

Stress in Parents of the Mentally Challenged

Upadhyaya, G.R. and Havalappanavar, N.B.

Karnataka Institute of Mental Health, Karnatak University,
Dharwad, Karnataka State. Dharwad, Karnataka State.

Fathers and mothers of 628 mentally challenged individuals are assessed for their perceived stress using Family Interview for Stress and Coping in Mental Retardation (FISC-MR). Socio demographic data pertaining to the mentally challenged individuals and their parents are collected. To assess behaviour disorder, BASIC-MR, Part B is used. Results show that mothers report higher stress compared to fathers, the difference being significant at 0.001 level. Most of the parents report mild to moderate stress and none of them report very high stress. In the areas of care, emotional and social stress, mothers report higher stress and in the area of financial stress, both fathers and mothers report equal levels of stress. It is noticed that more than one mentally challenged children in the family; higher levels of behaviour disorder; lower age of the mentally challenged individual and parents; and lower income of the family are associated with higher stress.

Key words: Mentally Challenged, Perceived Stress, Coping.

Once the parents come to realize that their child is mentally challenged; they are confronted with many challenges and problems. The nature of stress and areas of stress in parents of the mentally challenged have been studied extensively. Seth (1979) reported care stress and social stress in 83% of mothers, emotional stress in 80% of mothers and financial problem in 47% of mothers. Prabhu (1989) finds care stress, social stress and financial stress in parents. Venkatesan & Das (1994) report that the type of burden reported by family members may range from difficulties in transportation of the child to the place of service delivery, management of behaviour problems, disruption of their daily routine, economic, physical and social burden. Pariante & Carpiniello (1996) report more of emotional distress, poor social relationships and lack of holidays or free time. Various factors attributing to stress in such parents have

been studied. Datta, Russell, Swamidas, Gopalakrishna & Seetha (2002) find that expressed emotions toward the child, age of the child and income as important factors associated with burden. Gupta & Jain (2002) find that less educated, low income group and rural parents have more problems with their spastic mentally handicapped children. In the present study, some of the child characteristics namely; gender, IQ, age, presence of behaviour problems, number of mentally challenged children in the family and number of siblings in the family are studied. Similarly, parent characteristics namely; age, education, income, rural-urban status, occupation and presence of grandparents are studied.

Method

Sample:

In total 628 mentally challenged individuals with both father and mother living

with them are selected for the present study, who attended the Karnataka Institute of Mental Health, Dharwad, during the year 2002 and 2003. There are 387 male and 241 female cases. Age range of the mentally challenged individuals is from 4 to 30 years. IQ ranges from 20 to 62. 580 families have one and 48 families have 2 or 3 mentally challenged children. Families having only mentally challenged children and no other normal siblings are 44. There are 290 cases associated with behaviour disorder. 71 fathers and 374 mothers are aged less than 35 years. 265 fathers and 374 mothers are not educated. 493 families are rural and agricultural. 503 families are of low income. 272 families have grandparental support.

Tools:

BASIC-MR, Part B: Behavioural Assessment Scales for Indian Children with Mental retardation, Part B (Peshawaria & Venkatesan 1992) has been used to study the extent of behaviour disorder in the mentally retarded individual as perceived by parents. Test retest reliability is 0.68 (Peshawaria, Venkatesan, Mohapatra & Menon 1990). Test retest reliability for the kannada version is 0.63 (estimated by the present researchers in their pilot study). Each item is rated as 0 (never present), 1 (occasionally present) or 2 (frequently present). In total there are 75 items covering 10 domains and the maximum score is 150. Scores are converted into percentages.

FICS-MR: Parents were assessed for their perceived stress by using the FISC-MR: family interview for stress and coping in mental retardation, a tool developed by Girimaji et al. (1999) at NIMHANS, Bangalore, to study stress and coping in families of children with mental retardation. This scale has two parts. Part I- Perceived stress- This part has 11 subscales covering 4 areas namely; daily care stress, family emotional stress, social stress and financial stress.

Scoring - score 0 to 4 (0-nil, 1-low, 2-moderate, 3-high and 4-very high). Part II- Mediators or coping strategies, is not used in the present study. Reliability and validity of this tool- Cronbach's Alpha, a measure of internal consistency for section I and II was 0.9 and 0.67 respectively. 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 and 0.36 for section I and II respectively. Concurrent validity was 0.63. Construct validity was 0.51. Test-retest reliability for Kannada version for part-I is 0.722 and for part-II is 0.627(estimated by the present researchers in their pilot study).

Procedure: To confirm the clinical diagnosis and to find the IQ, Binet-Kamath test of intelligence has been administered. Fathers and mothers are studied separately using BASIC-MR, Part B and FISC -MR in 2 sessions. Raw scores are converted into standard scores in case of stress scores and into percentages in case of behaviour disorder scores. Student's t-test, ANOVA, regression analysis and correlation are undertaken. While correlating various factors to stress, average stress scores for fathers and mothers has been taken (the family total stress score).

