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## FAMILY BURDEN & QUALITY OF LIFE AMONG PARENTS HAVING CHILDREN WITH AUTISM AND MENTAL RETARDATION



Prashant Srivastava<sup>1</sup> and Monica Juneja<sup>2</sup>

### INTRODUCTION

Parents raising a child with a developmental disability face challenges that are not shared by parents of typically developing children (Stone-man, 1997). There is, however, substantial evidence that the challenges parents face and the ways in which they deal with these challenges vary with the nature of the child's disability (Dunst, Trivette, & Cross, 1986; Gallagher, Beckman, & Cross, 1983; Walker, Van Slyke, & Newbrough, 1992).

Mental Retardation and autism are two such developmental disorders. This term indicates a general deficit in cognitive function that emerges during childhood. Developmental disabilities present in the developmental period and

### Abstract

*Background: Parents having autistic and mentally retarded children experience periods of poor quality of life, disbelief, deep sadness, depression and family burden. Family members of children with autism and mental retardation are often perceived to experience negative psycho-social effects which leads to family burden as well as their quality of life also affected. Aims & Objectives: To Assess and Compare the Family Burden & Quality of Life among the parents having children with Autism and Mental Retardation. Method: 60 Parents (30 Parents having children with Autism & 30 Parents having children with Mental Retardation) have been included purposively as sample of study. Semi-Structured Socio Demographic datasheet was used to collect the relevant socio demographic information followed by Family Burden Schedule and WHO Quality of Life- Bref. Data collected was analyzed using Statistical Package for Social Sciences (SPSS- 20 version). Result: Result shows that in family burden, parents having children with mental retardation perceives more burden than parents having children with autism. But in quality of life, parents having children with autism, had better quality of life than parents having children with mental retardation.*

**Keywords :** Family Burden, Quality of Life, Autism and Mental Retardation.

### Short Profile

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are characterized by limitations in socio-adaptive functioning and intellectual abilities. These limitations in functioning of children with developmental disabilities can result in requirements for long term care far exceeding the usual needs of children as they develop, or the expectations of their families as a parent. Thus, while caregiving is a normal part of being a parent, providing the high level of care required by a child with long term functional limitations can become burdensome and may impact both physical and psychological health of caregivers. Parents having autistic and mentally retarded children experience periods of poor quality of

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life, disbelief, deep sadness, depression and family burden. Family members of children with autism and mentally retardation are often perceived to experience negative psycho-social effects which leads to family burden as well as their quality of life also affected.

### AUTISM AND MENTAL RETARDATION AMONG CHILDREN'S:

Autism is characterized by severe and pervasive impairments in several important areas of development: reciprocal social interaction and communication as well as behavior, and imagination (Eric Zander, 2005). In order to be diagnosed with autism, the behavioral symptoms in all of the above-named areas must be present by age 3. Even if the parents often notice that something is wrong during infancy, it is very difficult to diagnose autism before the age of eighteen months. This is because the behavioral symptoms used to establish the diagnosis have not clearly emerged developmentally until that age.

The American Association on Mental Retardation (AAMR) defines mental retardation as "substantial limitations in certain personal capacities. It is manifested as significantly sub-average intellectual functioning, existing concurrently with related disabilities in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation begins before the age of 18.

### Parenting Vs Family Burden and Quality of Life:

Caregiving and its related burden is considered to be an important aspect in determining the quality of life of caregivers. Quality of Life as a concept has been increasingly accepted as an important outcome measure in patients and caregivers of chronic illnesses (Katschnig, 2006). Quality of Life includes the conditions of life resulting from the combination

of the effect of complete range of the factors such as those determining health, happiness and a satisfying occupation, education, social and intellectual attainments, freedom of actions and freedom of expression (World Health Organization, 1995). The concept is further understood as an individuals' perception of their position in life in context of the culture and value systems in relation to their goals, expectations, standards and concerns.

Studies have reported that parents of children with various developmental disabilities experience heightened stress (Fizman S, Wolf L, 1991; Hedov G, Anneren G, Wikblad K, 2000), overburden and marginalization in society (Berill M, Brown I, 2006), sense of self blame (Raina P, O'Donnell M, Schwellinus H, Rosenbaum P, King G, Brehaut J, Russell D, Wood E, 2004), tiredness or exhaustion (Vitaliano PP, Zhang J, Scanlan JM, 2003). Commenting that little attention has been given to the health outcomes of caregivers of developmental disabilities. (Talley and Crews, 2007) identify caregiving as an issue that must be considered in the context of health (physical and psychological) that vary across the lifespan according to the characteristics and developmental levels of both caregivers and care recipients. Thus, it has been concluded that disability impacts the whole family and the determination of appropriate conceptualization of family outcomes requires an understanding of the impact of members' with disability on family members. This involves three main issues - 1) stress and caregiving burden and quality of life, 2) impact on family functioning and 3) eco-cultural adaptation (Summers JA, Poston DJ, Turnbull AP, Marquis J, Hoffman L, Mannan H, Wang M. 2005).

