

## Quality of Life of Children with ASD

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### Abstract

Autism Spectrum Disorder (ASD) describes a range of conditions classified as neurodevelopmental disorders in DSM-5, which are characterized by social deficits and communication difficulties, stereotyped or repetitive behaviours and interests, sensory issues, and in some cases, cognitive delays. In the past, autism was considered a rare condition, but plenty of recent studies indicate that prevalence can be nearly 1% for the broader autism spectrum. The researchers searched the digital library database for articles related to the quality of life (QoL) of autistic children. It proved that more research on the quality of life for autistic children and their parent's abroad. However, the original study was flawed by ascertainment etiology, pathogenesis and early autistic symptoms. Domestic rare research reports on the quality of survival. Moreover, compared with other conditions there has been a lack of focus on quality of life (QoL). With the conversion of the biomedical model to the bio-psycho-social medical model, measuring for children and young people with Autism Spectrum Disorder (ASD), thinking about how to improve the quality of life is more and more attention.

The most widely used diagnostic criteria for AD are those described in the revised text edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) of the American Psychiatric Association. This study examined Paediatric Quality of Life (PQOL) of autistic children, from a multidimensional perspective. The proposed model was based on the Cross-sectional survey, with Physiological function, emotional function, social function, and school performance as components. This study aimed to evaluate the validity of existing QoL questionnaires for use with children with ASD aged 8–12 years.

**Method:** 200 autistic children (male: 118, female: 82; 2 ~ 4 years old: 80, 5 ~ 7 year old: 87, 8 ~ 12 years old: 33) and 120 normal children (control group) are brought into this study. Separate path analyses were performed to evaluate models of QOL and Intelligent evaluation. The PedsQL (Pediatric Quality of Life Inventory) as robust measures used with children with neurodevelopmental disorders.

**Results:** In the study, the test group had lower scores on the PedsQL4.0 universality Core scale, in comparison with the control group. Behaviour problems had a negative indirect effect on Community adaptation, mental health and school performance and a lower intelligence-related quality of life for children with autistic disorder and clinically significant autistic symptoms in comparison with children and fewer symptoms.

**Conclusion:** Results suggest greater impairment in adaptive functioning and emotional disorders. For high-functioning autism children, potential positive development played significant roles in rehabilitation, to achieve and maintain the best level of intervention. The severity of the disorder and social support coping strategies were related with Life self-care ability and adaptation, coping with intelligent obstacle seriously. Physicians are encouraged to evaluate for early treatment in the overall care plan.

**Keywords:** Autism spectrum disorder; Neurodevelopmental disorders; Quality of life; Language barriers; Social barriers

### Introduction

As beginning, we have provided a brief background that autism is more and more become a common topic in China. Briefly stated, those criteria 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 behaviours. Most individuals with AD have significant life-long impairments in social and language functioning,

and only a small percentage of persons with AD are able to live and work independently as adults.

Increasing incidence of autism and related spectrum disorders in recent years [1], no specific treatment and the significantly high morbidity make the most of the children can't fit into society [2,3], the prognosis is a long-term social problems, therefore, attaching importance to and paying attention to the survival quality of the autistic children are urgent and necessary.

Its prevalence by initial is extremely rare to a few parts per thousand to now. Although there never was a more stable and provide the data, but the prevalence of rising is indeed a fact. Autism is defined as an incurable disease by most of the doctors in China. Autistic children's

parents are keen to achieve self-reliance. Some parents worry that their autistic children will not be able to live normally after the death of hope in relatives and friends, foster institutions receive the children. In addition, China's vast countryside knew little of autism, difficult to have a family willing to autistic children to investigators report. They were willing to have autistic children, all the life and gave birth to a healthy children accompany him forever. The public lack of awareness of autism will bring heavy burden to society. They are like the stars in the sky alone the faint light, the so called star child! In this paper, we focus on the need for Autism social existence in China.

