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## Quality of life for parents of children with autism spectrum disorders

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## ABSTRACT

This project describes health-related quality of life (HRQoL) of parents of children with autism spectrum disorders (ASDs) using mixed methods. Parents of children with ASDs ( $N = 224$ ) reported on their HRQoL, depression, and caregiving burden using quantitative tools. HRQoL scores were slightly worse than from those in normative populations especially related to stress and mental health. For example, parents reported average HRQoL scores from SF-6D of 0.74, which was clinically significant lower than an average normative U.S. population. 40% of parents reported having clinical depression symptoms. Married parents reported lower depression symptoms than parents who were not. In addition, families with three or more children with special health care needs (CSHCN) reported lower HRQL and higher caregiving burden than families with less CSHCN. In the qualitative study, we conducted five focus groups to gain insight as to the reasons a child's ASD might influence a parent's HRQoL. Qualitative data further supports the notion that parental HRQoL was negatively influenced by their child's ASDs. Studies that seek to quantify the influence of ASDs and to assess the effect of interventions for children with ASDs may consider measuring the effects on family members as well.

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Abbreviations: HRQoL, Health-related quality of life; ASDs, Autism spectrum disorders; QALY, Quality adjusted life years; AS-ATN, Autism Speaks Autism Treatment Network; DSM-IV, Diagnostic and Statistical Manual of Mental Disorders; IAN, Interactive Autism Network; HIPAA, Health Insurance Portability and Accountability Act; SF-6D, Six Dimension Short-Form Health Survey; EQ-5D, Five Dimension EuroQol; CES-D, Center for Epidemiologic Studies Depression Scale.

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## 1. Introduction

Autism spectrum disorders (ASDs) are complex conditions that involve impairments in social interaction, communication, and behavioral functioning such as repetitive and stereotyped behaviors (Strock, 2004). Many characteristics of ASDs, including limitations in social skills (Strock, 2004), behavioral problems (Aman, 2004; Militerni, Bravaccio, Falco, & Palermo, 2002), and sleep (Polimeni, Richdale, & Francis, 2005), are issues that likely have profound impacts on the parents of children and youth with ASDs. Additionally, many children with ASDs require intensive educational, behavioral and health services, which can be difficult for parents to access and when accessible can require parental time and resources to facilitate (Rapin, 2001; Roberts & Ridley, 2004).

Concerns about how parents of children with ASDs are faring have increased in recent years, partially due to the increasing prevalence of ASDs. Current estimates suggest that in the United States the rate of ASD is 1 in every 50 school-aged children (Blumberg et al., 2013). Accordingly, the number of parents affected by their child's ASDs has also increased along with demands for health and behavioral services for their children. Some insurers and payers have questioned whether such services are cost-effective relative to other services (Rothenberg & Samson, 2009).

Health-related quality of life (HRQoL) is a comprehensive health outcome concept that incorporates the various dimensions of health and functioning that contribute to an individual's overall well-being and quality of life. In addition to evaluating physical and psychological well-being, HRQoL assessments measure several other important components of health, such as role and social functioning. HRQoL is distinguished from many other health outcome measures by its multi-dimensional nature as well as its focus on capturing subjective experiences of health. HRQoL emphasizes an individual's perception of his/her functioning and well-being rather than focusing on objective measures of health. Cost-effectiveness evaluations of health care interventions typically measure the effectiveness component in terms of quality adjusted life years (QALYs, a measure of quality of life) gained for the patient or subject who is the focus of the intervention, in this case, the child with an ASD. More recently, however, methodological interest in economic evaluations of health interventions has included the measurement of potential 'spillover effects' on the family (Meltzer & Smith, 2011). This is the notion that the impact of a disease or treatment extends (or spills over) beyond the individual with that condition to others in the family or community. Researchers increasingly recognize that economic evaluations should account for family spillover effects (Brouwer, Van Exel, & Tilford, 2009). Methods to incorporate family spillover effects into economic evaluations are being developed (Basu & Meltzer, 2005; Basu, Dale, Elstein, & Meltzer, 2010). Accounting for spillover effects, if they exist, could lead to higher estimation of the benefits of effective interventions and better cost-effectiveness ratios and thus more support for interventions.

Parents of children with special health care needs are at increased risk for not being employed (Heck & Makuc, 2000; Kuhlthau & Perrin, 2001; Kuhlthau et al., 2010; Leiter, Krauss, Anderson, & Wells, 2004), financial stress (Strickland et al., 2004; Witt et al., 2011), and poor health-related quality of life (HRQoL) (Kuhlthau et al., 2010). To date, most studies focusing on parents of children with ASDs and other developmental disabilities have concentrated on mental health effects, evaluating factors such as parental stress, depression, and psychological well-being (Bromley, Hare, Davison, & Emerson, 2004; Duarte, Bordin, Yazigi, & Mooney, 2005; Hastings et al., 2005; Johnson, Frenn, Feetham, & Simpson, 2011; Olsson & Hwang, 2001). They also have focused on physical health, marital satisfaction, and coping strategies (Allik, Larsson, & Smedje, 2006; Knapp, 2004; Luther, Canham, & Cureton, 2005). Most studies were conducted using either qualitative or quantitative research, with few employing a mixed methods approach (Church, 2006; Crosby, 2009; Hu, 2008). Mixed methods research approaches have become widely used in health care research because they draw strengths and perspectives from both quantitative and qualitative methods and allow researchers to broaden understanding of a phenomenon (Creswell, Klassen, Plano Clark, & Smith, 2011). HRQoL of parents of children with ASDs is a complex phenomenon which may be better explained using both quantitative and qualitative findings. More studies are needed to fully understand the various domains of a parent's life that are influenced by their child's ASD and to understand possible mechanisms for these relationships.

In this study, we employed a triangulation, mixed method approach (Creswell et al., 2011) to generate more complete understanding the HRQoL of parents of children with ASDs and factors that may contribute to parent HRQoL using concurrent data analysis. In the quantitative research, we measured parent HRQoL related to having a child with an ASD using existing preference-based instruments used in cost-effectiveness analysis (Neumann, Goldie, & Weinstein, 2000; Neumann & Greenberg, 2009). Consistent with other studies, we applied the term preference-based HRQoL outcomes to describe measures commonly used for QALYs in cost-effectiveness analysis (Petrou et al., 2010; Tilford et al., 2012). By using both the quantitative data and the qualitative data we sought (1) to understand quantitatively which aspects of HRQoL were most commonly reported by parents of children with an ASD, (2) to determine qualitatively whether there were domains that were important but were not assessed in the quantitative evaluation, and (3) to understand whether parents attributed aspects of their own HRQoL to their child's health condition.

## 2. Methods

This cross-sectional study used a mixed methods approach with concurrent data analysis to explore HRQoL of parents of children with ASDs (Creswell et al., 2011). The quantitative research was conducted through two sites of the Autism Speaks Autism Treatment Network (AS-ATN) including a developmental center in Little Rock, Arkansas and an outpatient psychiatric clinic at Columbia University Medical Center in New York, NY. At an AS-ATN site, children suspected of having ASDs completed a multidisciplinary evaluation to confirm a diagnosis using the Autism Diagnostic Observation Schedule and

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