### MATERIAL & METHODS:

**AIM:** To compare the Family Burden and Quality of Life among parents having children with autism and mental retardation.

#### UNIVERSE OF THE STUDY:

The present study will be conducted at Child Development Centre, Department of Pediatrics, MAMC and Associated Lok Nayak Hospital, New Delhi.

#### SAMPLE TECHNIQUE:

The present study will be a hospital based cross sectional study by using purposive sampling technique.

#### SAMPLE SIZE:

The sample comprised of 60 subjects (parents) who will further divide into 30 parents having children with autism and 30 parents having children with mental retardation.

#### INCLUSION AND EXCLUSION CRITERIA:

Inclusion Criteria of parents having children with Autism

- Male or Female parents.
- Parents whose children diagnosed to meet the criteria for Autism Spectrum Disorder.
- Parents whose children having age range between 3-12 years.
- Subjects who given consent to participate in the study.

#### Exclusion Criteria of parents having children with Autism

- Parents whose children having history of any other co-morbid psychiatric conditions- ADHD, epilepsy, etc.
- Parents whose children having history of any other co-morbid physical illness.
- Parents more than one children having autism.
- Those who do not fulfill inclusion criteria.
- Family History of any psychiatric illness.

#### Inclusion Criteria of parents having children with Mental Retardation

- Male or Female parents.
- Parents whose children diagnosed to meet the criteria for Mental Retardation.
- Parents whose children having age range

between 3-12 years.

- Subjects who given consent to participate in the study.

#### Exclusion Criteria of parents having children with Mental Retardation

- Parents whose children having history of any other co-morbid psychiatric conditions- ADHD, epilepsy, etc.
- Parents whose children having history of any other co-morbid physical illness.
- Parents more than one children having mental retardation.
- Those who do not fulfill inclusion criteria.
- Family History of any psychiatric illness.

#### TOOLS USED FOR DATA COLLECTION:

- Socio-Demographic Data Sheet.
- Family Burden Interview Schedule (Shaila, Pai & Kapoor, R.L., 1981).
- Who Quality Of Life (Who –QOL BREF, Hindi Version) (Saxena et al, 1998).

#### DESCRIPTION OF TOOLS:

##### Socio- Demographic-Data-Sheet (self prepared):

It is self prepared socio- demographic data sheet to obtain background information of the subjects.

##### Family Burden Interview Schedule (Shaila, Pai & Kapoor, R.L., 1981):

This is a semi-structured interview schedule comprising of 24 items grouped under 6 dimensions: Financial burden, Disruption of routine family activities, Disruption of family leisure, Disruption of family interaction, Effect on physical health of others, Effect on mental health of others. The burden was rated on a three point scale for each item and a standard question to assess the schedule. This scale has been developed in Indian setup, keeping in mind the social-economic and the cultural conditions in India. The validity and reliability for each item was reported to be more than 0.78 by the

authors which mediates that this present schedule is reliable tool. The validity of the schedule was also assessed by co-relating objective burden rating and as reported by the relatives of patients. The correlation was found to be 0.72 which can be considered significant. The Hindi translation of the schedule as applied earlier by Kumar N, Kumar, M. (2002). All the items of this scale are rated on 3point scale (viz, severe burden, Moderate burden and No burden).

**Who Quality Of Life (WHO-QOL BREF, Hindi Version) (Saxena et al, 1998):**

It is a self-administered generic questionnaire developed in Hindi. It is a 26 item shorter version of the WHOQOL-100 scale which was developed as a measure that would be applicable cross-culturally. It lays emphasis on subjective evaluation of the respondent's health, living condition and functioning and quality of life on the dimensions of physical, psychological, level of independence, social relations, environmental and spirituality/ religion/ personal belief. Each of these domains is treated as a separate numeric variable and higher the score, higher the quality of life. The scale has good reliability, comparable to that of WHO-QOL-100 scale (r = 0.819). It also has good content and discriminate validity.

**STATISTICAL ANALYSIS:**

Appropriate statistical method was used for analysis with SPSS 20.0 for windows.

**RESULTS:**

**Table 1: Socio Demographic Characteristics among the parents having children with autism & mental retardation.**

Socio-Demographic Variables		Parents having children with Autism (N=30)	Parents having children with Mental Retardation (N=30)	$\chi^2$	Df	P
Gender	Male	12	14	.271	1	.602
	Female	18	16			
Domicile	Rural	10	09	.077	1	.781
	Urban	20	21			
Religion	Hindu	11	09	.700	2	.705
	Muslim	16	16			
	Sikh	03	05			
Education	Primary	09	08	.810	4	.937
	High School	07	09			
	Intermediate	06	05			
	Graduation	07	06			
P.G.		01	02			
Family type	Nuclear	11	16	1.684	1	.194
	Joint	19	14			
Occupation	Private Job	07	06	.664	3	.882
	Unemployed	13	16			