The influence of quality of life evaluation of autistic children to measure the effects of child illness, treatment, and guide the choice of treatment is of great significance from the aspects of quality of life.

In this paper, we focus on the need for Autism social existence in China. We shall first briefly introduce fuzzy sets and related concepts. Autism, a behaviourally defined group of disorders that is onset in infancy. The hallmark characteristics of autism include language barriers, social barriers, restricted interests and rigid and repetitive behaviours. It is more common in boys [4]. With the conversion of the biomedical model to the bio - psycho - social medical model, the quality of life [3] is more and more attention. More research on the quality of life for autistic children and their parents abroad [5,6]. The researchers used computer to search the articles related to the QOL of autism in the digital library database and CHKD periodical.

Due to the lack of awareness and public shame to help parents, lack of multicentre, systematic and professional data collection and investigation and study, so the domestic rare related multicentre study reports. Parents lack the knowledge, is constrained by economic conditions, lead to the long-term quality of life is still obvious damage. Improve the quality of life of autistic children, related to the overall situation of social integration in harmony. At present the main treatment is to relieve symptoms, social function and learning ability, improve the ability of self's survival and development, for return to mainstream society. The prognosis of autistic children and their quality of life: The rehabilitation of autistic children is a complex social problem of system, the economic situation of the family, parents' mentality, environment and social support can affect the prognosis of children, the whole society should pay close attention; improve rehabilitation resources and service system.

## Materials and Methods

### Sources of study

Test group included autistic children chosen from Nanhai MCH, Dongguan MCH, Foshan Shunde MCH, Foshan Chancheng Children's Rehabilitation Center, from June 2010 to June 2012, which met the inclusion criteria. Control group included normal children randomly picked from kindergartens, primary and secondary schools in Nanhai District. The total number of autistic children in test group was 200 (male: 118, female: 82; 2-4 years old: 80, 5-7 year old: 87, 8-12 years old: 33).

### Inclusion criteria

All autistic children in test group should be at the age of 2 ~ 12 years old, have integral data, and meet the diagnosis of children's autism in the Classification and Diagnostic Criteria for Mental Disorders in China 3rd Edition.

### Exclusion criteria

1. Having other serious diseases which significantly affect the quality of life
2. Having Rett syndrome, childhood schizophrenia, special language developmental disorder, Asperger syndrome, Heller syndrome, selective autism, etc.
3. During the study, children or their parents are not cooperating, or quite in the middle of the study.

### Methods

This is a cross-sectional and multicentre study. Autistic children (aged 2 ~ 12) from 4 different centres and their parents were randomly chosen as test group. Normal children from different grades and their parents were randomly chosen as control group. Quality of life of both groups were evaluated by Paediatric Quality of Life Inventory (PedsQL) 4.0 generic core scales (Determination of children's quality of life scale reliability and validity analysis of PedsQL4.0 Chinese version Lu Yiyun), which was accepted internationally. The evaluation includes two scales, one for children themselves, and the other one for their parents. The self-report version of the PedsQL was for 8 ~ 12 years old and the parent-report version is 2 ~ 7 years old, both of which include evaluation of physiological function (8 items), emotional function (5 items), social function (5 items), role function (5 items). 8 items of physiological function comprised physiology domain, and 15 items of emotional function, social function and role function comprised psychological domain [7,8]. Questionnaire survey was conducted to inspect the influence of autism in autistic children's quality of life. Children and their parents should finish the scales all by themselves, then scores of every domain were calculated according to evaluation standard and a total score would be summed up. Autism degree and intelligent judgment of autism children were conducted by psychometric doctors in this hospital, who were not involved in the evaluation to avoid subjective judgment. Language ability, reaction to object, reaction to people of both group were measured by development scale of Beijing. Quality of life would be compared between autistic children and normal children and relationship between quality of life and autism degree and intelligence level. Autism degree was measured by Clancy Autism Behaviour Scale (CABS), Autism Behaviour Checklist (ABC) and Childhood Autism Rating Scale (CARS). According to Yang Yu-Feng's Manual of children growth and development [4], autistic children were divided into high-functioning group and low-functioning group. Through analysis of relative factors, i.e., children's condition, parents' age, education degree, family income, etc. This study probed the main factors affecting quality of life autistic children.

