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A Comparison of Quality of Life in Caregivers of Mental Retardation and Autism Children

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Original Research Article

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Abstract: Autism and Intellectual disability have significant impact on family members. Both are associated with poor communication, academic and social skills that make the child more dependent on the caregiver than the normal child.so we aimed at assessing the Quality of life of caregivers of Mental Retardation and Autism children using WHO-QOL BREF. Our study showed that QOL of these caregivers has significantly affected ($p<0.05$). The QOL of Caregivers of MR is more affected than that of Autism. Among the individual domains psychological domain is the most affected. The index study points out that the parents with high as well as low education and of all socioeconomic groups suffer the same contrary to the findings of earlier studies. Further mothers need more help than fathers. Skills training to the caregivers can help them to deal effectively with the children with such disabled children.

Keywords: Mental retardation (MR), Autism, QOL, Caregiver.

INTRODUCTION

Parents of children with chronic health conditions run the risk of emotional distress and poor adjustment to the demands of caring for a child with special needs [1].The family members experience a range of emotions in response to the diagnosis of such disability .Two of those disabilities are mental retardation and autism.

MENTAL RETARDATION

Mental retardation is a condition of arrested or incomplete development of the mind, characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence. Mental retardation is divided into four degrees of severity; mild (50-70 IQ), moderate (35-49), severe (20-34) and profound (less than 20) [2].

Autism

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 [2].

A caregiver is an unpaid or paid person who helps another individual with impairment with his or her activities of daily living [3]. Caregiver burden threatens the physical, psychological, emotional and functional health of caregivers [4].

Quality of Life

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 [5].

Intention of current study is to bring out the amount of effect on the QOL of these caregivers which would help in preparing policies for enhancing the coping strategies for them and judicial allocation of funds for the upbringing of the health status, QOL and social living of both caregivers and challenged children.

AIMS AND OBJECTIVES

Aim

To assess quality of life of caregivers of mental retardation and autism children.

Objective:

- To measure and compare the quality of life in children with mental retardation and autism

PATIENTS AND METHODS

Study design

This is a cross – sectional study to measure the quality of life in caregivers of children with mental retardation and autism

AREA OF STUDY

Care givers of children presenting to outpatient department at Nloufer Children Hospital, Osmania Medical College, and Hyderabad

Sample size

Care givers of 40 children each group diagnosed to have mental retardation (Grp A), autism(GrpB).

INCLUSION CRITERIA

For caregivers

- Caregivers of children diagnosed to have mental retardation and autism
- Males and females aged between 18 and 60 yrs.
- Those who have given informed consent

For children

- Diagnosed to have mental retardation or autism according to ICD – 10 criteria
- Males and females aged between 3 and 17 years of age

EXCLUSION CRITERIA

For caregivers

- Those with organic psychosis or mental retardation
- Those who have previously diagnosed to have any other mental illness
- Those who did not give consent
- 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

There is no statistically significant difference in QOL scores in caregivers of mental retardation and autism children, gender (male and female) with p value > 0.05.

Procedure

Caregivers, of children attending the outpatient department and diagnosed to have mental retardation or autism, fulfilling the inclusion and exclusion criteria are 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 administered to the caregivers.

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 and ANOVA
- Tests of association include Pearson’s product moment correlation test and Spearman’s rank correlation test.

Tools

Administered in the study

- Semi structured intake proforma
- 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 (1) physical domain (2) psychological domain (3) social domain and (4) environmental domain [6].
- **Informed consent**

RESULTS

A total of 80 caregivers, 40 Grp A (of mental retardation children) and 40 GrpB(of Autism children) were interviewed .

Sociodemographic profile of the MR grp

The mean age of caregivers was 37.43±11.043 among them were, 47.5% males and 52.5%females. Marital status of caregivers was 87.5% Married, 10% Widowed, 2.5% Divorced .The mean age of children was 7.98±2.597 .Among them, 62.5% were males and 37.5% females. 32.5%, 37.5%, 27.5% and 2.5% were mildly, moderately, severely and profoundly mentally retarded respectively in Grp A (TABLE 1)

Sociodemographic profile of the Autism grp

The mean age of caregivers was 37.45±6.389.Among them, 30% was males and 70% were females. Marital status of caregivers was 92.5% Married, 2.5% Widowed, 5% Divorced .The mean age of children was 9.15±2.445.Among them, 65% were males and 37.5% were females.45%, 45%, 0 and 10% were mildly, moderately, severely and profoundly ill (TABLE 1)

Table-1: Sociodemographic profile

	MR (N=40)Grp A	**Autism (N=40)**Grp B
Caregiver		
Age(Mean±SD)	37.43±11.043	37.45±6.389
Gender(male) Gender(female)	47.5% 52.5%	30% 70%
Marital status		
Married Widowed Divorced	87.5% 10% 2.5%	92.5% 2.5% 5%
Children		
Age(Mean±SD)	7.98±2.597	9.15±2.445
Gender(male) Gender(female)	62.5% 37.5%	65% 35%
Severity of illness		
Mild	32.5%	45%
Moderate	37.5%	45%
Severe	27.5%	0
Profound	2.5%	10%

WHO QOL BREF SCORES

Means for individual domains of WHO QOL BREF TEST were compared among the 2 groups .For the MR group the individual mean in physical domain (59.63 ± 7.417), Psychological domain (40.65 ± 6.956), Social Relationships domain (48.55 ± 11.832) Environment domain (49.25±10.643). For the autism group, physical domain (58.48 ± 8.741), Psychological domain (44.70 ±7.559), Social Relationships domain (50.08 ± 7.065) Environment domain (54.70 ± 10.041)

