

# Quality of life of 8- to 12-year-old children with autism spectrum disorder in Colombo district, Sri Lanka; perspective of primary caregivers

de Silva Y<sup>1</sup>, Wijesekara S<sup>2</sup>

<sup>1</sup>Colombo South Teaching Hospital, Kalubowila, Sri Lanka.

<sup>2</sup>Faculty of Medical Sciences, University of Sri Jayewardenepura, Gangodawila, Nugegoda, Sri Lanka.

**Correspondence:** Dr. Yashica de Silva  
e-mail: [yashica3007@gmail.com](mailto:yashica3007@gmail.com)  
 <https://orcid.org/0000-0001-7021-7481>  
Submitted on 10.07.2021 and accepted for publication on 10.12.2021

## ABSTRACT

**Introduction:** Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder characterised by impairments in social interaction, verbal and nonverbal communication, and a restricted repertoire of activities and interests. As it is a condition which persists in one's entire life, maintaining a good Quality of Life (QoL) in such children is essential. The objective of the study was to assess the QoL in 8 to 12-year-old children diagnosed with ASD who are attending autism clinics in two major hospitals in Colombo District, Sri Lanka.

**Methods:** A descriptive study was carried out among the caregivers of 8 to 12-year-old children with ASD attending two major hospitals in Colombo. Paediatric Quality of Life Inventory (PedsQL) was used to assess the QoL in the children, according to the perception of the caregivers.

**Results:** Thirty-five caregivers were included in the study. Majority of the caregivers were mothers. Mean (SD) age of the children studied was 9.6 ( $\pm 1.6$ ) years. The median total score was 64.44. The median physical functioning, median emotional functioning, the median social functioning and the median social functioning scores were 81.25, 65.0, 40.0 and 35.0 respectively. The median psychosocial functioning score derived by combined scores of emotional, social and school functioning was 48.0, and it was lower than the median physical functioning score.

**Conclusion:** The QoL of this group of children with ASD attending autism clinics in two major hospitals in Colombo district were poor with the psychosocial component being more affected than the physical component.

**Keywords:** *Autism spectrum disorder, quality of life, children, Colombo, Sri Lanka.*

## Introduction

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder characterised by impairments in social interaction, verbal and nonverbal communication, and a restricted repertoire of activities and interests (1). Deficits in adaptive skills are seen in almost all children.

While some have intellectual disability, others have co-existing psychiatric disorders (2). The global prevalence of ASD is about 1 in 54 (3, 4). In Sri Lanka prevalence of ASD is reported to be around 1 in 93 (5).

Stress and psychological wellbeing are mental health-related factors that are being assessed in children with ASD. In addition, it is essential to assess the Quality of Life (QoL) in families of children with ASD. According to The World Health Organisation, QoL is defined as an individual's perception of their life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns(6). As it is a condition which persists in one's entire life, maintaining a good QoL in such children is essential. Though ASD is a lifelong neurodevelopmental disorder, the symptoms of affected children can be improved with intense therapy and cooperation of parents and therapists, to reduce the impact on QoL of both the children and parents.

Worldwide, there are various studies done with regard to the QoL in children with ASD. But in Sri Lanka, data on QoL in children with ASD are very scarce. Hence, the aim was to assess the QoL of children with ASDs as perceived by the primary caregivers in Sri Lanka in order to plan interventions to improve the QoL of affected children which will in turn improve the QoL of their parents and the entire family.

## Methods

A descriptive cross-sectional study was carried out among caregivers of children aged 8 to 12 years primarily diagnosed with ASD, without any other coexisting illness, attending autism clinics in two major teaching hospitals in the Colombo District, Sri Lanka, over a period of two months. Primary caregivers of children aged 8-12 years, diagnosed with ASD by a consultant paediatrician, psychiatrist or neurologist using Diagnostic and Statistical Manual of mental disorders – 5 (DSM-5) criteria (1) were included in the study. The sample size was calculated using the formula  $n = Z^2 p (1-p) / d^2$ , with  $Z = 1.96$ ; critical value of specified confidence, at 95% confidence interval,  $p = 0.02$ ; prevalence of ASD over > 8 years (7) and  $d = 5\%$  of accepted amount of absolute error. Caregivers of children with the presence of other debilitating medical conditions such as syndromic diagnosis, cerebral palsy, congenital or acquired neurological conditions, heart disease, renal disease, liver disease

and blood disorders were excluded. Study related measurements and data collection were done by one of the authors.