**Table 2: Comparison of Family Burden among the parents having children with autism & mental retardation.**

Family Burden	Sample Group		T Test	P Value
	Parents having children with Autism (M±SD)	Parents having children with Mental Retardation (M±SD)		
Financial	4.70±1.66	5.50±1.63	1.878	.065
Disruption of routine family activities	5.70±1.34	6.26±1.57	1.500	.139
Disruption of family leisure	2.83±1.44	3.66±1.18	2.448	.017*
Effect on physical health of others	4.63±1.51	5.20±1.80	0.21	.832
Effect on social relations of others	0.70±1.10	0.83±0.75	1.940	.057
Effect on work of others	1.10±0.92	1.36±0.96	1.094	.278
<b>Total Score of family burden</b>	<b>19.66±3.30</b>	<b>24.00±2.63</b>	<b>5.548</b>	<b>.000***</b>

**Table 3: Comparison of Quality of Life among the parents having children with autism & mental retardation.**

Quality of Life	Sample Group		T Test	P Value
	Parents having children with Autism (M±SD)	Parents having children with Mental Retardation (M±SD)		
Physical Health	20.73 ± 3.07	18.93±2.67	2.419	.019*
Psychological	19.86±2.20	18.13±2.64	2.753	.008**
Social Relationships	10.26±1.48*	09.23±2.14	2.264	.027**
Environment	22.93±3.03	20.63±2.14	3.388	.001***
<b>Total Score of Quality of Life</b>	<b>73.80±4.94</b>	<b>69.10±6.22</b>	<b>3.238</b>	<b>.002**</b>

**DISCUSSION:**

Thirty Parents having children with Autism and thirty Parents having children with



Mental Retardation were focus of the present study and the aim was to compare the Family Burden and Quality of Life among parents having children with autism and mental retardation. The samples were collected from Child Development Centre, Department of Pediatrics, MAMC and Associated Lok Nayak Hospital, New Delhi. The main tools administered were Family Burden Interview Schedule (Shaila, Pai & Kapoor, R.L., 1981) and Who Quality Of Life (Who –QOL BREF, Hindi Version) (Saxena et al, 1998). The samples of both groups were matched with the variables like gender, domicile, religion, education, family type and occupation. The analysis revealed that in socio demographic characteristics no significant differences were found in various variables of both groups. In family burden domains disruption of family leisure, significant differences was found among both study groups at 0.05 level, similarly in disruption of family interaction domain again significant differences was found at 0.01 level. But in total family burden the mean score of parents having children with mental retardation is (24.00 ± 2.63) is more than parents having children with autism (19.66± 3.30) and there was significant difference found at (.001 level). So the current study reveals that the parents having children with mental retardation had more family burden than parents having children with autism. This finding is consistent with the previous study Kerenhappachu M.S (2014) where parents of children with Mental Retardation showed significant difference on care givers burden than the mothers of normal children. The similar finding are found by Heykyung oh et al., (2009) conducted a study on Caregiver Burden and Social Support among Mothers Raising Children with Developmental Disabilities in South Korea. They found that respondents expressed a high level of overall burden, particularly in financial domains. Greater subjective caregiver burden for these mothers was associated with increased disability-related costs; maternal factors such as being younger and having higher educational attainment; and less

social support. Extra cost related to disabilities was the strongest predictor of increased caregiver burden and findings indicated that social support can reduce this burden.

The findings of the current study reveals in terms of Quality of Life in all domains significant differences were found (such as in physical health and social relationship at 0.05, psychological at 0.01 and environment at 0.001level) in both groups. So the present study reveals that in total quality of life the mean score of parents having children with autism is (73.80 ± 4.94) is more than parents having children with mental retardation (69.10± 6.22) and there was significant difference found at (0.01 level). So the current study reveals that the parents having children with autism had better quality of life than parents having children with mental retardation. This findings support the previous study by Shahzadi Malhotra(2012) where she finds that the level of quality of life was seen better in parents having children with autism in compare to parents having children with mental retardation.

#### CONCLUSION:

There were a significant Differences found in both the dimensions (Family Burden and Quality of Life). Result shows that in family burden, parents having children with mental retardation perceives more burden than parents having children with autism. But in quality of life, parents having children with autism, had better quality of life than parents having children with mental retardation.

#### IMPLICATION OF THE STUDY:

- ▲ Assessment of Family Burden and Quality of Life helps in counselling the parents to reduce the burden and to guide them to deal with children appropriately. This will help the parents to accept children as they are. They may not unnecessarily reject, punish, and show hostility towards their children.

- ▲ Skills training to the caregivers can help them to deal effectively with the children with MR. It will also help to improve the quality of life, and take positive steps to handle the children more constructively.

#### LIMITATIONS OF THE STUDY

- Presence of any other medical conditions associated with mental retardation and autism should have been ruled out as these can also add to the burden for caregivers.
- Sample size is not large enough to generalize the results.
- This study is limited to Autism and Mental Retardation, it would be better to have an additional comparison group such as children with other disabilities and children with behaviour problems.

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