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## Patient-Reported Outcomes

# Health Utility Assessment Using EQ-5D among Caregivers of Children with Autism

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### ABSTRACT

**Objectives:** Health utility of caregivers of children with autism was assessed by using the EuroQol five-dimensional (EQ-5D) questionnaire. Utility scores of autism caregivers were compared with norms for the general adult US population. Predictors of health utility were identified. **Methods:** A cross-sectional online survey design was used. Caregivers registered with the Interactive Autism Network were approached for participation in the online survey. Three hundred and sixteen usable responses were received. Health utility among caregivers was calculated and compared with the US population norms by using Student's *t* test. Problems in EQ-5D questionnaire domains and utility scores were analyzed by study characteristics by using Kruskal-Wallis analysis of variance. Factors predicting health utility were identified by using ordinary least square regression. **Results:** Roughly 94% of the caregivers who participated in the study were females. As compared to their counterparts in the general US population, caregivers who were aged 18 to 44 years and were females

had lower utility scores ( $P < 0.001$ ). Significant differences in utility scores were observed among caregivers. When compared to males, females had lower health utility. Caregivers of lower socioeconomic status had lower utility scores and reported more problems in EQ-5D questionnaire domains than did those from higher socioeconomic status. Caregiver burden was inversely correlated with health utility. Caregiver physical and mental health status, objective strain, education, and relationship with the care recipient were found to significantly predict health utility (adjusted  $R^2 \sim 57\%$ ). **Conclusions:** Autism caregivers had lower health utility than did the general adult US population. There is an immediate need to address health concerns among this growing population.

**Keywords:** autism, caregivers, EQ-5D, health utility.

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## Introduction

Autism is a neurodevelopmental disorder that is believed to be caused by an interplay of genetic and environmental factors [1]. A recent study by the Centers for Disease Control and Prevention found autism prevalence to have increased by 78% in the United States between early and late 2000s [2]. The etiology of autism is not yet fully understood. As a result, there have been several reasons cited in the literature for the increasing prevalence of autism. Greater awareness of the disorder, broadening of the diagnostic criteria, diagnostic substitution, differences in study methodology, and other social and environmental causes have been attributed for the increasing prevalence of autism [3,4]. In their examination of patient records with the California Department of Developmental Services, King and Bearman [5] found diagnostic substitution, that is, reclassification from mental retardation to autism, to account for approximately 26% of the increase in autism caseload in California. These factors, however,

cannot fully explain the substantial increase in autism prevalence over the last few decades. It is generally believed that at least part of the (if not all) increase in autism prevalence has been “real” or “true” [4]. Based on updated estimates, 1 in 88 children has autism in the United States [2]. Prevalence rates for autism vary from 1 in 54 among boys to 1 in 252 among girls [2]. Roughly 3 million individuals have autism in the United States [6], and with the increasing prevalence, these numbers are likely to rise over the next few years. Besides causing significant functional limitations among individuals with the disorder, autism places an enormous (and growing) financial burden on families, payers, and society [7–10]. The lifetime direct and indirect cost of care for an individual with autism is as high as \$2.3 million in the United States [11]. The total societal cost of autism is estimated to be \$126 billion per year [11].

Caring for a child with autism places a significant health toll on caregivers. A higher degree of stress has been found among mothers of children with autism than among mothers of children

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1098-3015/\$36.00 – see front matter Copyright © 2013, International Society for Pharmacoeconomics and Outcomes Research (ISPOR).

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<http://dx.doi.org/10.1016/j.jval.2013.04.007>

with other developmental disorders [12]. Depression has been reported to be a common occurrence among mothers of children with autism [13,14]. Some studies have found lower health-related quality of life (HRQOL) among caregivers of children with autism than among the general adult population or caregivers of children with typical development [12,15–18]. In a recent study, Khanna et al. [17] found lower physical and mental HRQOL among caregivers of children with autism than among age- and gender-matched general adult US population. Mental HRQOL scores among autism caregivers were found to be similar to US population norms for individuals with depression. Studies have consistently found behavioral problems and functional limitations among children with autism to influence caregivers' HRQOL [15,17]. In one of the first studies to investigate the HRQOL among autism caregivers, Allik et al. [15] found higher social competence (prosocial behavior) among children with Asperger's syndrome and high-functioning autism to be related to better physical HRQOL among caregivers. Lower levels of behavioral problems and higher social competence among children were associated with better mental HRQOL among caregivers. Similarly, Khanna et al. [17] found an inverse relationship between behavioral problems among children with autism and caregivers' physical HRQOL. Greater levels of functional impairment in the child with autism were found to negatively impact caregiver mental HRQOL. These studies highlight the significant impact of caring for a child with autism on caregivers' physical and mental health; however, not much is known about the health utilities in this caregiving population.