### Diagnostic criteria

Failing in interpersonal communication (It should be in accordance with at least 2 items below:

1. Lack of interest in social game, being self-closing, and failing to have empathy for collective joy.
2. Lack of skills of communication, failing to build up relationship with peers in a proper way (e.g. pulling, pushing, and hugging as a way to associate with peers).
3. Preferring to play alone, lack of interaction with surrounding environment, lack of observation and emotional reaction (even ignoring their parents' existences).

4. Lack of eye contact, failing to communicate with others uses facial expression, hand gesture, boy posture.
5. Failing to play role-play games and social imitation games (e.g. playing house).
6. Not willing to ask for comfort or sympathy when feeling uncomfortable or unpleasant; Failing to care or comfort others when they feel uncomfortable or unpleasant.

Failing in verbal communication, especially language usage (It should be in accordance with at least 1 item below):

1. Spoken language development delayed or incapable of speech, failing to use hand gesture and imitation to communicate with others.
2. Lack of spoken language comprehension skill, failing to follow oral orders, express their demands or suffering, not willing to ask questions or respond to others' words.
3. Having difficulty in learning language and using pronoun, but sometimes saying meaningless words by imitation or repetition of others' words.
4. Repeating saying words not related to the surroundings, or making strange noise.
5. Have language skills but unwilling to start and hold a dialogue.
6. Having difficulties in tone, stress, speed, rhythm, etc. (e.g. talking without rising and falling intonation, and stereotyped speech.

Having narrow interests, stereotyped and repeated behaviours, being obstinate in a changeless surroundings and life style (It should be in accordance with at least 1 item below):

1. Having limited interests, focusing on one or multiple patterns (e.g. rolling electric fan, one single music, advertising words, weather forecast, etc.)
2. Hyperactivity, strolling, running, circling to and fro, etcetera.
3. Refusing to change their stereotyped and repeated behaviours, otherwise being obviously irritable and nervous.
4. Being infatuated and fulfilled with some smells, objects, part of a toy (e.g., special smell, a piece of paper, a smooth fabric, wheels of toy car, etc.).
5. Being obstinate in special and useless routine or ritual activities.

#### Severity criteria

Social communication function being damaged.

#### Course criteria

Onset usually occurred before 3 years old.

#### Inclusion criteria

1. In accordance with diagnostic criteria of ASD.
2. Age: 2 ~ 12 years old.
3. Children's parents being capable of living, working, thinking and judging, not having diseases that severely affect normal life, working, thinking, judging.

#### Exclusion criteria

1. Not in accordance with diagnostic criteria of ASD.
2. Suffering from Rett syndrome, childhood schizophrenia, special language developmental disabilities, Asperger syndrome, Heller syndrome, elective autism, etc.
3. In accordance with diagnostic criteria and inclusion criteria, but having one of the situations below:

4. Suffering from other diseases that seriously affect their quality of life.
5. Not cooperating, or quitting the rehabilitation in the middle of the study.
6. Failing to be contacted for the follow-up survey.

#### Grouping methods

One test group of 200 autistic children and one control group of 120 normal children was set up. Test group included children in accordance with diagnosis criteria of ASD, inclusion criteria and exclusion criteria. Control group included normal children from the community.

#### Statistical analysis methods

Data was analyzed by SPSS 11.0. Statistical analysis methods: General data was analyzed by descriptive analysis; Measurement data was analyzed by statistical description; Statistical inference was analyzed by t-test or ANOVA; Comparison of categorical data was analyzed by X<sup>2</sup>-test; Comparison of counting data between groups was analyzed by t-test; Comparison of level data was analyzed by rank test; Correlation was analyzed by Pearson correlation analysis.

