performed to compare QOL variables in children with autism against children with ADHD/ADD, and typical controls.
• Methods of variance estimation accounting for the complex sample design (multi-stage sampling with weighting) were applied. Specifically, standard errors were obtained using the Taylor-series approximation method

Results

Tables 1-3 show results from multivariate analyses where confounding variables such as child sex, birth order, number of children in the household, child race, and family poverty level were adjusted in regression models.

• The autism group families reported significantly higher child-care burden than ADD/ADHD and typical controls across the 3 age strata.
• Families of children with an autism diagnosis were 6.7 times more likely to leave a job because of child care issues than control families.
• Children with autism were significantly less likely than were ADD/ADHD and typical controls to participate in any organized social activities (adjusted ORs 0.27-0.56).
• Overall, children with autism were more likely to miss school or repeat a grade than ADD/ADHD and typical controls.
• Children with autism were significantly less likely than were typical controls to participate in community service or volunteer work at school, church, or in the community (42% less likely).
• Parents of children with autism were significantly more concerned about their children’s achievement, self-esteem, stress coping, learning difficulties, and being bullied by classmates than parents of typical controls.
• Overall, parental concerns over children’s learning’s difficulties and being bullied were significantly higher in autism group than in the ADD/ADHD group.

Discussion

Findings from this study indicate that quality of life for children with autism may be compromised; and that caring burden on their families can be substantial. Families with children diagnosed with autism reported more profound quality of life effects than families of children with ADD/ADHD or typical controls. Families of children with ADD/ADHD also reported nontrivial adverse impacts on their quality of life in a number of domains - although the magnitudes of these effects were not as great as in autism families.

Acknowledgment: This study is supported by CDC cooperative agreement U10CCU320408-05