

Care Giver's Burden and Perceived Social Support in Mothers of Children with Mental Retardation

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Abstract- Introduction: Parents of children with mental retardation experiences high level of emotional, financial and physical stress. There are multiple problems of having a mentally retarded child in the family. The problems are mainly related to the social ridicule and social stigma. Feelings of depression are common, particularly when realization of the child's retardation is recent. Mothers of children with disability have the higher the perception of economic situation and income adequacy, parenting social support, and religious practices, and the lower the symptoms of depression and found that minority mothers showed the higher the religious coping, the lower the symptoms of depression.

Aim: The aim of this investigation was to study the Caregiver's Burden and Social Support in Mother's of children with Mental Retardation as compared to Mother's of Normal children.

Method: The sample for the study consisted of a group of 30 mothers of children with Mental Retardation and the control group consists of 30 Mothers of Normal children. The age range of the children is 3 to 15yrs and the age range of the mothers is 25 to 45yrs. Socio-demographic Data Sheet was prepared for the study, Caregiver's Burden Scale (CBS) and Berlin Social Support Scales (BSS) tools were used in this study.

Results: Mothers of children with Mental Retardation showed significant difference on care givers burden than the mothers of normal children in the areas of General Stain, Disappointment, and Emotional Involvement. And there is also a significant difference in social support for mothers of children with mental retardation and mothers of normal children in the areas of support seeking and actually received support.

Conclusion: Mothers of children with mental retardation are experiencing more caregiver's burden and seeking more social support than the mothers of normal children.

Index Terms- A Mental Retardation, Social Support, Burden and Mothers

I. INTRODUCTION

The birth and continuing care of mentally retarded children are often stressful experiences for family members as these children's difficulties touch the lives of those around them (Crnic, et al., 1983; Featherstone, 1980). The effect on the family unit can be far-reaching, restrictive and disruptive and they may be economic, social or emotional (Schonell & Watts, 1956). Parents of children with mental retardation experiences high level of emotional, financial and physical stress (Byrne & Cunningham,

1985; Singh et al., 1990). There are multiple problems of having a mentally retarded child in the family. The problems are mainly related to the social ridicule and social stigma. As the child grows up and disability becomes quite noticeable by others parents face is a very distressing predicament of social embarrassment and stigma. This may lead to isolation of the child even within the family the child may be restricted from coming out when relatives and friends visit the house or may be left back at home when parent go out. Crnic and Greenberg (1985) found that the cumulative impact of daily parenting hassles and difficulty in dealing with children represent significant stressors that may subsequently affect parents and family conditioning. Consequently parents of the retarded children have been viewed as being at risk for a variety of family life problems and emotional difficulties. As the child develops, many families must have begun coping with long-term uncertainties regarding the children's present and future functioning and sometimes their questionable validity (Kazak & Marvin, 1984). In addition, families often face increased financial burdens (Holoroyd, 1974; McAndrew, 1976). Children may require special equipment, medical care, and programming and at the same time; family income may be reduced because caregiving responsibilities make it difficult for two parents to work outside the home. An added area of concern for some families is difficulty managing family relations (Featherstone, 1980; Fredrich & Fredrich, 1981; Gath, 1973). Roles within the family may need to be restructured (Faber, 1960; Kazak & Marvin, 1984) and the resulting strain may manifest itself in family problems, including high rates of dissatisfaction, divorce, family quarrelling and marital breakdown (Gath, 1973; Holt, 1958); establishing and maintain satisfying social networks (Gayton, 1975; Kazak & Marvin, 1984). Relationships with professionals also may be a source of added stress (Turnbull, 1986) as parents face difficulties in their efforts to secure adequate services for their child or obtain information about their child's disability. Parents undergo chronic sorrow which is periodic in nature, precipitated by child's deviants from normal performance. The intensity of reaction was related to the particular developmental stage and the individual coping strengths of the family (Wilker et al., 1981). Feelings of depression are common, particularly when realization of the child's retardation is recent. Some mother's react to the retarded child as if he had died and manifest the typical grief reaction associated with the loss of a loved one.

Mothers are more active in their child's care and bear most of the burden associated with it. They tend to give themselves little time to adjust, as the child with the disability continues to require ongoing care. Mainly mothers have difficulty on child

care taking, difficulty of feeding, bathing and dressing and caretaking time (Erickson and Upshur 1989). Many mothers suffer loss of self-esteem when they recognize retardation in their child. A serious defect, and may feel responsible for disappointing her mate and other family members by presenting them with a defective child. Closely allied to loss of self-esteem and with the feeling of shame they may anticipate social rejection, pity or ridicule and related loss of prestige. Some studies shows that mothers have to tend to do more work than their fair share, and their activities are often restricted (Goldman 1962). It also found that more severe handicapping conditions are associated with poorer psychological wellbeing for mother; they have only being able to speculate about the reason for such patterns and one speculation is that the additional daily responsibilities and usual caregiving demands associated with raising a related child may result in maternal psychological dysfunction (Holroyd 1974). The family of children with mental retardation experience burden due to various problems encountered with regard to financial conditions, routine family interaction, leisure, physical and mental health of other members of the family caused by the handicapped family member. The psychological trauma of the family members is generally more profound. One study reported that parental burden in the form of interfaces in their family routine or leisure and recreational, which even resulted in social, partial familial and emotional problems in the home setting of individuals with mental handicap. The mothers of mentally handicapped children reported higher social burden than those of the physically handicapped children. When comparing the burden perceived by mothers of handicapped boys and girls it was found that the disruption in family leisure and effect on mental health of the mothers were reported more often by the mothers of the female children. Majority of the mothers (both the handicapped groups) rated the overall burden as moderate to severe (Pai and Kapur 1981). The presence of a child with mental handicap can indeed become a source of perceived burden for family members even though it does not appear to be significantly influenced by specific variables like child, family characteristics or some characteristics of service delivery. Further the nature or type of perceived burden by family members may range from difficulties in transportation of child to place of service delivery, management of child's behavior, problems, disruption of their daily routine, economic, physical and or social burden (Venakatesan and Das 1994). Mothers of children with developmental disabilities expressed a high level of overall burden, particularly in financial domains, greater subjective caregiver burden, 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 the social support can reduce the burden (Heykyung oh et al., 2009). As the child grows the families are trying accept the child and one study also found that older caregivers more apt to mobilize their families to acquire and accept the child and experienced significantly less personal burden. It also concluded that younger caregivers are more predisposed toward seeking outside help and have higher expectations of the service system (Mary E Hayden & Tamar Heller 1997).