Data were collected using a questionnaire consisting of two parts. Part A was used to collect demographic data and data regarding associated factors, and it was an interviewer-administered questionnaire developed by the investigators. Part B was the Paediatric Quality of Life Inventory (PedsQL) questionnaire version 4, which has been validated in Sri Lanka (8). PedsQL has two 23-question surveys, one self-report to be completed by the child and one proxy-report to be completed by the child's parent or caregiver. We used only the proxy-report in this study as we are assessing the QoL of children in the perspective of their caregivers. Total PedsQL score for each report was the sum-total average of item scores across the four subdomains; physical (8 items), emotional (5 items), social (5 items) and school (5 items) functioning, on a 0–100 scale. Higher the scores better the Health-Related Quality of Life (HRQoL). A total score for each subdomain is obtained by taking a sum-total average of the individual item scores within the subdomain, also reported on a 0 – 100 scale; higher scores representing better HRQoL. If the parent-proxy reported PedsQL score is  $\leq 65$ , HRQoL was considered as poor. Subdomain scores were also reported as physical functioning and psychosocial functioning, where the psychosocial subdomain is taken as a sum-total average of the item scores from the emotional, social and school functioning sections of the questionnaire.

Ethical approval for the study was granted by the Ethics Review Committee of the Sri Lanka College of Paediatricians (Ref. No. SLCP/ERC/2020/30). Written informed consent was obtained from the parents/ guardians of the children included in the study.

Collected data were entered using standard SPSS software. As the data were not normally distributed nonparametric tests needed to be considered. Results were interpreted with frequency tables with the central tendency described using median. Statistical significance was computed using the relevant nonparametric tests.  $p < 0.05$  was considered statistically significant.

## Results

Thirty five caregivers were included in the study. The relationship to the child and demographic factors of child and caregiver are given in Table 1.

Majority of the caregivers were mothers. Mean age of the children was  $9.6 \pm 1.6$  years. Majority (65.7%) were boys and 88.6% of the sample were Sinhala. Majority (74.3%) of the children had siblings. Most (88.6%) of the children attended school, 34.3% attending a normal class in a normal school.

## Quality of Life (QoL)

The data were not normally distributed; therefore central tendency is described using median values and the interquartile ranges (IQR) and analysis is done by using the relevant nonparametric tests. The PedsQL QoL scores are shown in Table 2. The median total score was 64.44 (IQR 36.72 to 69.32), which indicates a poor quality of life overall.

**Table 1:** Socio-demographic factors of study participants (n = 35)

Child		Caregiver	
Socio-demographic factor	n (%)	Socio-demographic factor	n (%)
<i>Age (years)</i>		<i>Relationship to child</i>	
8	13 (37.1)	Mother	28 (80.0)
9	06 (17.1)	Father	06 (17.1)
10	06 (17.1)	Grandmother	01 (02.9)
11	02 (05.7)		
12	08 (22.9)		
<i>Gender</i>		<i>Employment</i>	
Male	23 (65.7)	Employed	11 (31.4)
Female	12 (34.3)	Unemployed	24 (68.6)
<i>Ethnicity</i>		<i>Highest educational level</i>	
Sinhala	31 (88.6)	Primary	14 (40.0)
Tamil	02 (05.7)	Secondary	11 (31.4)
Muslim	01 (02.9)	Tertiary	10 (28.6)
Other	01 (02.9)		
<i>Having siblings</i>		<i>Marital status</i>	
Yes	26 (74.3)	Married	31 (88.6)
No	09 (25.7)	Divorced	01 (02.9)
		Separated	03 (08.6)
<i>Schooling</i>		<i>Monthly income of family (SLRs)</i>	
Yes	31 (88.6)	<50,000/=	20 (57.1)
No	04 (11.4)	50,000 – 100,000/=	15 (42.9)
<i>Type of school</i>			
Normal school normal class	12 (34.3)		
Normal school special class	08 (22.9)		
Special school	11 (31.4)		

**Table 2:** PedsQL Quality of Life scores in the study group

Score	Median	Interquartile range	Interpretation
Total score	64.44	36.72 - 69.32	Poor
Physical functioning score	81.25	53.13 - 90.63	Good
Emotional functioning score	65.0	55.0 - 80.0	Poor
Social functioning score	40.0	20.0 - 60.0	Poor
School functioning score	35.0	20.0 - 45.0	Poor
Psychosocial functioning score	48.0	36.72 - 69.32	Poor

*PedsQL: Pediatric Quality of Life Inventory*

The median psychosocial functioning score is lower than the median physical functioning score (48.0 vs 81.25,  $p < 0.001$ ). When considering the subscale scores, the lowest QoL was reported for the school functioning score (35.0) which was lower than the other subscales ( $p < 0.001$ ).

Of the participants 71.4% had a good physical score while 28.6% had a poor physical score. But only 8.6% of the participants had a good psychosocial functioning score while 91.4% had a poor psychosocial functioning score ( $p = 0.004$ ).

