

“A Comparative Study of Quality of Life in Caregivers of Autism And Normal Children.”

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Abstract: Quality of life (QOL) represents the wellbeing of a person which is influenced by various factors. The aim of this study is to assess the QOL of caregivers of autism children and compare it with that of normal children caregivers.

Method: sample is collected from caregivers of children attending OPD of Niloufer children hospital, Hyderabad using semi structured intake proforma and WHOQOL BREF scale.

Results: as a whole QOL of caregivers of autism children is significantly affected ($p = <0.05$) than that of normal children's caregivers.

Conclusion: These finding must be taken into account in policy making to provide better and more specific supports

Keywords: caregivers, autism, QOL.

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I. Introduction

Birth of a child with disabilities can be a traumatic and shattering event for that family. One of those disabilities is autism. **Autism** is a pervasive developmental disorder defined by the presence of abnormal and/or impaired development that manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behavior⁽¹⁾.

Quality of Life: "Quality of life is defined as individuals' perceptions of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."⁽²⁾ The four assessed domains of QOL are physical domain, psychological domain, social domain and environment domain.⁽³⁾ Caring for a dependent person is a stressful situation that may lead to psychological health risk for the caregiver. A **caregiver** is an unpaid or paid person who helps another individual with impairment with his or her activities of daily living. Care giver may be the patients close relative, parents, sibling who is an adult staying with the patient and takes prime responsibility of care⁽⁴⁾.

II. Aims And Objectives

To compare Quality of life in care givers of children with autism and normal children

Patients and methods:

Study Design: This is a cross – sectional study to measure the quality of life in caregivers of children autism and to compare with those of caregivers of normal children

Area Of Study: care givers of children presenting to outpatient department at NLOUFER CHILDREN HOSPITAL, OSMANIA MEDICAL COLLEGE, HYDERABAD

Sample Size: care givers of 40 children diagnosed to have autism, 40 normal children as control

Inclusion criteria:

For caregivers

1. Caregivers of children diagnosed to have autism and common ailments of children (like common cold, cough, fever)
2. Males and females aged between 18 and 60 yrs.
3. Those who have given informed consent

For children

1. Diagnosed to have autism according to ICD – 10 criteria
2. Males and females aged between 3 and 17 years of age

Exclusion criteria:

For caregivers

1. Those with organic psychosis or mental retardation
2. Those who have previously diagnosed to have any other mental illness
3. Those who did not give consent
4. Those who are aged less than 18 yrs. and more than 60 yrs.

For children

1. Those who have been aged less than 3yrs and more than 17 yrs.
2. Children with hearing impairment, visual impairment, motor impairment, speech impairment.
3. Children with epilepsy and any other significant medical illness

Null hypothesis:

1. There is no statistically significant difference in QOL scores in caregivers of autism children and normal children with p value > 0.05 .

Procedure:

Caregivers, of children attending the outpatient department and diagnosed to have autism and common ailments, fulfilling the inclusion and exclusion criteria were included in the study at the time of entry into the study, after taking an informed consent socio demographic details are taken through an intake proforma. WHOQOL – BREF is administered to the caregivers.

III. Statistical analysis

- Descriptive statistics depicting numbers – frequency averages – mean median and dispersion – standard deviation, standard error, quartiles.
- Tests of comparison for discrete variables – chi square test.
- Tests of comparison for continuous variables – independent student's t – test

TOOLS administered in the study:

1. Semi structured proforma
2. **WHO QOL BREF:** The brief-version of WHOQOL-100 test developed by the World Health Organization in order to determine individual quality-of-life in general. The test was self-reporting and consisted of 26 items with 5-point scales. Four domains were divided in WHOQOL-BREF test, including (1) physical domain (2) psychological domain (3) social and (4) environmental domain ⁽⁵⁾.
3. **Informed consent:** (English, Telugu, Hindi and Urdu)

IV. Results

A total of 80 caregivers were interviewed -40 were of children with autism (Grp A), 40 were caregivers of normal children (Grp B).

Sociodemographic profile of the sample:

The mean age of caregivers was 37.45 ± 6.389 (Grp A) and 35.83 ± 7.984 (Grp B). Among them, 30% (Grp A), 22.5% (Grp B) was males and 70% (Grp A), 77.5% (Grp B) were females. Marital status of caregivers was 92.5% Married, 2.5% Widowed, 5% Divorced in Grp A and 95% Married, 2.5% Widowed, 2.5% Divorced in Grp B. The mean age of children was 9.15 ± 2.445 (Grp A) and 8.58 ± 3.129 (Grp B). Among them, 65% (Grp A), 35% (Grp B) were males and 37.5% (Grp A), 37.5% (Grp B) were females. (TABLE 1)

Comparison among Group A and Group B:

In this study, means for individual domains of WHO QOL BREF TEST were compared among the 2 groups shown in the table. For the autism group the individual mean in physical domain was 58.48 ± 8.741 , Psychological domain was 44.70 ± 7.559 , Social Relationships domain was 50.08 ± 7.065 and Environment domain was 54.07 ± 10.041 . The caregivers in Group A showed lower scores in physical, psychological, social relationships and environment domains of WHO-QOL BREF compared to those of Group B. Among them the scores were lowest in psychological domain. Statistically significant differences were observed ($p < 0.05$) ie; ($p = 0.000$) between the scores of the two groups. (TABLE 2)

