



## PedsQL-4.0 in children with Autism Spectrum Disorder

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### ABSTRACT

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder in DSM-5, characterized by social deficits and communication difficulties, stereotyped or repetitive behaviors and interests, sensory issues, and in some cases, cognitive delays. The prevalence of ASD is ever-increasing recently throughout the world. There aren't enough studies that have considered the qualities of life (QoL) of Autistic children through there are many comparing the QoL of parents of children with ASD. The diagnostic criteria for ASD are available in the revised text edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) of the American Psychiatric Association. This study assesses the Paediatric Quality of Life (PQOL) of ASD children from a multidimensional perspective based on the Cross-sectional survey, which considered Physiological function, emotional function, social function and school performance. This study aimed to evaluate the QoL of children with ASD aged 2-12 years. 98 autistic children (male: 69, female: 29; 2- 4 years old: 40, 5- 7 year old: 43, 8 - 12 years old: 15) and 100 normal children (control group) are brought into this study. The children are satisfying the DSM-5 as ASD were subjected to assessment of their QoL with the Pediatric Quality of Life Inventory (PedsQL) questionnaire by their parents, compared with standard scores. The present study shows lower scores in the test group on the PedsQL4.0 universality Core scale in comparison with the control group. Behavior issues had a negative effect on Community adaptation, mental health, lower intelligence-related quality of life for children and clinically significant autistic symptoms in comparison with children with fewer symptoms. For mild-moderate ASD children, better development probably played a significant role in response to rehabilitation, to achieve and maintain the best level of the overall outcome. Hence pediatricians are must evaluate these children for early interventions and medications, if needed, and have QoL integrated in the overall care plan.



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### INTRODUCTION

Autism is becoming a common, Neurodevelopmental disorder in India. The criteria for diagnosis involve (a) qualitative impairment of reciprocal social interactions, (b) marked impairment in the development of communication, and (c) severely restricted, stereotyped, and repetitive patterns of interests and behaviors. Most individuals with ASD have significant permanent impairments in social and language functioning; a small percentage is able to live and work independently as adults. There is an increasing incidence of autism spectrum disorder.

der in recent years ([Whoqol, 1993](#)), with no specific treatment and significantly high morbidity resulting in poor adaptability and acceptability of these children into society ([Renty and Roeyers, 2006](#)). This necessitates better attention to the QoL of ASD children getting various interventions, including drugs, for managing specific difficulties.

Its incidence in India is 1:146 now, with a rising trend with a pooled prevalence of 9/1000 ([Singh et al., 2019](#)). Parents of ASD children need their children to be self-reliant in life. Most worry that their children will not be able to live normally after them. In addition, most of the public in villages lack the awareness of autism and this increasing numbers will bring a heavy burden on society.

Quality of life evaluation has a great influence on the management of children with ASD with respect to selecting intervention/treatment options, effects of the problem in child and in parents. The criteria for the diagnosis of ASD are defined with DSM-5 criteria as a disorder with significant interference in the use of language, social interaction, repetitive interests and rigid and repetitive behaviors in addition to abnormal sensory perceptions. It is more common in boys ([Halladay et al., 2015](#)). The use of the biopsychosocial model for intervention makes it more important for assessing the QoL of these children. Lack of awareness, lack of acceptance by parents in early stages and resource constraints prevent early interventions making it more complicated, affecting the QoL of these children later in life. Data regarding this aspect will help in formulating the policies directed towards interventions for this at a social level necessitating the need for this study.

The rehabilitation of autistic children is a complex social problem with interference in the financial stability of the family, parent's psycho-social well being and environmental and social support can affect the prognosis of children. Hence direct attention should be paid to QoL of ASD children to improve service delivery, including choice of rehabilitation resources and service system.

## MATERIALS AND METHODS

This is a multicentric prospective study (cross-sectional) done after getting IEC approval from Saveetha University, Chennai and getting a written consent form of parents of children with ASD. A pre-designed questionnaire was designed for data collection and after getting pediatric QL 4 core. The autistic children coming to the Child development center (SCDC) at Saveetha medical college, three branches of Vistara CDC and normal children coming to the pediatric outpatient depart-

ment for immunization and other checks up without any chronic ailments were taken for comparison to include in the study. Convenient sampling methodology was chosen to include all children in both groups. 102 ASD children were initially recruited, but four lost up in follow up as they discontinued care in our settings due to difficulty in transportation and similar issues. Ninety-eight children with ASD of different grades of severity (male: 69, female: 29; 2- 4 years old: 40, 5- 7 years old: 43, 8 - 12 years old: 15) and 100 normal children were finally present for the entire study.

### Inclusion criteria

All ASD children in 2-15 years with documented diagnosis by a developmental pediatrician and a clinical psychologist or psychiatrist according to DSM-5 criteria were included in the study.

### Exclusion criteria

All children with other co-morbidities like other system disorders like heart disease, autistic symptoms as part of other disorders, including neurodegenerative disorders, other psychiatric disorders like schizophrenia, depression, etc. were excluded.

### Method of study

This is a multicentre cross-sectional study from the above-said centers and children enrolled were rechecked for DSM-5 scoring and confirming the diagnosis. The two groups of children were assessed for their QoL with Paediatric Quality of Life Inventory (PedsQL) 4.0 generic core scales. PedsQL has two scales- one for children and the other one for their parents. We used the self-report version of the PedsQL in children 8 - 15 years old normal school-going children and the parent-report version in normal 2 - 7 years old children as well as all ASD group.

