

## Quality of life among Parents having Children with Autism

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### ABSTRACT

**Background:** Autism is a complex developmental disability that typically appears during the first three years of life. Both children and adults with autism typically shows difficulties in verbal and non verbal communication, social interactions and leisure or play activities. However, autism is being increasingly seen as a spectrum disorder with affected children experiencing varying degrees of severity of the disorder. **Objective:** ‘To assess the, ‘Quality of life among parents having children with autism’. **Methods:** 40 participants (caregivers), 20 having children with autism, and 20 as control group, from two special schools in Delhi were enrolled and they were given WHOQOL-BREF (Murphy et al., 2000), in a semi structured interview form. **Results:** indicated poor quality of life and health in, parents of children with autism group, as compared to the control group. Further, due to the complex treatment and regular visits to hospitals, the psychological aspects in the caregivers of autism group, was most affected. **Conclusion:** Poor quality of life in caregivers of children with autism, indicates the importance of a lifelong psychosocial support for prevention of mental health issues, including promotion of a clear understanding of the disease.

**Keywords:** Autism, Caregivers, Quality of life

One type of developmental disorder found in children is known as ‘autism’. It is derived from the Greek word ‘Autos’ meaning ‘self’. Autism is a serious developmental disorder of childhood characterized by an inability to relate socially. The terms autism, autistic, autistic spectrum disorders are used interchangeably and refers to the broader umbrella of pervasive developmental disorders.

### *The Federal Definition of Autism*

The Individuals with Disabilities Education Act (IDEA, 2004) defines, Autism as “A developmental disability significantly affecting verbal and non-verbal communication and social interaction, generally evident before age three that adversely affects a child’s educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movement, resistance to environmental change or change in daily routine and unusual responses to sensory experiences. The term does not apply if a child’s educational performance is adversely affected because the child has an emotional disturbance.

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### *History*

(Kanner, 1943) first described a syndrome of “autistic disturbances” with case histories of 11 children who presented between ages of 2 and 8 years and who shared “unique” and previously unreported patterns of behaviour, including social remoteness, obsessiveness, stereotypy, and echolalia.

### *Clinical Features and Diagnostic Criteria*

All children on the autistic spectrum demonstrate the deficits in reciprocal social interactions and verbal and nonverbal communication, with restricted and repetitive behaviours or interests (American Psychiatric Association, 1994, 2000). There is, nonetheless, marked variability in the severity of symptoms among patients, and cognitive functions can range from profound mental retardation through the superior range on conventional IQ tests.

### **DSM IV**

At least six of the following with at least two items from the first group and one each from the second and third:

- qualitative impairment in social interaction as manifested by at least two of the following:
  - (a) marked impairments in the use of multiple non-verbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
  - (b) failure to develop peer relationships appropriate to developmental level
  - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people
  - (d) lack of social or emotional reciprocity
  
- qualitative impairments in communication as manifested by at least one of the following:
  - a) delay in, or total lack of, the development of spoken language
  - b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
  - c) stereotyped and repetitive use of language or idiosyncratic language
  - d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
  
- restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:
  - a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
  - b) apparently inflexible adherence to specific, nonfunctional routines or rituals
  - c) stereotyped and repetitive motor mannerisms
  - d) persistent preoccupation with parts of objects

Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

- social interaction
- language as used in social communication
- symbolic or imaginative play

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The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder

### ICD 10

A pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifest before the age 3 years, and by the characteristic type of abnormal functioning in three areas of social interaction, communication and restricted repetitive behaviour. This disorder occurs in boys three to four times more often than in girls. Usually there is no prior period of unequivocally normal development but, if there is, abnormality becomes apparent before the age of 3 years. There are always qualitative impairments in reciprocal social interaction. These take the form of an adequate appreciation of socioemotional cues, as shown by a lack of responses to other people's emotions and/or a lack of modulation of behaviour according to social context; poor use of social signals and a weak integration of social, emotional and communicative behaviours; and, especially, a lack of socioemotional reciprocity

Similarly, qualitative impairments in communication are universal. These take the form of a lack of social usage of whatever language skills are present; impairment of make-believe and social imitative play; poor synchrony and lack of reciprocity in conversational interchange; poor flexibility in language expression ; relative lack of creativity and fantasy in thought processes; lack of emotional response to other people's verbal and non-verbal overtures; impaired use of variations in cadence or emphasis to reflect communicative modulation; and a similar lack of accompanying gesture to provide emphasis or aid meaning in spoken communication.