Majority (51.4%) had a poor emotional functioning score; 77.1% and 88.6% of the participants had poor social and school functioning scores respectively. Of the participants 88% had a good physical functioning score but a poor psychosocial functioning score, while only 12.0% had both good physical and psychosocial functioning scores. All the participants who had a poor physical functioning score also had a poor psychosocial score. Table 3 shows the comorbid conditions that these children had. Majority (82.9%) had a comorbid condition.

In the sample, 68.8% of the children who had Attention Deficit Hyperactivity Disorder (ADHD) as a comorbid condition showed a poor QoL overall score, while 57.9% without ADHD had a good QoL ( $p = 0.176$ ).

**Table 3:** Comorbid conditions of participants

Comorbid condition	n (%)
Intellectual disability	19 (54.3)
Epilepsy	07 (20.0)
Sleep problems	07 (20.0)
ADHD	16 (45.7)
Language problems	10 (28.6)
Gastrointestinal problems	01 (02.9)
Regression	03 (08.6)
Aggression	02 (05.7)
Mood disorders	03 (08.6)
OCD	02 (05.7)
Other	02 (05.7)

*ADHD: Attention deficit hyperactive disorder,*

*OCD: Obsessive compulsive disorder*

## Discussion

Initial studies, conducted when autism was considered to be a severe disorder, usually associated with intellectual disability, reported a prevalence of four to five cases per 10,000 children (9). However, the current prevalence of ASD reported is 1 in 54 worldwide (3, 4). Increased prevalence is partly because of altered diagnostic criteria and assessment practices (10). In Sri Lanka, prevalence of ASD is reported to be around 1 in 93 (5). Despite advances,

children with ASD are still at risk of developing significant physical and psychiatric problems (11). Having a good QoL indicates positive perceptions of overall health, well-being and satisfaction with life experiences.

This study revealed that the children 8 - 12 years old in the Colombo district who were diagnosed with ASD had an overall PedsQL score of 64.44, which is poor, with a lower psychosocial score (48.0) compared to a physical score (81.25). Overall score of QoL reported in this study by caregivers of ASD children was much lower than overall scores described by the creators of the PedsQL tool in healthy children (83.0) and in acutely (78.7) and chronically (77.2) ill children in United States (12). A Sri Lankan study, which assessed the QoL using PedsQL in children with asthma and healthy controls of 12 - 14 years, reported higher overall PedsQL scores of 76.3 and 87.2 respectively (8). Another study done among obese and overweight 8 to 12-year-old children in Sri Lanka using the PedsQL showed an overall score of 80.4 and physical and psychosocial scores of 78.1 and 81.7 respectively (13). A previous meta-analysis of ten studies and some other studies shows that the QoL in ASD were not affected by the age of the children (14, 15). Therefore, children with ASD in Colombo district appear to have a lower QoL in comparison to healthy Sri Lankan children and Sri Lankan children with diseases like asthma and conditions like obesity.

When considering the 4 subscale scores, the children in our study had the lowest score in school functioning followed by social functioning, emotional functioning and physical functioning scores. According to the DSM-5, major manifestations of ASD include impairment in social communication and behavioral problems such as fixed interests and repetitive movements. This was seen when taking the subscale scores of our study into consideration.

Various studies have shown that children with ASD experience poorer HRQoL across multiple domains. A study comparing HRQoL of 96 children with ASD, aged 8-17 years, with 211 typically developing peers, showed that parents of children with ASD reported lower HRQoL scores across all domains, in comparison with controls (16).

A study done in UK regarding QoL in ASD using KIDSCREEN-52, in a sample of 51 revealed significantly low HRQoL across many dimensions (17). Many studies have found that in children and youth with ASD, higher levels of behavioural, emotional and social problems were related to lower levels of HRQoL (18).

In our study, 68.8% of the children who had ADHD as a comorbid condition showed a poor QoL overall score, while 57.9% without ADHD had a good QoL, although this was not statistically significant. There were significantly lower scores on all PedsQL domains in young people with comorbid ADHD symptoms in comparison with ASD alone (19). Chen *et al.*, Kose *et al.*, and Kuhlthau *et al.*, in their studies have compared the HRQoL in children and young adults and have shown that the HRQoL levels were lower in the ASD groups than their control groups (16, 20, 21). Our study was in line with the findings of these studies done worldwide.

Using a pre-validated, international generic QoL questionnaire which is acceptable is a strength of this study. The usage of the Sinhala version of this tool which is also validated and pre-tested in Sri Lanka was another strength of this study. This enabled us to compare the data regarding QoL in ASD children as well as normal and children with other medical conditions from Sri Lanka as well as from other regions of the world. Although we used data from other studies which used the same tool in Sri Lanka to compare the data, inclusion of a healthy group of children as the control group would provide useful information in future research.

