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A Comparative Study of Quality of Life in Caregivers of Mental Retardation and Normal Children

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Abstract: Caregivers of young children with disabilities are faced with ongoing challenges affecting various aspects of their life. Little is known about their quality of life (QOL). The overall aim of this study is to assess the QOL of caregivers of children with mental retardation and compare it with that of normal children caregivers. Sample is collected from caregivers of children attending OPD of Niloufer children hospital, Hyderabad using semi structured intake proforma and WHOQOL BREF scale. As a whole QOL of caregivers of mentally retarded children is significantly affected (p= <0.05) with caregivers of children with profound illness most effected current findings provide evidence for importance of family focused approach to intervention to provide support to such families in need of it.

Keywords: caregivers, mental retardation (MR), QOL.

INTRODUCTION

Birth of a child with disabilities can be a traumatic and shattering event for a family. The feeling of grief and loss that the family goes through is caused by realization that the anticipated normal child they had waited for nine months was never born [1]. 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 [2]. One of those disabilities is mental retardation.

Mental retardation

Mental retardation is a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Mental retardation is divided into four degrees of severity; mild (50-70 IQ), moderate (35-49), severe (20-34) and profound (less than 20) [3]. The prevalence of MR in India varies from 0.22%-3.7 % [4]. Among the more common disorders in children and adolescents the prevalence rates for intellectual disability/mental retardation are estimated to be 3–4 per 1000 population [5].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 [6].

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."[7]. Psycho-social intervention programs for family caregivers of children with developmental disorders should incorporate building upon specific strategies to enhance their quality of life. In a study, significant differences in the MR and autism groups compared to controls were present both in mothers and fathers, with impairment in all the four assessed domains of QOL- physical domain, psychological domain, social domain and environment domain [8].

Intention of current study is to bring out the amount of effect on QOL of these caregivers which would help in preparing policies for enhancing the coping strategies for them.

Aims and objectives

To compare Quality of life of care givers of children with mental retardation and normal child.

Patients and methods

STUDY DESIGN

Cross – sectional study to measure the quality of life in caregivers of children with mental retardation to compare with those of caregivers of normal children

Area of study

Care givers of children attending outpatient department at NLOUFER CHILDREN HOSPITAL, OSMANIA MEDICAL COLLEGE, and HYDERABAD

Sample size

Care givers of 40 children diagnosed to have mental retardation, 40 normal children as control

INCLUSION CRITERIA

For caregivers

Caregivers of children diagnosed to have mental retardation and common ailments of children (like common cold, cough, and fever)

- Males and females aged between 18 and 60 yrs.
- Those who have given informed consent

For children

- Diagnosed to have mental retardation 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

- Those who have been aged less than 3yrs and more than 17 yrs.
- Children with hearing impairment, visual impairment, motor impairment, speech impairment.
- 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 normal 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 common ailments, 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 is 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

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 were divided in WHOQOL-BREF test, including (1) physical domain, (2) psychological domain, (3) social domain, and (4) environmental domain [9].
- **Informed consent:** (English,Telugu,Hindi and Urdu)

RESULTS

A total of 80 caregivers were interviewed .out of which 40 were of children with mental retardation (Grp A), 40 were caregivers of normal children (Grp B).

Sociodemographic profile of the sample

The mean age of caregivers was 37.43±11.043 (Grp A) and 35.83±7.984 (Grp B).among them, 47.5% (Grp A), 22.5 %(Grp B) was males and 52.5% (Grp A), 77.5% (Grp B) were females. Marital status of caregivers was 87.5% Married, 10% Widowed, 2.5% Divorced in Grp A and 95% Married, 2.5% Widowed, 2.5% Divorced in Grp B.The mean age of children was 7.98±2.597 (Grp A) and8.58±3.129 (Grp B).Among them, 62.5% (Grp A), 62.5% (Grp B) were males and

37.5% (Grp A), 37.5% (Grp B) were females. 32.5%, 37.5%, 27.5% and 2.5% were mildly, moderately, severely and profoundly mentally retarded respectively in Grp A (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 MR group the individual mean in physical domain was 59.63 ± 7.417, Psychological domain was 40.65 ± 6.956, Social Relationships domain was 48.55 ± 11.832 and Environment domain was 49.25±10.643.