Results

Table 1: Difference between fathers (n=628) and mothers (n=628) for total stress scores

Group	Mean	SD	t value
Fathers	50.00	8.183	9.48***
Mothers	54.98	10.34	

*** p< 0.001

Table 2: Frequency distribution of parents reporting different levels of stress
Number of parents

Level of stress	Daily care		Emotional		Social		Financial		Total	
	Fr	Mr	Fr	Mr	Fr	Mr	Fr	Mr	Fr	Mr
No Stress	228	122	0	1	3	4	33	34	0	1
Mild Stress	396	256	565	322	182	54	68	66	424	206
Moderate Stress	4	236	63	305	410	472	497	498	204	401
High Stress	0	14	0	0	33	98	30	30	0	20
Very High Stress	0	0	0	0	0	0	0	0	0	0
Average Score (out of 4)	0.6	1.2	1.1	1.5	1.8	2.1	1.8	1.8	1.3	1.7

Table 3: Correlation coefficients between subscale scores and area total scores

Area of stress	Sub Scales	Correlation coefficient	
		Fathers	Mothers
Care	1 Extra inputs of care	0.7403*	0.8270*
	2 Decreased leisure time	0.5871*	0.8475*
	3 Neglect of others	0.0969	0.1456*
	4 Disturbed behaviour	0.8559*	0.7954*
Emotional	1 Personal distress	0.6809*	0.6166*
	2 Marital problems	0.1498*	0.1996*
	3 Other interpersonal problems	0.0000	0.0372
	4 Effect on sibs and others	0.8570*	0.8966*
Social	1 Altered social life	0.9840*	0.9857*
	2 Social embarrassment	0.9830*	0.9862*
Financial	1 Only one subscale and so subscale score and area sub total score are the same		

N=628, critical value of $r = +/- 0.1205$ at 0.05 level of significance.

Table 4: Factors correlating significantly with total stress score for the family

Variables	r- value
Age of MR	- 0.2002*
No. of MRs	0.2160*
Father's Age	- 0.1710*
Mother's Age	- 0.1708*
Income	- 0.1786*
Behaviour disorder score	0.7176*

N = 628, critical value of $r = +/- 0.1205$

* $p < 0.05$

Figure 1: Mean stress scores for parents in four areas and total stress

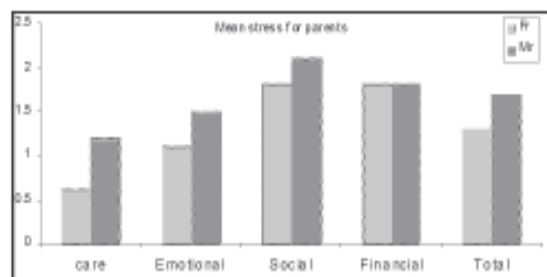
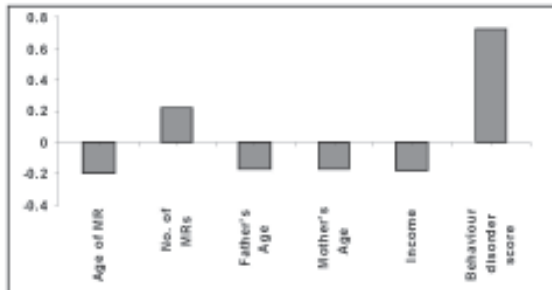


Figure 2: Factors contributing significantly to stress



Discussion

Nature of stress: The fathers and mothers are studied separately to find the difference between them in their perception of stress. The mothers experience higher stress than the fathers (Table 1). Heller, Hsieh and Rowitz (1997) report higher stress in mothers. When different areas of stress are considered, it is noticed that the mothers are stressed more compared to the fathers in daily care, emotional and social stress (Figure 1). Regarding financial stress, there is no difference between fathers and mothers. Most of the fathers and mothers have reported mild and moderate levels of stress (Table 2). The regression analysis for areas of stress indicates that all areas of stress are contributing significantly to the total stress for fathers and mothers.

Care stress: Some parents report no stress regarding daily care. The reason may be that, some mentally challenged children are not causing any problem and also some parents may not feel the burden of care. It is noticed that for fathers disturbed behaviour and extra inputs of care are the prominent factors of care stress, the other one being decreased leisure time. For mothers, decreased leisure time and extra inputs of care are the major factors and the other one is disturbed behaviour (Table 3). Sequeira, Rao, Subbakrishna and Prabhu (1990) report disruption in the family routine.

Venkatesan (2003) reported that disciplining and management of problem behaviours in their children appear to be the major source of burden.