#### Results

##### Baseline analysis of test group and control group

Baseline analysis of children and their parents in two groups showed no significant difference between two groups, suggesting comparable (Tables 1 and 2).

##### Comparison of gender and age between two groups

Baseline analysis of children and their parents in two groups showed no significant difference two groups, suggesting comparable.

		Test group	Control group	P
Gender	Boy	118	64	X <sup>2</sup> =2.219, P=0.136
	Girl	82	56	
Age (years)		7.97 ± 2.64	7.78 ± 3.46	t(0.0100)=2.613 P>0.01

**Table 1:** Comparison of gender and age between groups. P.S: Categorical data analysed by X<sup>2</sup> test, count data analysed by t-test, heterogeneity of variance analysed by approximate t-test.

##### Comparison of general situation of children's parents between groups

		Test group	Control group	P
Gender (n)	Man	92	44	P=0.102
	Female	108	76	
Age (years)		32.74 ± 4.23	34.16 ± 3.84	P=0.248
Education level	Junior middle school or below	70	42	
	Senior high school	84	41	

	College or above	46	37	P=0.416
Family income (per month)	<3000 yuan	68	49	
	3000 ~ 5000 yuan	79	39	
	>5000 yuan	53	32	P=0.434

**Table 2:** Comparison of gender, age, education level and family income of parents between groups. P.S: Categorical data analysed by X<sup>2</sup> test, count data analysed by t-test, level data analysed by rank test, α=0.01.

### Clinical Data of Test Group

There were 200 autistic children in test group. 84 cases were spontaneous delivered and 116 cases were born by caesarean section. At birth, 26 cases birth were less than 2.5 kg and 149 cases were between 2.5 ~ 4 kg, 25 cases were more than 4 kg. 103 cases had high-risk factors during the gestation period, including that mothers of 35

cases had suffered from influenza during their early pregnancy, and that mothers of 17 cases had touch with pets during their early pregnancy, and that mothers of 11 cases had been exposed to radiation during their early pregnancy, and that 15 cases had fetal asphyxia, and that 12 cases had asphyxia at birth, and that 5 cases had fetal distress, and that 8 cases was one of the multiple births. 32 cases had similar relatives suffering from delay of movement or intelligence, autism, hyperactivity, etc. in their family history. Families of 89 cases had family members with disability or chronic diseases. 56 cases spent less than 5000 Yuan monthly on their treatment and 87 cases spent 5000 ~ 10000 Yuan and 57 cases spent more than 10000 Yuan. 89 cases were treated for less than 1 year and 63 cases were treated for 1 ~ 3 years and 48 cases were treated for 3 ~ 5 years.

### Comparison of quality of life between test group and control

Comparison of quality of life between groups was analyzed by t-test, which showed that autistic children's quality of life was significantly lower than that of normal children in single or overall domains. The difference was statistically significant (Table 3).

Type n	Physiological function	Emotion function	Social function	Psychological domain	Overall
Test group (n=200)	62.30 ± 25.05	53.57 ± 26.69	44.63 ± 27.91	38.69 ± 30.60	49.86 ± 23.3
Control group (n=120)	90.16 ± 13.32	79.09 ± 19.56	86.39 ± 15.45	82.75 ± 16.03	85.23 ± 14.2
t	t=-12.967	t'=-9.900	t'=-17.216	t'=-16.868	t=-16.863
P	P<0.01	P<0.01	P<0.01	P<0.01	P<0.01

**Table 3:** Comparison of quality of life between groups.

### Relation between intelligence type and quality of life of autistic children

Comparison of quality of life between autistic children with different intelligence type by ANOVA showed that high-functioning

autistic children's quality of life exceeded that of low-functioning ones in all domains, which had statistically significant difference (Table 4).