PedsQL-4 Generic Core Scales, which has 23 items, measure the core dimensions of health as delineated by the World Health Organization and the role (school) functioning ([Varni et al., 2003](#)). There are four multidimensional scores and three summary scores, which include physiological function (8 items), emotional function (5 items), social function (5 items), and role function (5 items). Data were analyzed using SPSS-20 and the results. The general data were descriptively analyzed and the statistical inference obtained by the t-test. Category data compared by the Chi-square test and heterogeneity of variance between groups was analyzed by approximate t-test. Pearson's correlation analysis was also obtained.

**Table 1: Comparison of gender and age of ASD with normal population**

	ASD	Normal	P
Male	69	56	X <sup>2</sup> =4.414 p=0.03536
Female	29	44	
Age(yrs)	5.2+/-0.5	4.5+/-0.59	t' 1.89; P= 0.608

**Table 2: Comparison of socioeconomic status in ASD and normal population**

Socio-economic status	ASD	Control	P
Lower SES	36(37%)	42	0.541
Other SES	61	58	

**Table 3: QoL of ASD Vs. Normal children**

Type (N)	Physiological function	Emotional function	Social function	Psychological function	Overall function
ASD(98)	61.8+/-26.01	52.97 ± 26.62	45.03 ± 26.92	36.69 ± 31.60	49.27 ± 24.3
Control(100)	90.17 ± 12.98	78.89 ± 19.26	84.89 ± 16.41	81.75 ± 17.03	83.23 ± 15.2
t	t=12.988	t'=9.951	t'=17.131	t'=16.786	t=16.872
P	P<0.01	P<0.01	P<0.01	P<0.01	P<0.01

**Table 4: Disease severity Vs. QoL in ASD children**

Groups	Physiological function	Emotional function	Social function	Psychological function	Overall function
1. Severe ASD	51/02 ± 21.79	41.75 ±	31.73 ±	23.15 ± 21.58	36.59 ±
2. (n=28)		23.50	21.04		14.89
3. Mild- moderate ASD (n=70)	83.767 ± 14.94	75.81 ± 16.70	70.13 ± 19.89	68.68 ± 22.25	74.49 ± 15.05
3. Normal (n=100)	90.14 ± 13.42	79.17 ± 19.47	85.29 ± 16.42	82.55 ± 16.33	85.63 ± 13.89
A&B (t)	17.274	15.149	17.641	19.239	19.436
P	0	0	0	0	0
B&C (t)	1.60	0.034	0.035	3.154	2.31
P	0.922	0.494	0.976	0.989	0.0\54
A&C (t)	10.957	11.4474	9.401	10.798	10.92
p	0	0	0	0	0

## RESULTS AND DISCUSSION

Male & female There is a significant difference in male: female distribution in the test population (ASD group) than the control and the X<sup>2</sup> test done shows a significant p-value <0.05, as seen in Table 1.

This is also similar to a recent study reported by others recently (Loomes *et al.*, 2017). The male to female ratio also shows 2.3:1 and not at 4:1 as reported in early studies (Idring *et al.*, 2015). There is no significant correlation between the age of parents, educational levels, socio-economic status (SES), dietary habits of mother during pregnancy,

mode of delivery and birth weight. The risk factors during pregnancies were the following- 28 mothers had suspected viral fever of which 12 were during the first trimester, 19 had fetal distress with low Apgar scores at birth, 4 had birth asphyxia, but without other neurological signs or Imaging evidence of neurological damage, 29 had other relatives having learning disabilities, speech difficulties and 12 had relatives with seizures. Only 37(n=36%) were from lower socioeconomic status. When comparing the socioeconomic status of children with ASD and normal, the present study did not give any statistically significant impact of SES on QoL of chil-

dren with the Chi-square is 0.3719 and the p-value is 0.54195(<0.05), as perceived by parents as given in Table 2.

Quality of life between groups was analyzed by t-test, which showed that the QoL of autistic children was significantly lower than that of normal children in both the individual and overall domains, as analyzed in Table 3.

All domains were significantly impacted, though the effect in the Physiological domain was lesser. A psychological function is the most affecting, bringing the overall score lower significantly.

When compared with normal children, ASD children, especially in severe grades, showed considerable difficulty in having a good quality of life. In both the mild-moderate variety and severe variety, QoL showed statistically significant problems. The physiological functions of body movement showed not much difference in mild-moderate variety. In all other domains, there was a significant difference in both when compared to normal children, as depicted in Table 4. ASD groups had significant problems with emotional expression, verbal output, participation in peer interaction even for entertainment and had more issues with senses like taste and touch, which is very much reported earlier (Lee et al., 2008). Parental concerns over learning issues, bullying, coping with stress and achievement were significant in the autism group relative to the normal groups. However, we also have to make a multidimensional approach in formulating a management plan for autistic kids as parental concerns and perceptions may vary for mother and father (Pozo et al., 2014).

## CONCLUSION

QoL is significantly affected in children with autism, whether mild or severe, as perceived by parents and hence all interventions which we consider to correct the core deficits in Autism should address the core concerns of QoL also. The significant impact in social, emotional and psychological domains has to be considered in all ASD as even in a high functioning, it will affect the scholastic and overall performance in life. There is a need to assess prospectively the effect of each intervention, like for joint attention, speech therapy, etc. on each of the domains affecting QoL in children with autism on a larger scale.

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