The caregivers in Group 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).

Within Group A, caregivers of children with profound MR showed lower scores followed by those with severe MR, moderate MR and mild MR respectively, which were statistically significant with (p<0.05)ie;(p=0.000) (Table 3).

Table−1: Sociodemographic profile of caregivers and children of Group A and Group B

	MR (N=40)Grp A	N (N=40)Grp B
Caregiver		
Age(Mean±SD)	37.43±11.043	35.83±7.984
Gender(male)	47.5%	22.5%
Gender(female)	52.5%	77.5%
Marital status		
Married	87.5%	95%
Widowed	10%	2.5%
Divorced	2.5%	2.5%
Children		
Age(Mean±SD)	7.98±2.597	8.58±3.129
Gender(male)	62.5%	62.5%
Gender(female)	37.5%	37.5%
Severity of illness		
Mild	32.5%	-
Moderate	37.5%	-
Severe	27.5%	-
Profound	2.5%	-

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

QOL Domains/Groups	MR(Mean±SD)	N(Mean±SD)	p Value
Physical	59.63±7.417	71.53±8.174	0.000
Psychological	40.65±6.956	62.88±7.763	0.000
Social relationships	48.55±11.832	7123±8340	0.000
Environment	49.25±10.643	69.53±6.210	0.000

Table−3: Comparison of WHO-QOL BREF scores within Grp A

Severity of illness/QOL Domains	Physical	Psychological	Social relationships	Environment	pValue
Mild	65.23±4.086	46.31±3.038	57.15±7.267	59.77±3.632	0.000
Moderate	61.47±5.592	41.53±6.034	50.80±8.752	50.53±6.854	0.000
Severe	51.36±4.523	33.64±4.523	36.91±9.576	36.73±2.832	0.000
Profound	50.00±-	31.00±-	31.00±-	31.00±-	0.000

DISCUSSION

In the study done by Diego Mugno *et al.* The study group consisted of 212 parents of 135 children affected by PDDs, MR or CP The control group consisted of 77 parents of 89 healthy children The MR group consisted of 89 parents of 55 children and adolescents. Family status was: 76% married/cohabitating, 21% separated/ divorced, 3% widowed. Average age of children within the MR group was 6.3 ± 7 years (range 4–16). Average age of children within the CG was 8 ± 4 years (range 4–15)[10]. Our study consisted of 80 caregivers of 80 children divided into 2 groups of 40 each, based on their diagnosis as MR and Normal children. The mean age of the caregivers was 37.8yrs (SD = 9.9). In study done by Deepthi NS and Aditi Krishnamurthy [11] 22 of the twenty three caregivers were females.(20 (87%) caregivers were the mothers of the individuals [11].

In this study by Azeem *et al.* mean age of mothers was 37.42 (S.D 8.8] years and of fathers was 42.9 (S.D 8.8) years. The mean age of the children was 10.5 (S.D 5.0) years (range: 2-18 years), with 30% females and 70% males. Twenty-five percent children had mild ID, 42% moderate ID, 20% severe ID and 13% had profound ID [12].

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. Maximum (60%) children had moderate level of mental retardation, 13.50% had mild level, and 26.20 % had severe level of mental retardation [4].

According to a study by Olsson *et al.* [13] .The children in their sample were on average 8.4 years (SD 3.5) old. The majority of children were male (87 %). mostly mothers (89 %) On average, caregivers were 39.4 years (SD 8.3) old study predominantly were married mothers in their forties [14] Hoefman *et al.*

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 [15].

