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# Study of level of stress and burden in the caregivers of children with mental retardation

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**Abstract.** Mental retardation is one of the most prevalent developmental disabilities. Family is the main source of support for the persons with disabilities in any society. Families experience a great deal of physical and emotional burden whilst caring for such relatives. This study tries to look into the issues such as the impact of severity of mental retardation on the level of stress and burden perceived by the caregivers.

Key words: Mental retardation, caregivers, stress, burden

## 1. Introduction

Family is the main source of support for the persons with disabilities in any society. Mental retardation (MR) is one of the most prevalent developmental disabilities. Those who are closest to the persons with MR and care for them bear the brunt of their disability. Families experience enormous physical and emotional burden whilst caring for such relatives (1-5).

Poor performance by the person with disability, be it physical, psychological or social, needs to be compensated by the caregivers. This leads to unavoidable stress and psychological trauma among the families. In a country like India where care provided for MR is mainly home based and alternate support systems such as day care centers, weekend care and special schools are meager the burden of care can be enormous. Not much work has been done to gauge the impact of severity of MR on the level of stress and burden perceived by the caregivers. This study tried to look into these issues.

## 2. Materials and methods

The study was conducted at the department of psychiatry, PGIMS, Rohtak, India. Purposive sampling was done and one hundred and eighty subjects who were the parents of the children with well established diagnosis of MR were selected for the study. Only children who had both parents interviewed were included in the study. The sample was divided into three groups (A, B and C) depending upon the level of IQ. Groups A, B and C each consisted of 60 parents (30 mothers and 30 fathers) of children with severe to profound mental retardation, mild to moderate mental retardation and borderline intelligence respectively. Children with MR were matched for age and gender but not for IQ. Each parent was interviewed separately.

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 (6). 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. Further details of this section are shown in Table 1.

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Table 1. FISC-MR-Section I

Area	Sub-scales
Daily care stress	Extra inputs for care Decreased leisure time Neglect of others Disturbed behavior
Family emotional stress	Personal distress Marital problems Other interpersonal problems
Financial stress	Altered social life Social embarrassment Financial implications

The carers were rated on a 5-point scale (most favorable to most unfavorable) where zero meant absence of stress and score of 4 meant a very high level of stress.

For analysis parametric statistical methods such as t- test and ANOVA (SPSS-10.0 version) were applied.

### 3. Results

The data was analyzed for the differences in various socio-demographic characteristics. No significant difference was noticed between the 3 groups as a whole as well as when mothers and fathers were compared amongst themselves for age, educational level and income of family. 41% of the carers were illiterate. Most mothers were home-makers and the fathers were farmers or laborers. 52% belonged to the nuclear families. However mothers spent significantly more time (15.43 ± 0.46 hours per day) caring for the disabled children than their spouses (10.83 ± 0.47 hours per day).

Table 2 compares the FISC scores of mothers and fathers in each group separately. Mothers in groups A and B differed significantly from their spouses (p<0.01 each) whereas no significant difference was found in the FISC scores of mothers and fathers in group C.

Table 3 compares the perceived stressors among the parents in 3 groups. Comparing groups A and B a significant difference was noticed in all the perceived stressors except marital problems, other interpersonal problems and effects on sibs and other family members. Comparison was similar between groups B and C except non-significant difference was also found

in the areas of social embarrassment and financial implications. When groups A and C were compared a significant difference was noted in all the perceived stressors except marital problems.

### 4. Discussion

Mental retardation is one of the most common developmental disorders. With a movement away from the institutional care and towards the home based care of persons with MR, it is the family that bears the brunt in caring for their disabled relative. A combination of factors appears to predict the likelihood of stress experienced by the carers. In our study subjects in group A i.e. parents of children with severe to profound MR had very high level of stress and burden. When compared with their spouses, mothers experienced higher level of stress and the level of stress increased as the severity of MR increased. These findings are in keeping with those by the earlier investigators (7-10). Further the finding that the fathers experienced less stress is in concordance with other studies (5,9). The possible reasons for this could be that: a) mothers spent more time with the children while caring for them, b) most mothers were home-makers without additional help and also were restricted to home with no time or provision for leisure activity.

Parents' education and economic status of the family did not make any difference to the perceived stress and burden. This finding is in contrast to the observations by the other investigators (5,7) wherein the family's education and income had an inverse relationship with perceived stress and burden. Most of the

Table 2. Comparison between the FISC scores of mothers and fathers

Groups	FISC scores of fathers (Mean ± SD)	FISC scores of mothers (Mean ± SD)	t	p
A	23.89 ± 3.60	28.31 ± 2.84	-4.05	<0.01
B	16.76 ± 2.61	20.81 ± 3.45	-3.48	<0.01
C	13.46 ± 3.60	13.92 ± 2.32	-0.40	NS

NS: Not significant

Table 3. Comparison of perceived stress among parents of three groups

Perceived Stressor	A vs B	B vs C	A vs C
Extra inputs of care	p<0.01	p<0.01	p<0.01
Decreased leisure time	p<0.01	p<0.01	p<0.01
Neglect of others	p<0.01	p<0.01	p<0.01
Disturbed behavior	p<0.01	p<0.01	p<0.01
Personal distress	p<0.01	p<0.01	p<0.01
Marital problems	NS	NS	NS
Others interpersonal problems	NS	NS	p<0.01
Effects on sibs & other family members	NS	NS	p<0.01
Altered social life	p<0.01	p<0.01	p<0.01
Social embarrassment	p<0.01	NS	p<0.01
Financial implications	p<0.01	NS	p<0.01

NS: Not significant

subjects in our study belonged to lower socioeconomic group. Comparison with other socioeconomic groups is needed to see the effect of these factors.

## 5. 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.

Amongst the parents, mothers perceive more stress and burden in caring their disabled children than the fathers.

### 5.1. Limitations

Presence of any other medical or psychiatric co-morbidity associated with mental retardation should have been ruled out as these can add to the burden of care. Also the traits like neuroticism, that might have influenced the perception of stress by the caregivers were not been taken into account.

Comparison of the children with disability with normal children and the children from different socioeconomic groups would have thrown more light on other factors responsible for the stress and burden.

### 5.2. Implications

The caregivers of persons with MR should also be consulted and considered while planning and providing various intervention services for mentally retarded.

The index study points out that the parents with high as well as low education and of all socio-economic 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 MR.

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