The condition is also characterised by restricted, repetitive and stereotyped patterns of behaviour, interest and activities. These take the form of a tendency to impose rigidity and routine on a wide range of aspects of day to day functioning; this usually applies to novel activities as well as to familiar habits and play patterns.

In early childhood there may be attachment to unusual, typically non-soft objects. The children may insist on the performance of particular routines or rituals of a non-functional character; there may be stereotyped preoccupations with interests such as dates, routes or timetables; often there are motor stereotypes; a specific interest in non-functional elements of objects (such as their smell or feel) is common; and there may be resistance to changes in routine or details of the personal environment.

### **AETIOLOGICAL THEORIES**

Theories of autism fall into three broad categories: psychogenic; biogenic and cognitive. Psychogenic theories argue that psychosocial processes are central in the aetiology of autism, whereas biogenic theories look to biological factors as the basis for the condition. Cognitive theories are concerned not with identifying the primary causes of autism, but with explaining the patterning of symptoms in terms of specific underlying cognitive deficits.

### *Quality of Life*

Quality of Life (QOL) as a concept has been increasingly accepted as an important outcome measure in patient's and caregiver's of chronic illnesses. Quality of Life (QOL) has been defined by the (World Health Organization, 1994) as individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad concept incorporating the

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person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment.

QOL is especially relevant to conditions that are chronic and impairing, such as pervasive developmental disorder (PDD) i.e., autism. Care giving and its related burden is considered to be an important aspect in determining the quality of life of caregivers. In the present study, quality of life of parents having children with autism, are studied. Autism makes a person incapable of living an independent life. In India, family bears the main burden of caring for such a person unlike in the developed world. Family members, particularly parents are most affected by the condition. There is need to find out how autism affects the family, in order to help those who are having negative impact. Taking into consideration the same, the present study was planned, with the following aim: - to study the quality of life among parents having children with autism.

### **MATERIAL AND METHODS**

A case control study, to determine the quality of life among parents of children with autism and control group was undertaken in two special schools in Delhi. After obtaining permission from the head of the special schools, a written informed consent was obtained from parents of children with autism before inclusion in the study. Those parents were not included in the study who did not give consent and who had any other child with any physical or mental disease, disability or disease. 20 participants (caregivers) aged 18 years and above, with children aged from birth to 3 years and having confirmed diagnosis of autism (20), and those having children without autism from birth to 3 years i.e., control group (20), were enrolled for the study. The subjects in the control group were matched in all parameters to the other two group subjects, except them having no physical or mental disease, disability or illness. The samples were selected by purposive method.

After obtaining consent form from parents, basic data identification schedule, was used to elicit information regarding demographic details of children and caregivers, and thereby Hindi version of WHOQOL - BREF developed by (Murphy et al., (2000), was administered on the parents. WHOQOL-BREF, of 26 items, was used to measure quality of life. Its 26 items are rated on a 5 point scale, which gives a profile with four domain scores (physical health, psychological health, social relationship and environment) and two individually scored items about an individual overall perception of quality of life and health (Q1 and Q2). The four domains are scaled in positive direction, with a score range of 0-100 and higher score denoting higher quality of life. WHOQOL-BREF – World Health Organization Quality of Life BREF – Assessment Instrument: short version - contains 26 questions divided into four domains:

- A. *Physical health:* general health assessment, pain and discomfort, dependence on medication and medical aids, energy and fatigue, sleep and rest, ability to work and perform daily living activities, mobility.
- B. *Mental health/Psychological:* body image, positive and negative feelings, self-esteem, personal beliefs, spirituality, religion, thinking, learning, memory and concentration.  
*Social relationships:* personal relationships, received social support, sexual activity.
- C. *Environment:* freedom, safety, environment, physical environment, transport, finances, information, accessibility of health and social care, leisure time.

Each question is assigned an appropriate number of points from 1 to 5, and the patient must choose from the following possible answers: 1 point – very dissatisfied, 2 points dissatisfied, 3 points – neither satisfied nor dissatisfied, 4 points – satisfied, 5 points – very satisfied. The

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scale includes items (questions) that are analyzed separately: Question 1: pertaining to the individual overall perception of quality of life; Question 2: pertaining to the individual overall perception of own health.

### *Statistical Analysis*

For the statistical analysis, Mean Standard deviation, Chi-square and ANOVA was calculated.