Majumdar *et al.* The mean age of fathers in group B was 38.27 years (SD±0.83) and it was higher as compared to that of those in groups A (36.03 years; SD±1.44) and C (34.37 years; SD±0.89). The mean age of mothers in group C (27.9 years; SD±1.07) was comparatively lower than the mean ages of those in groups A (31.3 years; SD±1.77) and B (31.3 years; SD±0.84). More than 60% of the parents in all the three groups belonged to nuclear families [16].

Nagarkar *et al.* the mean age of the study population was around 11.6 years (standard deviation [SD ±5.11). Most of the patients in the study belonged to the age group of 5-15 years (approximately 77%). The study sample included 60 mentally retarded patients, of which 40 were males (66.7%) and 20 were females (33.3%). More than half, i.e. 58% of the patients had mild MR, while 30% had moderate MR. Severe retardation was evident in around 12% of the patients [17].

In our study, the mean age of caregivers was 37.43±11.043 (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 7.98±2.597 (Grp A) and8.58±3.129 (Grp B). There is equal number of male and female children in the groups. 32.5%, 37.5%, 27.5% and 2.5% were mildly, moderately, severely and profoundly mentally retarded respectively in Grp A (Table 1).

In a study done by Mugno *et al.* [10] 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 ($p < 0.01$) [10]mothers of children with MR displayed lower physical health, impairment in social relationships, in their psychological state and poorer perception of their environment [18] 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 [19].

caregivers of Multiple sclerosis presented a HRQoL lower than that of the general population, being especially true where the mental HRQoL is concerned [20]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 [21]. The overall prevalence of psychological problems among mothers was 52%. [22] 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 [23].Quality of life for caregivers of developmentally disabled children was shown to be lower than the general population [15]. The psychological and environmental domains of QOL were found to be most affected, while the physical and social domains were relatively better. The mean age of the caregivers was 37.8yrs (SD= 9.9) [11].

In this study, means for individual domains of WHO QOL BREF TEST were compared among the 2 groups shown in the table. For the MR group the individual mean in physical domain was 59.63 ± 7.417, Psychological domain was 40.65 ± 6.956, Social Relationships domain was 48.55 ± 11.832 and Environment domain was 49.25±10.643. The caregivers in Group 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 ($p<0.05$) i.e. ($p=0.000$) between the scores of the two groups. (Table 2) Within Group A, caregivers of children with profound MR showed lower scores followed by those with severe MR, moderate MR and mild MR respectively, which were statistically significant with ($p<0.05$)ie;($p=0.000$) (Table 3).

Limitations

The study done was a cross-sectional study.

Implications

The mothers need more help than fathers. Skills training to the caregivers can help them to deal effectively with the children with such disabled children helping them to improve their QOL

CONCLUSIONS AND SUMMARY

- The mean age of caregivers was 37.43±11.043 (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 7.98±2.597 (Grp A) and8.58±3.129 (Grp B).There is equal number of male and female children in the groups. 32.5%, 37.5%, 27.5% and 2.5% were mildly, moderately, severely and profoundly mentally retarded respectively in Grp A
- The caregivers in Group 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 ($p<0.05$) i.e.;($p=0.000$) between the scores of the two groups.
- Within Group A, caregivers of children with profound MR showed lower scores followed by those with severe MR, moderate MR and mild MR respectively, which were statistically significant with ($p<0.05$)i.e.;($p=0.000$)

