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A cross-sectional study on stress perceived by families of mentally retarded children enrolled in special schools of a city of central India

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ABSTRACT

Background: Presently we are passing through a phase in the area of rehabilitation where in efforts are being made to spread services and training programs to raise awareness level related to mainstreaming and provision of equal rights and opportunity for the mentally retarded individuals. The present study was undertaken keeping in view the fact that an increasing number of children are being diagnosed with mental retardation parallelly an increase number of families will have to address and cope with the stress. The objective of the study was to study the stress perceived by the families having mentally retarded children and to find out the various factors influencing the perceived stress

Methods: 100 families and 102 mentally retarded children were studied. Section I of family interview for stress and coping in mental retardation (FISC-MR) was used to find out the family burden of care.

Results: 47.97% of fathers and 68% of mothers are in the age group of 30-40 years. The severity of retardation was mild in 36 children, moderate in 46 children while 20 had severe retardation, 32% of mother feel mild stress of which 59.3% having education level up to degree college. 61% of mother showing moderate stress of which 68.8% having education level up to degree college. (67.3%) nuclear families show mild stress while only 22 (52.3%) joint families show mild stress.

Conclusions: Living with and caring for the person with MR is very stressful and burdensome. 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 Mental Retardation.

Keywords: Mental retardation, Family, Stress

INTRODUCTION

The term mental retardation is often mis understood and seen as derogatory. Mental retardation is also termed as mental deficiency, mental sub normality and intellectual deficiency. Mental retardation is a unique disorder, both as a symptom as well as syndrome, which fall under the broad rubric of neurodevelopmental disabilities. Intellectual disability (ID), also called intellectual development disorder (IDD) or general learning disability, and formerly known as mental retardation (MR), is a generalized neurodevelopmental disorder

characterized by significantly impaired intellectual and adaptive functioning. It is defined by an IQ score below 70 in addition to deficits in two or more adaptive behaviors that affect every day, general living. The presence of a mentally handicapped child shakes the family to its foundations. Family experiences a kind of initial shock to stress and reacts with grief, hopelessness, and shame and guilt feelings. They need an understanding & supportive physician who can provide reassurance, consolation, support and guidance regarding children which cannot be completed without parental counseling. The provide reassurance and the complete without parental counseling.

Having a child with mental retardation in family is certainly not the same as having a child without such disability. Presence of a mentally retarded child in the family is known to impact family in varied ways, generating special needs, not only for the child but also for the members of the special family.

The institution of family is considered essential for the existence of society. Family serve as a shock absorber in times of crisis and stress. Families of children with mental retardation undergoes a variety of adaptive and non-adaptive reactions to the presence of a disability in a family member. The problem of mental retardation is inseparable from the problems faced by the families, it is clear that the organized services are definitely needed by families to adapt well and face the situation with confidence and the least amount of stress. To achieve these aims, professionals from many field, families, governmental and non-governmental organizations and society as a whole have to work together.³

Presently we are passing through a phase in the area of rehabilitation where in efforts are being made to spread services and training programs to raise awareness level related to mainstreaming and provision of equal rights and opportunity for the mentally retarded individuals. Unfortunately, not much attention has been or is being directed towards the family members, having mentally retarded persons, despite the fact that they are the directly affected population and are also the prime care takers to provide lifelong support and security to the mentally retarded persons.

The present study was undertaken keeping in view the fact that an increasing number of children are being diagnosed with mental retardation parallelly an increase number of families will have to address and cope with the stress. These parents will need help to identify the problem, obtain evaluation and diagnosis, treatment or remediation for the child. With the help of this study we try to make an attempt to analyze the factors that are most related to the wellbeing of parent and their perceived stress.

Aims and objectives

- To study the stress perceived by the families having mentally retarded children.
- To find out the various factors influencing the perceived stress by family members having a mentally retarded child.

METHODS

Study design

A cross sectional study was conducted over a time period of four month from September 1, 2017 to 31st December, 2018.

Study population

All the (number=100) families of children (age <16 years) with presence of any degree of mental retardation, who were enrolled at the time of study in any of the special education centers of Ujjain city were taken as the study population. Two families with two mentally retarded children thus total 102 mentally retarded children and two families have no father thus total of 198 parents studied.

Methods

A list of special schools was obtained from "Ujjain society for the mentally retarded children". Then the directors of the schools were contacted and briefed about the purpose of research. After that list of students with age, sex and severity of retardation and their family address was procured. Families of 20 children with assessed severe retardation, 36 with moderate and 46 with mild retardation were selected, classification of mental retardation was as provided by the school authorities, as reported in their admission forms by the registered clinicians.

The families were first contacted on phone and the purpose of interview was explained to them. A time was fixed for meeting at the place of their convenience.