## RESULTS AND ANALYSIS

The sample for the present study consisted of 20 participants (caregivers), aged 18 years and above, with children having confirmed diagnosis of autism, from birth to 3 years. 20 participants were taken as control group, having children without any physical or psychological illness, disease or disability. The mean age of participants/caregivers in autism group was 31.6, with age range of 24-45 years, and the mean age for control group participants was 32.6, with age range of 25-40 years. The female: male ratio in the two groups was as follows- 19:1, 20:0, and showing that most of the participants in the study were females and mostly mothers of children. The educational qualification of most of the participants was graduate. The monthly income, of majority of participants falls in the category of 8000 - 15000 [Table I].

*Table I: Description of the Identified Sample*

	Autism group	Control group
<b>N</b>	20	20
<b>Range</b>	24 – 45	25 – 40
<b>Age <math>\bar{x}</math></b>	31.6	32.6
<b><math>\sigma</math></b>	10.60	1.64
<b>Sex F</b>	19	20
<b>M</b>	1	0
<b>Education</b>		
<b>6 – 9</b>	0	1
<b>10 – 12</b>	6	8
<b>Graduate</b>	14	11
<b>Income (Monthly)</b>		
<b>Up to 7000</b>		
<b>8000 – 15000</b>	0	7
<b>15000 and above</b>	18	9
	2	4
<b>Occupation:</b> Most of the participants were housewives (n = 30), teachers (n = 7), service in private sector (n =3).		
<b>Relationship with the child:</b> Most of the participants were mothers of the child (n = 29, rest father n= 11).		

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**Table 1:  $\chi^2$  for Item No. 1, WHOQOL-BREF (overall perception of quality of life,) frequencies in three groups**

	Very Poor	Poor	Neither Poor Neither Good	Good	Very good
<b>Autism group</b>	12	7	1	0	0
<b>Control group</b>	0	0	0	16	4

$\chi^2$  64.94, df 8, found to be significant at .01 level.

**Table 2:  $\chi^2$  of WHOQOL-BREF; Item No. 2 (Overall Perception of health)**

	VD	D	N.S. N.D.	S	V.S.
<b>Autism group</b>	2	11	6	1	0
<b>Control group</b>	0	0	2	15	3

$\chi^2$  47.78, df = 8, significant at .01 level

**Table 3: Mean & Standard Deviation of two groups on Item No. 1 (WHOQOL – BREF)**

	$\bar{x}$	$\sigma$
<b>Autism group</b>	2.15	0.59
<b>Control group</b>	4.15	0.37

As can be seen from the table, the mean for the autism group was lower than control group, on item No. 1, which assess the overall perception of quality of life.

**Table 4: Mean & Standard Deviation of two groups on Item No. 2 (WHOQOL – BREF)**

	$\bar{x}$	$\sigma$
<b>Autism group</b>	2.30	0.73
<b>Control group</b>	4.15	0.49

As can be seen from the table, the mean for the autism group was lower than control group on item No. 2, which assesses the overall perception of health.

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**Table 5: Mean & Standard Deviation on 4 domains of WHOQOL-BREF in each of the two groups.**

	Physical	Psychological	Social	Environmental
<b>Autism group</b>	x = 40.85 σ = 9.96	x = 36.6 σ = 7.35	x = 50.75 σ = 15.49	x = 44.45 σ = 9.09
<b>Control group</b>	x = 73.6 σ = 11.72	x = 75.3 σ = 10.18	x = 81 σ = 8.98	x = 72.25 σ = 13.16

The mean for autism group was lowest in the, psychological domain, followed by physical, environmental and social domain and as compared in the control group, there was not much difference found in the mean of the four domains.

**Table 6: Showing the F (AVONA) values for the 4 domains of WHOQOL-BREF, for the two groups**

	Physical	Psychological	Social	Environmental
<b>F Values</b>	66.82	68.13	52.79	268.21

**F values in all the four domains were significant at .01 level.**

### **DISCUSSION**

Care-giving is a normal part of being the parent of a young child, but this role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence. The impact of children with autism on parents and other family members has long been of interest to professionals. Consequently understanding of relationships within the family has grown considerably over time. In the present study an attempt has been made to assess the quality of life among parents of children with autism as compared to the controlled matched group, so that they could be helped to manage these problems in the best possible way.

#### **Quality of life**

Talking about the Quality of Life, the results of the study revealed that, overall perception of quality of life and perception of health (WHOQOL-BREF), was very poor and dissatisfied, in the autism group participants, as compared to the control group participants, among whom quality of life was found to be good.