As there are no published data regarding the QoL of children with ASD in Sri Lanka, multicentre studies with data from all over the island would help in getting an idea of the situation of ASD children in rural and semi-urban areas so that special programmes can be implemented in these areas to improve the QoL in these children. To the best of our knowledge, there are no published studies in Sri Lanka on the QoL of children with ASD. The cohort of children with ASD in this age group will be stepping into the society within the next few years. Hence it is of utmost importance to implement strategies to improve the QoL of these children in order to make them independent citizens in the country.



## Conclusions

The QoL in 8- to 12-year-old children with ASD attending autism clinics in two major hospitals in the Colombo district were poor with the psychosocial component being more affected than the physical component.

## References

1. Diagnostic and Statistical Manual of Mental Disorders: DSM-5. 5<sup>th</sup> ed., American Psychiatric Association, 2013.
2. Moyal W, Lord C, Walkup J. Quality of Life in children and adolescents with Autism Spectrum Disorders: What is known about the effects of pharmacotherapy? *Paediatric Drugs*. 2013; **16**(2): 123-128.
3. Elsabbagh M, Divan G, Koh Y, K *et al*. Global prevalence of autism and other pervasive developmental disorders. *Autism Research*. 2012; **5**(3): 160-179.
4. Baio J. Prevalence of autism spectrum disorders-Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. Atlanta, GA: U.S, Department of Health and Human Services, Centers for Disease Control and Prevention; 2012.
5. Perera H, Wijewardena K, Aluthwelage R. Screening of 18-24-month-old children for Autism in a semi-urban community in Sri Lanka. *Journal of Tropical Paediatrics*. 2009; **55**(6): 402-405.
6. The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science & Medicine*. 1995; **41**(10):1403-1409.
7. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016 Surveillance Summaries / 27 March 2020; **69**(4); 1-12.
8. Danansuriya M, Rajapaksa L. Psychometric properties of the Sinhala version of the PedsQL™ 4.0 Generic Core Scales in early adolescents in Sri Lanka. *Health and Quality of Life Outcomes*. 2012; **10**(1): 105.
9. Gillberg C, Wing L. Autism: not an extremely rare disorder. *Acta Psychiatrica Scandinavica*. 1999; **99**(6): 399-406.
10. Hansen S, Schendel D, Parner E. Explaining the increase in the prevalence of Autism Spectrum Disorders. *JAMA Pediatrics*. 2015; **169**(1): 56.
11. Gabis L, Pomeroy J, Andriola M. Autism and epilepsy: Cause, consequence, comorbidity, or coincidence? *Epilepsy & Behaviour*. 2005; **7**(4): 652-656.
12. Varni JW, Seid M, Kurtin PS. PedsQL™ 4.0: Reliability and validity of the Pediatric Quality of Life Inventory™ version 4.0 generic core scales in healthy and patient populations. *Medical Care*. 2001; **39**: 800-812.
13. Katsiana A, Strimpakos N, Ioannis VS, *et al*. Health-related Quality of Life in Children with Autism Spectrum Disorder and children with Down Syndrome. *Materia Socio Medica*. 2020; **32**(2): 93.
14. van Heijst B, Geurts H. Quality of life in autism across the lifespan: A meta-analysis. *Autism*. 2014; **19**(2): 158-167.
15. Gunawardana S, Gunasinghe C, Harshani M, Seneviratne S. Physical and psychosocial quality of life in children with overweight and obesity from Sri Lanka. *BMC Public Health*. 2021; **21**(1). 86.
16. Cohen I, Sudhalter V. PDDBI. Lutz, FL: Psychological Assessment Resources, Inc.; 2005.
17. Coales C, Heaney N, Ricketts J, *et al*. Health-related quality of life in children with autism spectrum disorders and children with developmental language disorders. *Autism & Developmental Language Impairments*. 2019; **4**: 239694151985122.
18. Sikora D, Vora P, Coury D, Rosenberg D. Attention-Deficit/Hyperactivity Disorder symptoms, adaptive functioning, and Quality of Life in children with Autism Spectrum Disorder. *Paediatrics*. 2012; **130**(Supplement 2): S91-S97.
19. Egilson S, Ólafsdóttir L, Leósdóttir T, Saemundsen E. Quality of life of high-functioning children and youth with autism spectrum disorder and typically developing peers: Self- and proxy-reports. *Autism*. 2016; **21**(2): 133-141.
20. Kose S, Erermis S, Ozturk O, *et al*. Health related Quality of Life in children with Autism Spectrum Disorders: The clinical and demographic related factors in Turkey. *Research in Autism Spectrum Disorders* 2013; **7**(2): 213-20.
21. Kuhlthau K, Kovacs E, Hall T, Clemmons T, Orlich F, Delahaye J, *et al*. Health-related quality of life for children with ASD: Associations with behavioural characteristics. *Research in Autism Spectrum Disorders* 2013; **7**(9): 1035-1042.