



Health Related Quality of Life in children with Autism Spectrum Disorders: The clinical and demographic related factors in Turkey

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ABSTRACT

We aimed to investigate the Health Related Quality of Life and related clinical variables (HRQoL) of children with Autism Spectrum Disorders (ASD). We included 102 children with ASD (46 with autism, 38 with pervasive developmental disorder not otherwise specified (PDD-NOS) and 18 with Asperger's syndrome (AS)) and 39 typically developing children as a control (TDC), between 3 and 18 years of age. The mothers scored the Pediatric Quality of Life Inventory 4.0 (PedsQLTM 4.0). The physical health, psychosocial health and total summary score of ASD group were significantly lower than TDC. Within ASD group, psychosocial ($p < 0.001$), social, school functioning and total summary score ($p < 0.001$) of the autism group were lower than AS, and PDD-NOS. The scores of AS and PDD-NOS were similar. PedsQL scores differed between the groups who take psychotropic medication and continue to special and formal education in ASD. PedsQL scores were negatively correlated with the Childhood Autism Rating Scale (CARS) score and positively correlated with the age that first signs appeared ($p < 0.01$). Within ASD group the children with autism had the poorer HRQoL than AS and PDD-NOS. The correlation between HRQoL and CARS scores was moderate. The severity of ASD has negative effects on HRQoL.

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1. Introduction

Autism Spectrum Disorders (ASD) are early onset neurodevelopmental disorders defined in terms of abnormalities in social and communicative development and the presence of marked repetitive behavior and narrow interests (American Psychiatric Association, 2000). Generally these deficits affect multiple areas of development and lead to chronic functional losses. In comparison to children with typical development, children with ASD experience significant problems related to psychological, social, and emotional health. The deficits in social skills and communication are prominent. In the children with ASD self-harming behaviors, atypical and aggressive behaviors toward others can be observed. These problems lead to poor social adjustment. Children with ASD also exhibit greater rates of depression, stress, and anxiety (Gurney, McPheeters, & Davis, 2006; Hill, Berthoz, & Frith, 2004), poorer physical health, sleep disruption, gastrointestinal problems, and allergies (Allik, Larsson, & Smedje, 2006; Cotton & Richdale, 2006; Hill et al., 2004; Kuhlthau et al., 2010).

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Currently the studies put emphasis on the quality of life in several chronic and psychiatric disorders. Quality of life is a broad notion which also involves the personal wellbeing beyond the personal health (Eser et al., 2008). It means that the individual's response in everyday life to the physical, psychological and social effects of the problems that affect that individual's satisfaction in certain life conditions. For these reasons the measurement of the QoL has a broader notion and comprehension than the criteria related to health (Orley & Kuyken, 1993; The WHOQOL Group, 1996). The measurement of health related QoL consists of questions about the symptoms, clinical status, functioning, psychosocial well-being and social support of the patient and life satisfaction.

There are limited studies about the HRQoL of children with ASD in literature. Kuhlthau et al. (2010) compared the HRQoL of children with ASD to the children with physically chronic conditions and healthy control by using Pediatric Quality of Life Inventory 4.0 (PedsQL 4.0) (Varni, 1998) parent forms. They found the HRQoL scores of ASD group significantly lower than both the healthy and chronic condition groups. The most prominent difference was in social functioning domain. They found that HRQoL was consistently related to internalizing and externalizing problems as well as repetitive behaviors, social responsiveness, and adaptive behaviors in ASD (Kuhlthau et al., 2010). Lee, Harrington, Louie, and Newschaffer (2008) also found that the HRQoL in ASD is lower than the children with attention deficit and hyperactivity disorder (ADHD) and normal control and the concerns of parents are overwhelming in ASD. Similarly Bastiaansen, Koot, Ferdinand, and Verhulst (2004) showed that ASD children have lower psychosocial and emotional scores than the psychiatric patient group involving ADHD, other disruptive behavior disorders, anxiety and affective disorders, and lower emotional scores than the healthy control group. Limbers, Heffer, and Varni (2009) found in their study that parents of children with Asperger syndrome reported significantly lower HRQoL in their children compared to the parents of an equivalent individual from the control group. Shipman, Sheldrick, and Perrin (2011) also reported lower QoL in adolescents with ASD when compared with adolescent reports. Montalbano and Roccella (2009) assessed both parents of 54 subjects with PDD, and found that PDD has a considerable impact on both the child's development and the entire family. They reported that the problems centered on self-care skills, difficulty in explaining the child's illness to others and looking after the child. The most important problems about the other children in the family concerned was providing them with necessary attention and the restrictions their brother or sister's illness placed on their own activities (Montalbano & Roccella, 2009). To our knowledge there is not a study comparing the HRQoL within ASD group separately.

While we know the psychiatric, psychological, physical and neurological comorbidities are high in ASD, and the goals of treatment are to maximize the child's ultimate functional independence and quality of life by minimizing the core ASD features, and reducing maladaptive behaviors (Myers & Johnson, 2007), the studies about the overall HRQoL of these children is scarce. We aimed to investigate the HRQoL of children with ASD, and to compare to both the healthy control group and within ASD group. Also we aimed to investigate the relation between HRQoL and sociodemographic characteristics, symptom severity and other clinical variables. We hypothesized that the children with ASD have poorer HRQoL and those with the most severe symptoms of ASD are related to poorer HRQoL.

2. Method

2.1. Participants and procedures

All ASD participants were recruited from Ege University School of Medicine Child and Adolescent Psychiatry Department Developmental Disorders polyclinics. All participants were individually briefed on the aim of the study and signed an informed consent form in accordance with the Declaration of Helsinki. The local Ege University School of Medicine Institutional Review Board approved the study.

We recruited 110 children diagnosed with ASD aged between 3 and 18 years during their routine visit. Eight of them did not get the necessary requirements for the study, so they were excluded. Finally we completed the study with 102 children; 46 children diagnosed with autistic disorder (AD), 38 with pervasive developmental disorder–not otherwise specified (PDD-NOS), and 18 with Asperger's syndrome (AS).

Participants were examined for the presence of ASD using a two-stage evaluation. In the first stage, the children were diagnosed by the child psychiatrist, who had at least 5 years experience in child psychiatry, using a structured interview using the evaluation form which is developed by the authors and based on the DSM-IV-TR A–B, and C criteria of autistic disorder and Asperger's syndrome assessing the social functioning (5 items), communication (4 items), and stereotypic-ritualistic behavior/interests (4 items) domains. In the second stage, the autistic symptoms of these children were scored on the Childhood Autism Rating Scale (CARS) (Schopler, Reichler, DeVellis, & Daly, 1980; Sucuoglu, Oktem, Akkok, & Gokler, 1996). Finally, the researchers, who had at least 5 years of experience working with children and adolescents with ASD, gave a diagnosis of ASD, including AD, AS and PDD-NOS, according to DSM-IV-TR (American Psychiatric Association, 2000) criteria, by consensus.

Control subjects were recruited from the hospital staff. The history of psychiatric treatments was the exclusion criteria for control subjects. Thirty-nine typically developing control (TDC) children were included to the study. Control subjects had no family history of autism/AS. The parents of ASD and TDC children completed the PedsQLTM 4.0 (Varni, 1998) for their children.

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