After taking the informed consent the families of selected mentally retarded children were interviewed by using a specially designed Performa which included:

A semi-structured Performa was used to collect the details including child variables such as age, gender and level of mental retardation, and parent variables such as age, education, occupation, religion, type of family and family income. Family interview for stress and coping in MR (FISC-MR) was used to find out the family burden of care (4). This is a semi-structured interview schedule that consists of 2 sections; section I measures perceived stress and section II measures mediators or coping strategies (awareness, attitudes, expectations, rearing practices and social support). Section I was used in this study.

Statistical analysis

Present part of the study utilizes the section I. Reliability and validity of this tool- Cronbach's Alpha, a measure of internal consistency for section I was 0.9. Inter rater reliability was 0.81 for any one rater and average for all 3 raters was 0.93. Test- retest reliability was 0.71 for section I. Concurrent validity was 0.63. Construct validity was 0.517. A Likert scale was used to grade the stress levels into mild (score 0-11), moderate (score 12-22), severe (score 23-33) and very severe stress (score 34-44).

The data collected were analyzed with SPSS version 18.0. Questionnaires were checked for completeness and

correctness before entering into the work sheet. Data validation checks were performed at a regular interval for data entered into the worksheet of Microsoft excel. Chisquared tests used for analysis. The level of significance was p < 0.05.

RESULTS

Table 1: Sociodemographic characteristics of family.

Variables	Males N=98		Total N=198
Age groups (in years)			
<20	0	0	0
20 - <30	5	7	12
30- <40	47	68	115
40-<50	46	25	71
>50	0	0	0
Educational status			
Illiterate	0	3	3
Primary education	03	05	08
Secondary education	30	29	59
Degree and above	65	63	128
Occupational status			
In service	35	13	48
Self employed	62	07	69
Unemployed/ housewife	1	80	81

Table 1 reflects that 47.97% of fathers and 68% of mothers are in the age group of 30-40 years. Regarding educational qualification 63% of mothers had degree course or above. 80% of females were housewives, 63.26% of fathers were self-employed.

Table 2 describes the age, sex and severity distribution of the affected children. Out of 102 children, 63 were males and 39 females. The largest age group was formed by 6-12 yrs. with 49 children. The severity of retardation was mild in 36 children, moderate in 46 children while 20 had severe retardation. No statistical significance was found between family stress and any of the variables.

Table 2: Demographic variables of mentally retarded children and family stress score.

Variables	Stress	score		
Age groups	Mild	Moderate	Severe	Total
(in years)	stress	score	score	Total
0-<6	3	14	3	20
6-<12	16	30	3	39
12-<16	13	19	1	33
Sex				
Male	20	39	4	63
Female	12	24	3	39
Severity of reta	rdation			
Mild	13	20	3	36
Moderate	12	30	4	46
Severe	7	13	-	20

Table 3: Stress experienced by the family.

Sub scale	0	1	2	3	4	Total
Daily care stress score						
Extra input for care	14	11	22	46	7	100
Decreased leisure time	8	13	30	31	18	100
Neglect of other	11	28	42	14	5	100
Disturbed behavior	43	42	4	9	2	100
Family emotional stress score						
Personal distress	12	13	47	28	00	100
Marital problem	44	38	17	01	00	100
Other interpersonal problems	45	42	09	04	00	100
Effect on siblings and other family member	39	13	11	04	01	100
Social life stress score						
Altered social life	48	27	19	07	00	100
Social embarrassment	49	25	21	05	00	100
Financial stress score						
Financial implication	36	21	23	11	09	100

Table 4: Descriptive analysis of socio-demographic study variables according to stress score level.

	Age in year	i.		Sibling		Family		Maternal education	education			Total
Stress score	9>	>6-<12	>12-<18	Presence of sibling	Absence of sibling	Type of family	mily	Illiterate	primary	secondary	Degree	No. (%)
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	Nuclear		No. (%)	No. (%)	No. (%)	No. (%)	
0-11 (Mild stress)	3 (2.9)	16 (15.6)	13 (12.7)	18 (18.1)	14 (14)	15	17	0 (0)	1(1)	12 (12)	19 (19)	32 (31.3)
12-22 (Moderate stress)	14 (13.7)	30 (29.4)	19 (18.6)	44 (44.1)	17 (17)	39		3 (3)	2 (2)	14 (14)	42 (42)	63 (61.7)
23-33 (severe stress)	3 (2.9)	3 (2.9)	1 (0.98)	06 (5.8)	01 (1)	4	3	0 (0)	2 (2)	03 (3)	02 (2)	7 (6.8)
Total	20 (19.6)	49 (48)	33 (32.3)	(89) 89	32 (32)	58		3 (3)	5 (5)	29 (29)	63 (63)	02 (100)