Health utilities reflect individuals' preferences for different health states [19]. Using utility measures, HRQOL can be summarized into a numeric index ranging from 0 (representing death) to 1 (representing perfect health). Utilities are traditionally used as weights in the calculation of quality-adjusted life-years, and constitute a key component of economic evaluations. As health care resources become scarce, policymakers are increasingly opting for economic analysis to make resource allocation decisions. Evaluations of interventions aimed at improving the health of autism caregivers are disadvantaged in the absence of baseline utility scores in this growing population. A thorough review of the literature did not reveal any previous study that has assessed health utility in autism caregivers.

This study aims to fill an important gap in the autism literature by determining health utility among caregivers of children with autism. For this purpose, we used the EuroQol five-dimensional (EQ-5D) questionnaire, a generic HRQOL instrument [20]. The EQ-5D questionnaire is one of the most commonly used health status and preference instruments [21]. With its low respondent burden, ease of administration, and ability to provide health utility information, the EQ-5D questionnaire was considered an appropriate instrument for study purposes. Health utility scores of autism caregivers were compared with population norms. Factors predicting health utility among autism caregivers were also identified.

## Methods

### Study Design and Sample

A cross-sectional survey design methodology was used. Data were collected through an online survey. The target population for the study was primary caregivers of children with autism. Families of children with autism registered with the Interactive Autism Network (IAN) were approached for survey completion. Established in 2006 by the Kennedy Krieger Institute, the IAN is a Web-based autism research registry [22]. The IAN serves an important role in increasing our understanding of this complex disorder by providing researchers access to families of those affected with the disorder. More than 40,000 individuals are

registered with the IAN, making it a valuable data pool for researchers working in the area of autism. From the list of families registered with the IAN, those having a child with autism aged 18 years or younger were identified. Among these families, those having more than one child with autism were excluded. The remaining families were emailed a cover letter (in May 2012) explaining the purpose of the study. The cover letter requested primary caregivers of children with autism to participate in the survey. A survey link was included in the e-mail. Sample identification and cover letter mailing were conducted by the IAN to protect information related to their members. To maximize survey response, a \$15 Amazon gift card was provided for survey completion. The Qualtrics survey software system (Qualtrics, Inc., Provo, UT) was used to field the study survey. Three hundred and twenty-six survey responses were received from caregivers of children with autism. The study was acknowledged under exempt status by the University of Mississippi Institutional Review Board.

## Measures

### The EQ-5D questionnaire

The EQ-5D questionnaire consists of five health profile domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression [20,23]. Each domain is assessed by using a single item that has three levels: 1) no problems, 2) moderate problems, and 3) extreme problems. For example, a response of "22113" indicates moderate problems in mobility and self-care, no problems in usual activities and pain/discomfort, and extreme problems in anxiety/depression. The five-domain structure of the EQ-5D questionnaire encompasses 243 different health states. A scoring algorithm based on preference weights for the US population [24] was used to calculate EQ-5D questionnaire utility scores. The EQ-5D questionnaire utility scores calculated by using this algorithm have a range between  $-0.11$  (representing death) and 1.00 (representing perfect health). The EQ-5D questionnaire also includes a visual analogue scale, a vertical line that ranges from a scale of 0 (worst imaginable health state) to 100 (best imaginable health state). Participants are requested to rate their current health states (0–100 range) on the EQ-5D questionnaire visual analogue scale.

As mentioned earlier, we also ascertained the predictors of caregiver health utilities. For this purpose, we looked at the role of caregiver physical and mental health status and sociodemographics (age, gender, race, marital status, education level, employment status, income, and relationship to the child with autism), caregiving situational factors (caregiver burden, caregiver coping, social support, and family functioning), and care recipient characteristics (autism severity, gender, age, type of autism, age at diagnosis, other physical and mental illness, and medication use) in influencing caregiver health utilities. Relevant measures used for this purpose have been described in this section.

### Medical Outcomes Study Short-Form Health Survey version 2

The Medical Outcomes Study Short-Form Health Survey version 2 was used to determine caregiver physical and mental health status. It is a 12-item generic HRQOL instrument that assesses an individual's health profile [25]. The instrument provides scores for two summary scales: Physical Component Summary (PCS) and Mental Component Summary (MCS). The QualityMetric SF Health Outcomes Scoring Software was used to calculate norm-based scores for PCS and MCS. Higher scores for both PCS and MCS indicate better physical and mental health status.

### Caregiver Strain Questionnaire

The burden experienced by caregivers of children with autism was determined by using the 21-item Caregiver Strain

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