The caregivers in Group showed lower scores in 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 ($p<0.05$) between the scores of the two groups only in social relationships domain. (TABLE 2)

Table-2: **Comparison of WHO-QOL BREF scores between Grp A and Grp B**

QOL Domains/Groups	**MR(Mean±SD)**	**Autism(Mean±SD)**	**F**	**p Value**
Physical	59.63±7.417	58.48±8.741	1.336	.251
Psychological	40.65±6.956	44.70±7.559	.002	.967
Social relationships	48.55±11.832	50.08±7.065	9.077	.003
Environment	49.25±10.643	54.07±10.041	1.053	.308

DISCUSSION

In our study, the mean age of caregivers was 37.45±6.389 (Autism grp), 37.43±11.043 (MR grp). 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 7.98±2.597 (MR grp), 37.45±6.389 (Autism grp) For both the groups the individual mean in Psychological domain was most affected followed by Social Relationships domain. The caregivers in Group A showed lower scores in 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 ($p<0.05$) between the scores of the two groups only in social relationships domain. (TABLE 2)

In the study by Singh TK *et al.* There were a total of 65 parents; their age range was 21-63 with the mean of 37.43± 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. It shows that there were 65 children in the age range of 5-28 years. The mean age was 11.38 and standard deviation 5.76. There were 66.2% and 33.8% male and female children. Maximum (60%) children had moderate level of mental retardation, 13.50% had mild level, and 26.20 % had severe level of mental retardation [7].

In a study done by Mugno *et al.* 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 parents in the PDD group reported impairment in physical activity and social relationships (p < 0.01), and worse overall perception of their QOL and health (p < 0.01) 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). 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]. Mothers of children with MR displayed lower physical health, impairment in social relationships, in their psychological state and poorer perception of their environment [9].

Severity of illness had negative correlation with WHO QOL score indicating that the quality of life is worsening as the parameters are increasing in severity [10]. Caregivers of Multiple sclerosis presented a HRQoL lower than that of the general population, being especially true where the mental HRQoL is concerned [11].

Mothers experienced higher level of stress and the level of stress increased as the severity of MR increased. High level of stress and burden is associated with increased level of disability; it being the maximum in the caregivers of persons with severe to profound MR [12].

Shobana M *et al.* 52% of the mothers of children with DD experienced psychological problems. Mothers of children with ID exhibited the highest prevalence of psychological problems (62%) when compared with their counterparts with AD (59%).The mean overall score for mothers of children with AD (24.52 ± 6.93) was significantly higher than their counterparts .The mean score of mothers of children with ID (24.55 ± 6.43) was also significantly different from their counterparts. However, no significant difference was noted in psychological problems between the mothers of children with AD and ID. The overall prevalence of psychological problems among mothers was 52%. Mothers of children with DS scored the lowest in somatic symptoms, anxiety, and social dysfunction [13].

Shahzadi Malhotra *et al.* This study investigated QoL in family caregivers of children with Mental Retardation (MR) and autism as compared to a control group (CG).The sample consisted of 240 parents (40mothers and 40 fathers in each of the three groups) of 120 children having MR, autism and normal healthy children. QOL of parents was assessed by the WHOQOL-BREF questionnaire. Compared with parents of healthy children, parents in the MR and autism group reported impairment in all the four domains of QoL. Little differences were observed between MR and autism groups. 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 Mothers in both MR and autism group had highly significantly impaired QoL in all the four domains as compared to mothers of normal healthy children [14].

Browne *et al.* 91.7% females, 70% males in Group One (children with disability), and 92.3% females, 23.1% males in Group Two (children without disability) were there. In Group One the mean age for caregivers was 42.2 years ± 6.6, and the mean age of the child was 11.2 ± 3.3 years. Group Two's caregiver mean age was 38.5 years ± 7.1, and the mean age of child was 9.6 years ± 2.3. With marital status 75% and 69.2% for Group One and Group Two respectively were married. The 20% and 23.1% in Group One and Two were single or divorced. Quality of life for caregivers of developmentally disabled children was shown to be lower than the general population [15].

In study done by Deepthi NS and Aditi Krishnamurthy 22 of the twenty three caregivers were females. (87%) caregivers were the mothers of the individuals. The other caregivers were the father, the grandmother and in one case the sister-in- law the psychological and environmental domains of QOL were found to be most affected, while the physical and social domains were relatively better [16]. The mothers of autistic children experienced more psychological distress than those of mentally retarded children [17].

Gowda MR *et al.* 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 [18].

Kheir NM *et al.* Most of the QoL domains of caregivers of children with autism reflected poorer mental health compared to caregivers of neurotypical children, although the differences were not reaching statistical significance in most of the domains compared[19].Higher levels of stress, and depression and lower levels of QoL and wellbeing for mothers[20].

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. Further mothers need more help than fathers. Skills training to the caregivers can help them to deal effectively with the children with such disabled children.

CONCLUSIONS:

A total of 80 caregivers, 40 Grp A(of mental retardation children) and 40 GrpB(of Autism children) were interviewed .

Sociodemographic profile of the MR grp:

- Among caregivers females were more than males and most of them were married.
- Among children males were more than females and most of them were moderately mentally retarded.

Sociodemographic profile of the Autism grp:

- Among caregivers females were more than males and most of them were married.
- Among children males were more than females.
- Children with mild and moderate illness were equally distributed.

WHO QOL BREF SCORES:

- The caregivers in Group A showed lower scores in 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

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