REFERENCES

1. Marsh DT. Families and mental retardation : new directions in professional practice / Diane T. Marsh. New York: Praeger; 1992.
2. Kersten P, McLellan L, George S, Mullee MA, Smith JA. Needs of carers of severely disabled people: are they identified and met adequately? Health & social care in the community. 2001;9(4):235-43.
3. Organization WH. The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines: Geneva: World Health Organization; 1992.
4. Singh TK, Indla V, Indla RR. Impact of disability of mentally retarded persons on their parents. Indian Journal of Psychological Medicine. 2008;30(2):98.
5. Larson SA, Lakin KC, Anderson L, Kwak N, Lee JH, Anderson D. Prevalence of mental retardation and developmental disabilities: estimates from the 1994/1995 National Health Interview Survey Disability Supplements. American journal of mental retardation : AJMR. 2001;106(3):231-52.
6. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the Impaired Elderly: Correlates of Feelings of Burden. The Gerontologist. 1980;20(6):649-55.
7. Group W. Development of the World Health Organization WHOQOL-BREF quality of life assessment. Psychological medicine. 1998;28(03):551-8.
8. Ferrans CE. Development of a conceptual model of quality of life. Scholarly inquiry for nursing practice. 1996;10(3):293-304.
9. Wisessathorn M, Chanuantong T, Fisher E. The impact of child's severity on quality-of-life among parents of children with autism spectrum disorder: the mediating role of optimism. Journal of the Medical Association of Thailand= Chotmaihet thangphaet. 2013;96(10):1313-8.
10. Mugno D, Ruta L, D'Arrigo VG, Mazzone L. Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. Health Qual Life Outcomes. 2007;5:22.
11. Shanbhag DN, Krishanmurthy A. Mental Health and Quality of Life of Caregivers of Individuals with Cerebral Palsy in a Community Based Rehabilitation Programme in Rural Karnataka. 2012. 2012;22(3):10.
12. Azeem MW, Dogar IA, Shah S, Cheema MA, Asmat A, Akbar M, Kousar S, Haider II.

Anxiety and depression among parents of children with intellectual disability in Pakistan. Journal of the Canadian Academy of Child and adolescent Psychiatry. 2013 Nov;22(4):290.

13. Olsson MB, Hwang C. Depression in mothers and fathers of children with intellectual disability. Journal of Intellectual Disability Research. 2001;45(6):535-43.
14. Hoefman R, Payakachat N, van Exel J, Kuhlthau K, Kovacs E, Pyne J, Tilford JM. Caring for a child with autism spectrum disorder and parents' quality of life: application of the CarerQol. Journal of autism and developmental disorders. 2014 Aug 1;44(8):1933-45.
15. Browne NJ, Browne NJ. Quality of life for caregivers of a child aged 6-16 years with Autistic Spectrum Disorder and/or an intellectual disability: a comparative study: a thesis presented in fulfilment of the requirements for the degree of Master of Arts in Psychology at Massey University, Turitea, New Zealand 2010.
16. Majumdar M, Pereira YDS, Fernandes J. Stress and anxiety in parents of mentally retarded children. Indian journal of psychiatry. 2005;47(3):144.
17. Nagarkar A, Sharma JP, Tandon S, Goutam P. The clinical profile of mentally retarded children in India and prevalence of depression in mothers of the mentally retarded. Indian journal of psychiatry. 2014;56(2):165.
18. Singh K, Kumar R, Sharma N, Nehra DK. Study of burden in parents of children with mental retardation. Journal of Indian.13.
19. Singer GH, Floyd F. Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. American journal on mental retardation. 2006;111(3):155-69.
20. Aymerich M, Guillamón I, Jovell AJ. Health-related quality of life assessment in people with multiple sclerosis and their family caregivers. A multicenter study in Catalonia (Southern Europe). Patient preference and adherence. 2009;3:311.
21. Sethi S, Bhargava SC, Dhiman V. Study of level of stress and burden in the caregivers of children with mental retardation. Eastern Journal of Medicine. 2007;12(1/2):21.
22. Shobana M, Saravanan C. Comparative Study on Attitudes and Psychological Problems of Mothers towards Their Children with Developmental Disability. East Asian Archives of Psychiatry. 2014;24(1):16.
23. Malhotra S, Khan W, Bhatia M. Quality of life of parents having children with developmental disabilities. Delhi Psychiatry Journal. 2012;15(1):173-4.