Table 5: Stress compared on the basis of socioeconomic status of family

	Class I	Class II	Class III	Class IV	Class V	Total
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
0-11 (Mild stress)	18 (18)	6) 6	04 (4)	01 (1)	(00) 00	32 (32)
12-22 (Moderate stress)	33 (33)	20 (20)	05 (5)	02 (2)	01 (1)	61 (61)
23-33 (severe stress)	01 (1)	3 (3)	03 (3)	(0) 00	(00) 00	(7)
0-11 (Mild stress)	52 (52)	32 (32)	12 (12)	03 (3)	01 (1)	100 (100)

In the area of daily care for sub scale extra input 46 families experience high stress that is significant time or energy needs while 7 families report very high stress care felt demanding throughout the day. In subscale neglect of other 42 family report somewhat affected. Nearly half of the family do not have any marital and inter personal problems. Other members of the family and sibling reported no demonstrable effect. In area of social life stress sub scale of altered social life and social embarrassment 48 and 49 families respectively reported nil effect on them, while 5 families had persistent apprehension leading to child being frequently kept away from social situation. Only 9 families reported high financial stress.

The Table 4 shows family of 63 children show moderate stress out of which 30 (29.4%) children were in age group of 6-12 year. Family of 7 children shows severe stress out of which 3 children were in age group of 6-12 year. The result is not statistically significant with Chi square value= $2.08 \text{ p} \ge 0.05 \text{ df} = 6.44\%$ of family showing moderate stress have sibling while 6% of family with sibling feel severe stress. The result is not statistically significant with p>0.05.

39 (67.3%) nuclear families show mild stress while only 22 (52.3%) joint families show mild stress. The chisquare value on comparing the severity on the type of family is 2.5098 with p=0.285102. The result is not statistically significant

The above table interpreted that 32% of mother feel mild stress of which 59.3% having education level up to degree college. 61% of mother showing moderate stress of which 68.8% having education level up to degree college, the result is statistically significant with Chi square value=68 p \leq 0.05 df=4.

The above table shows that 52% of the family experiences stress were belong to class I. Of 61% family experiencing moderate stress, 33 (54%) were in class I. Higher socioeconomic status family perceived more stress and the above result is not statistically significant with chi square value of 13.6, p>0.05.

DISCUSSION

The present study aims to know the various factors leading to stress in families having mentally retarded children. The stress was analyzed on variables related to child age, severity of retardation, presence of sibling and type of family.

It is evident that Majority of the children (48.3%) were in the age group of <6->12 year, followed by 32.3% of <12->16. Of the total children 61.7% were males and 38.2 were females. On categorization of M.R. children on the basis of severity we found that 35.2% of children belonged to mild group, whereas 45% belonged moderate

category. Regarding educational status of 198 parents 64.6% parents were having educational qualification up to or more than bachelor degree while only 1.5% were illiterate.

In the present study 80.3% of children were in age group of 6-12 year with 48% having moderate stress and the result is not statistically significant while Pakrasi et al showed the incidence of mental retardation is significantly associated with age of children, while study conducted by Upadhyaya et al shown that lower age of the mentally retarded child to have significant relation with stress, while other studies have also shown significantly more psychosomatic problems as the age of their child increases.^{3,5,6}

In the present study we found that nuclear family feel more stress than joint family, 39 (67.3%) nuclear families show mild stress while only 22 (52.3%) joint families show mild stress, the result is not statistically significant. This may be because of lack of emotional and social support of other family members. In accordance to our study Morya et al found that nuclear families faced significantly more stress in comparison to joint families in managing the mentally retarded children. While Peshwaria et al find that parents living in joint or extended families face greater extra demands, career adjustment, mental worries and strained relationships, while parents from nuclear family reported face ridicule, loss of support and social restriction.

In our study we find that family with higher socioeconomic status experiencing more stress as compared to lower socioeconomic status family. This finding is in favor to the observations by the other investigator. Our finding is in accordance with Emerson et al and Lavee et al who concluded that the rate of psychological distress is increased by socioeconomic deprivation, wherein the family's education and socioeconomic status had an inverse relationship with perceived stress and burden. 8,9

A significant association of stress with maternal education was however found. This may be because educated mothers can better understand the clinical aspect of their child's condition. This is consistent with findings of similar studies in India where it was found that higher educated parents face greater stress.^{3,10}

The present study found that families with children of 6-12 years perceived more stress compared to other age group, the result is not statistically significant. It was also found that family with sibling feel more stress as compared to those family without sibling. In contrast to the findings in current study, a study outside India, lower stress is reported when higher number of siblings is present. In a study conducted by Upadhyaya et al the presence or absence of normal siblings in the family of

mentally challenged children does not make significance difference in stress experienced by the parents.⁶

CONCLUSION

Living with and caring for the person with MR is very stressful and burdensome. 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. Multiple stressors seem to be responsible for the stress and burden experienced by the caregivers. Lower socio-economic group family suffers more in handling the mentally disabled children. Amongst the parents, mothers perceive more stress and burden in caring their disabled children than the fathers.

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