The mean for the Item No 1 & 2 (WHOQOL-BREF), for the autism group was found to be 2.15 & 2.30 respectively, which was found to be lower than matched controlled group mean i.e., 4.15 & 4.15 respectively ( Table 3 & 4), thus indicating very poor quality of life and

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perception of health in this group. Further, more frequencies were in the sphere of very poor and poor category of (Item No 1 WHOQOL-BREF) (Table No 1), in the autism group, as compared to the controlled group, in which frequencies were found more in the good and very good category. In the same line, in the autism group participants, more frequencies were found in the very dissatisfied and dissatisfied category of perception of health (Item No2 WHOQOL-BREF) (Table No 2), as compared to the controlled group, where more frequencies were found in the category of satisfied and very satisfied category. These results are also in line with Chi – Square, for Item no 1&2 i.e., 64.94 & 47.78 (Table 1& 2), which was found to be significant, thus showing difference in overall perception of quality of life and health in the two groups.

During the semi structured interview also, it was found that mothers of children with autism, reported greater no of physical problems and feelings of meaninglessness of life and dissatisfaction with their own self, as compared to the controlled group participants. These results are in consonance with the study done by (Dardas & Ahmad., 2014) on quality of life among parents of children with autistic disorder: a sample from the Arab World, with the purpose of the study to examine the differences in the QoL between fathers and mothers of children with autistic disorder in a sample from Arab country and to examine the psychosocial correlates of the QoL of Arab parents of children with autistic disorder. Self administered questionnaires on parents QoL, stress,, coping strategies, and demographic characteristics were completed by 184 parents of children with autistic disorder. Results indicated that fathers and mothers of children with autistic disorder showed no significant differences in their physical, psychological, social, and environmental health. Further, both parents showed almost similar bivariate correlations between the reported QoL levels and their parenting stress, coping strategies, and demographic characteristics. This is the first study to examine the QoL of parents of children with autistic disorder in the Arab world. QoL of Arab parents of children with autistic disorder crosses lines with their stress levels, coping strategies, demographic characteristics and to some extent their cultural context.

Similar findings were found in a study done by (Alhazmi et al., 2018), on QoL of south African parents caring for children with autism spectrum disorder as compared with parents of typically developing (TD) children from the same community. QoL of 52 children (26 parents of children with ASD versus 26 parents of TD children) was evaluated using the structured measure (WHOQOL-BREF), with results showing that QoL of parents of children with ASD is significantly lower than that of the parents of their TD peers across all domains and is an important component in management of the family which needs to be explored and addressed.

### ***Four domains of WHOQOL-BREF***

Results of the study also signify that there was a significant difference in four domains of WHOQOL-BREF, in the two groups. The ANOVA values (Table 6), in the two groups for the four domains, came out to be significant, thus showing difference in four domains of quality of life in two groups. In autism group, the quality of life was poorest in the domain of psychological domain (Mean=36.3), followed by physical domain (mean=40.85), environmental domain (mean=44.45), and social domain (mean= 50.75) (Table 6). In our research, comparing the psychological domain of parents of children having autism and parents of healthy children, the biggest differences were in the assessment of enjoyment of life, the meaning of life, acceptance of physical appearance and experience of negative feelings. The parents of healthy children chose the more positive answers for all the questions.



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These findings are supported by the findings of the study done by (Nikmat et al., 2008), on prevalence of parental stress and psychological wellbeing among parents of children with autism spectrum disorder and their association with dimensions of support system. Those parents who attended psycho-education session on management of autistic children at Health Psychology Unit were randomly selected to enroll in the study. General health questionnaire, (GHQ-28), Parenting stress index (PSI), and Provision Social Relation (PSR), respectively were used. Results indicated that of the total 52 parents with autistic child (34 female and 18 male), about 90.4% of parents had significant parenting stress and 53.8% of parents showed clinical disturbance in psychological wellbeing. Parents with autistic children had high prevalence of stress and psychological disturbances, which indicate that interaction of various factors need to be acknowledged and considered in order to reduce the burden of parents with autistic children.

Similar results were found in a study done by (Koydemir & Tosun, 2009) studying the impact of 10 autistic children on lives of Turkish mothers using the consensual Qualitative Research (CQR) and found a variety of themes related to the experiences of mothers, such as the reactions to the disability of the child, sources of stress, coping strategies and to deal with stress, involvement with the education of the child and evaluation of the facilities of the special education center.

### CONCLUSION

To conclude, the results of the present study points, that since there is poor quality of life and health, among parents of children with autism as compared to the controlled matched group, therefore it is imperative to provide psychosocial support, including promotion of a clear understanding of the disease to these participants. However, our results should be interpreted in the light of small sample size and more studies with large sample sizes are required.

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### ***Conflict of Interest***

The authors carefully declare this paper to bear not conflict of interests.

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