Family-emotional stress: Fathers and mothers have moderate emotional stress and stress is more in mothers compared to the fathers (Figure 1). The important finding is that fathers and mothers have reported effect on siblings equally as a major factor in personal emotional stress (Table 3). Emerson, Robertson and Wood (2004) found elevated psychological distress in 47% of the parents. Fisman, Wolf, Ellison and Freeman (2000) finds more adjustment problems in siblings of the retarded. Fahey (2005) finds positive adaptation in the siblings of the retarded. In the present study, it is seen that parents report negative effect on siblings.

Social stress: Mothers report higher social stress than fathers (Figure 1). Gumz and Gubrium (1972), and McAllister, Butler and Lie (1973) noticed social stress.

Financial stress: Majority of parents report moderate financial problems and stress level is similar for fathers and mothers (Figure 1). Datta, Russell, Swamidas, Gopalakrishna and Seetha (2002) report income as an important factor in stress.

Factors of stress: Each factor is discussed separately as to whether it influences stress experienced by parents of mentally retarded individuals. Statistical details are not mentioned regarding those factors, which do not appear as significant (for significant factors also tables are not given to save the space, but statistical figures are referred in discussion).

In the present study gender of the mentally challenged individual has not shown any influence on parental stress. Tangri and Verma (1992) report higher stress in parents of female retarded children; Leyser and Dekel (1990) notice higher stress in parents of male retarded children. Lower age of the mentally

challenged individual is associated with an increase in stress. ANOVA for 4 age groups indicates significant difference (F value is 5.07 for fathers and 14.69 for mothers, $p < 0.001$ for both). Lower age increasing the stress has been reported by Smith (1997).

In the present study IQ of the mentally challenged individual does not show any influence on parental stress. Studies by Gosch (2001) and Pisula & Gorska (2002) noticed that parents of severe and profoundly retarded children have higher stress. Prabhu (1989) find higher stress in parents of mildly retarded group. Incidence of having more than one mentally challenged child in the family significantly increases the stress experienced by parents (t-value is 4.69 for fathers and 4.73 for mothers, $p < 0.001$ for both).

In the present study 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. Leyser and Dekel (1990) reported that when the number of siblings in their family is small, the stress is higher. The difference in stress is significantly different when parents having children with behaviour disorder are compared with those without behaviour disorder (t-value is 23.32 for fathers and 22.88 for mothers, $p < 0.001$ for both). Several studies indicate similar results (Venkatesan 2003; Hastings, Daley & Burns 2006 and Blacher & McIntyrase 2006.).

Parents aged less than 35 years when compared with parents above 35 years, show significant difference (t-value is 1.97 with $p < 0.05$ for fathers and 4.57 with $p < 0.001$ for mothers) and lower is the age of parents higher is the stress. This has been reported by Gandotra (1985). Educational level of parents does not show clear influence on parental stress in the present study. Behari (1995) reported higher stress in educated group.

Two variables of occupation (Agricultural/ non-agricultural) and rural-urban status are considered together here as the statistical findings are the same for these two variables. The present study finds no significant difference in fathers and slightly significant difference for mothers (t value is 0.71 with $p > 0.05$ for fathers and 2.37 with $p < 0.05$). Prabhu (1978) finds that mental retardation is not considered as a serious problem especially in the agricultural communities. No significant influence of income on stress has been found in t test. However Table 4 shows negative and significant correlation indicating that low income group has higher stress. Gandotra (1985) reports similar finding.

It appears that grandparental support reduces parental stress. Parents having and not having grandparental support do not show significant difference regarding stress. Hornby and Ashworth (1994) indicate that grandparental support decreases stress.

On the whole, as seen in Table 4 and Figure 2, more than one mentally challenged child in the family, higher levels of behaviour disorder in the index child, lower age of the mentally challenged child and parents, and lower income of the family are associated with higher stress.

Conclusion

Mothers report higher levels of stress compared to fathers. Most of the parents report mild to moderate stress. None of the parents report very high stress. In three areas of stress (care, emotional and social) mothers report higher stress and in the area of financial stress, both fathers and mothers report equal levels of stress. For fathers, disturbed behaviour and extra inputs of care are the prominent factors, the other one being decreased leisure time. For mothers, decreased leisure time and extra inputs of care are the major factors, the other one being disturbed behaviour. Parents have reported effect on siblings as a major factor.

Regression analysis indicates that all areas of stress are contributing significantly to the total stress. Results indicate that more than one mentally challenged child in the family, higher levels of behaviour disorder in the index child, lower age of the mentally challenged child, lower age of parents and lower income of the family are associated with higher stress

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G. Ramesh Upadhyaya is a Clinical Psychologist at Karnataka Institute of Mental health, Dharwad, Karnataka State. E mail: ramesh_psychologist@yahoo.co.in

N.B. Havalappanavar, PhD, is presently Professor at Department of Psychology, Karnatak University, Dharwad, Karnataka State.