Group	Physiological function/area	Emotional function	Social function	School function	Total
1. Low-functioning (n=130)	50.98 ± 21.69	41.83 ± 23.40	31.03 ± 21.16	23.26 ± 21.48	36.78 ± 14.70
2. High-functioning (n=70)	83.77 ± 14.94	75.84 ± 16.40	70.43 ± 19.79	68.70 ± 22.04	74.69 ± 14.95
3. Normal (n=120)	90.16 ± 13.32	79.09 ± 19.56	86.39 ± 15.45	82.75 ± 16.03	85.23 ± 14.20
1. and 3. (t)	17.293	15.152	17.634	19.254	19.451
(P)	0	0	0	0	0
2. and 3. (t)	1.59	0.036	0.036	3.244	2.071
(P)	0.943	0.486	0.971	0.999	0.04
1. and 2. (t)	10.929	11.464	9.528	10.85	11.72
(P)	0	0	0	0	0

**Table 4:** Comparison of quality of life between normal children and autistic children of different intelligence types.

### Correlative analysis (Table 5)

Survival quality of test group	ABC	CARS	CABS	DQ of social adaptation	DQ of language
F	35.12	44.31	23.372	153.651	113.084
r	-0.7351	-2.0904	-1.9111	0.8447457	0.7491829
P	0	0	0	0	0

**Table 5:** Correlation of autistic children's survival quality with stage of autism and DQ of intelligence.

### Discussion

#### Autistic children's quality of life

Scores of QoL of autistic children in the study of the single field as well as the overall quality of life were lower than normal children, there is statistical significance ( $P < 0.01$ ), suggesting impaired in autistic children quality of life.

But research shows some difference among the influence in different domains of quality of life. There is slight impairment in autistic children's physiological function of body movement, but their average level of social mental health, school performance and social activities is significantly lower than that of control group (normal children). Autistic children show difficulty in mood control, lack of emotional and verbal communication, failure in participation in communication and entertainment with their peers, need for more assistance when confronted with study difficulty, tease, pressure, etc. and even incapability for school, which is intimately in accordance with the conclusion of the research done by Lee et al. [9] based on the data of the physical conditions of children survey 2003, studying the quality of life of autistic patients aged 3 ~ 17 year old. More acceptance, understanding and spiritual supports should be given to autistic children due to their social defeat and emotional disorders. It will help them participate in social activities by meeting their psychological and emotional needs and building relationships experience with the positive guidance. Centering the demands of autistic children, it's the interventions that improve the ability of development and adjustment. In addition, recovery of autistic children is far from being desired by relying on special training institutions only. Family rehabilitation and education program should be relied on and infiltrated into autistic children's lives for enhancing their engagement, improving their practical communication skills and mitigating the problem of school attendance at the same time.

#### The state of an illness, intelligence and quality of life of autistic children

China has about 5 million autistic children and prognosis mala accounts for 47 ~ 47% of it, and about 2/3 of them have categorical social maladjustment. In this study, high-functioning autistic children's quality of life exceeded that of low-functioning ones in all domains, which had statistically significant difference ( $P < 0.05$ ). The correlation between DQ of speech, DQ of social adjustment and quality of life is positive ( $r = 0.9557551, 0.8458974, P < 0.0001$ ), and the correlation between the CBS, ABC, CARS and the quality of life is negative, which suggested that the more severe the disease is and the lower the intelligence level is, the worse the quality of life will be.

The possibility of autism completely being cured is low now, clinical interventions should focus more on improving autistic children's social adjusting capacity and speech function, comply with the behavioural and feature of cognizance and learning, involving appropriate guidance. As for high-functioning autistic children, they should be considered with the balance between special needs and their own interest, and their talent of memory, music and so on should be developed. By the Intelligent compensation and potential development, it builds up the spirit and social function, to achieve and maintain the best level of intervention [10-12].

Positive psychotherapy, game therapy, self-control and self-adjust will help to control the hyperactivity, correct and control the destroying and stereotypic behaviour, improve self-care ability and significantly reduce troublesome behaviours.

In this study, rehabilitation may improve the short-term prognosis, but many children didn't catch up with the best timing for early rehabilitation.

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