V. Discussion

In the study by Aditi Krishnamurthy et al, There were a total of 65 parents; their age range was 21-63 with the mean of 37.43, and standard deviation 8.78. With regard to sex, there were 49.2% of male parents and 50.8% of female parents Most of the parents (95.4%) were living as couples, only 4.6% had single status. The mean age was 11.38 and standard deviation 5.76. There were 66.2% and 33.8% male and female children. ⁽⁶⁾

Deepthi NS, Aditi Krishnamurthy (2012) The psychological and environmental domains of QOL were found to be most affected, while the physical and social domains were relatively better.⁽⁷⁾

In the study done by Diego Mugno et al Average age of parents was 40 ± 13.5 years (20–58 years). Family status was: 76% married/cohabitating, 21% separated/ divorced, 3% widowed. Average age of children within PDDs group was 7.5 ± 5 years (range 3–17). Average age of children within the CG was 8 ± 4 years (range 4–15). Fathers in the PDDs group showed statistically significant lower scores in the social relationship domain, and mothers showed lower scores in the physical domain ($p = 0.001$) Parents of children with PDDs showed a significant impairment of QOL as compared to the other groups. It has been found that both fathers and mothers in the MR and autism group have impaired functioning in physical, psychological domain of QoL. The impairment is more pronounced in mothers of both the groups. The domain ‘social relationship’ showed highly significant impairment in autism group as compared to normal healthy control group.⁽⁸⁾

Shobana M et al (2014) 52% of the mothers of children with DD experienced psychological problems. The mean overall score for mothers of children with AD (24.52 ± 6.93) was significantly higher than their counterparts⁽⁹⁾.

The mothers of autistic children experienced more psychological distress than those of mentally retarded children⁽¹⁰⁾. Natasha Jane Browne (2010) The study results indicate that QoL is lower for those caring for a child with a disability when compared to those caring for a child without a disability.⁽¹¹⁾

Shahzadi Malhotra et al (2012) This study investigated QoL in family caregivers of children with Mental Retardation (MR) and autism as compared to a control group (CG). Compared with parents of healthy children, parents in the MR and autism group reported impairment in all the four domains of QoL. Such impairments were found both for fathers and mothers. Thus, parents of children with MR and autism seem to display a higher burden and impaired QoL⁽¹²⁾ Gowda MR et al (2013) the results indicated that half of the sample suffered from poor mental health and a reduced quality of life. Overall perceptions of quality of life were significantly associated with the age of the child requiring care and the contact hours per day spent with the child⁽¹³⁾

In our study, the mean age of caregivers was 37.45 ± 6.389 (Grp A) and 35.83 ± 7.984 (Grp B). Among them, percentage of females was more than males in both groups. Caregivers are mostly married in both groups. The mean age of children was 9.15 ± 2.445 (Grp A) and 8.58 ± 3.129 (Grp B). There were more male children in Grp A compared to Grp B. (TABLE 1) For the autism group the individual mean in Psychological domain was most affected followed by Social Relationships domain.

The caregivers in Group A showed lower scores in all four domains of WHO-QOL BREF compared to those of Group B. Statistically significant differences were observed ($p < 0.05$) ie; ($p = 0.000$) between the scores of the two groups. (TABLE 2)

Limitations: The study was cross-sectional that did not include the impact of child’s severity and optimism on parental quality-of-life overtime. Future study may employ longitudinal design to test and confirm existing causal pathways within the period of time.

Implications: The caregivers of persons with MR and autism should also be consulted and considered while planning and providing various intervention services for them.

VI. Conclusions And Summary

Means for individual domains of WHO QOL BREF TEST were compared among the 2 groups. For the autism group the individual mean in Psychological domain was most affected followed by Social Relationships domain. The caregivers in Group A showed lower scores in all four domains of WHO-QOL BREF compared to those of Group B. Statistically significant differences were observed ($p < 0.05$) ie; ($p = 0.000$) between the scores of the two groups.

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Tables:

	Autism(N=40)Grp A	N (N=40)Grp B
Caregiver		
Age(Mean±SD)	37.45±6.389	35.83±7.984
Gender(male)Gender(female)	30%	22.5%
	70%	77.5%
Marital status		
Married	92.5%	95%
Widowed		
Divorced	2.5%	2.5%
	5%	2.5%
Children		
Age(Mean±SD)	9.15±2.445	8.58±3.129
Gender(male)	65%	62.5%
Gender(female)	35%	37.5%

QOL Domains/Groups	Autism(Mean±SD)	N(Mean±SD)	p Value
Physical	58.48±8.741	71.53±8.174	0.000
Psychological	44.70±7.559	62.88±7.763	0.000
Social relationships	50.08±7.065	71.23±8.340	0.000
Environment	54.07±10.041	69.53±6.210	0.000

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