Mothers of children with mental retardation also uses different types of coping strategies to overcome with the problem. Denial, Rehearsal of outcome, finding a purpose and seeking emotional support were the commonly utilized coping styles by the mothers of mentally handicapped children (Pai and Kapur 1981).

Social support is broad term encompassing a variety of constructs, including support perceptions (perceived support) and receipt of supportive behaviours (received support). The recent studies report no difference between mothers and father's in terms of their social isolation (Beckman, 1991). Evidence exists that in some instances families of children without disabilities may have larger and less dense social networks than families of children who are disabled (Fredrich & Fredrich, 1981); Kazak & Wilcox 1984), both attributes indicative of less adequate support. Mothers of children with disability have the higher the perception of economic situation and income adequacy, parenting social support, and religious practices, and the lower the symptoms of depression and found that minority mothers showed the higher the religious coping, the lower the symptoms of depression. Some studies found that the presence of social support significantly predicts the individual's ability to cope with stress and it was knowing that they are valued by others is an important psychological factor in helping them to forget the negative aspects of their lives, and thinking more positively about their environment. It also found that social support not only helps improve a person's well-being, it affects the immune system as well. Thus, it also a major factor in preventing negative symptoms such as depression and anxiety from developing (Corey 2005). Studies found that both hardiness and social support were predictive of successful adaptation.

II. METHODOLOGY

Aim: The aim of this investigation was to study the Caregiver's Burden and Social Support in Mother's of children with Mental Retardation as compared to Mother's of Normal children.

Method: The sample for the study consisted of a group of 30 mothers with Mental Retarded children of varying degree, aged between 3 and 15 years. Mother's for study group were drawn from a Special School attached to two NGOs situated at Secunderabad, A.P. For the control group, 30 Mothers of Normal children were recruited from a nearby regular school at Secunderabad. Age range of the mothers is between 25 to 45 years and the age range of the children is 3 to 15yrs. Consent form was taken from the mothers who are willing to participate in this study and administered the questionnaires individually.

Inclusion criteria

- Having a child diagnosed with Mental Retardation (F70.0) according to ICD-10 criteria
- Mother should be the Primary caregiver of the child and living with child in the same household.
- Mothers education upto high school or above

Exclusion criteria:

- Mental retardation with behavior problems or any neurological conditions, any physical disability

- Single mothers, widows, separated and divorced
- Past or current psychiatric or chronic physical illness

Tools: Socio-demographic Data Sheet was prepared for the study, Caregiver’s Burden Scale (CB Scale) developed Oremark and Berlin Social Support Scales (BSS) developed by Schwarzer & Schulz in 2000 were used for the study.

Procedure: The mothers recruited for the study after obtaining the written consent were interviewed to elicit the relevant socio-demographic details and were administered Caregiver’s Burden Scale and Social Support Scale individually. Subject requiring any clarifications was attended by the researcher.

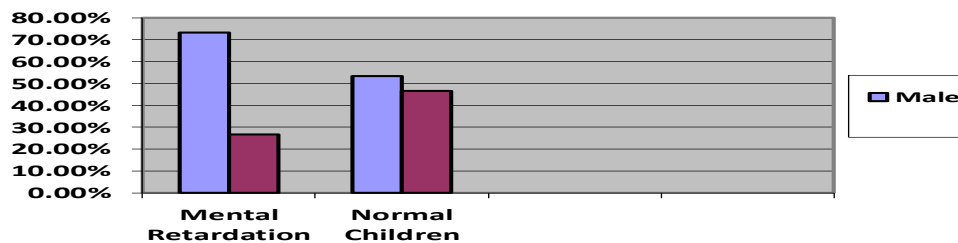
Statistics: The data was analyzed using SPSS (16 version) software package. The Mean and SD for each variable for each

group was calculated, and an independent “t” test was performed for between group comparisons on each variable.

III. RESULTS AND DISCUSSION

The results were analyzed using descriptive statistics like mean, SD, and “t” test. The results are presented and interpreted keeping the aim in view. Initially the socio demographic data which has name of the mother, education of the mother, type of the family, domicile and socio economic status has been taken for discussion followed by, discussion about data related to caregiver’s burden scale and social support of mothers of children with mental retarded and normal children. In this study 30 mothers of children with mental retardation and 30 mothers of normal children were taken respectively.

Graph: 1- Gives gender of the children



Graph-1 shows the percentage value of gender of children with mental retardation and normal children. Children with mental retardation males and female children are 73.3% and 26.6% respectively; normal children males and female children

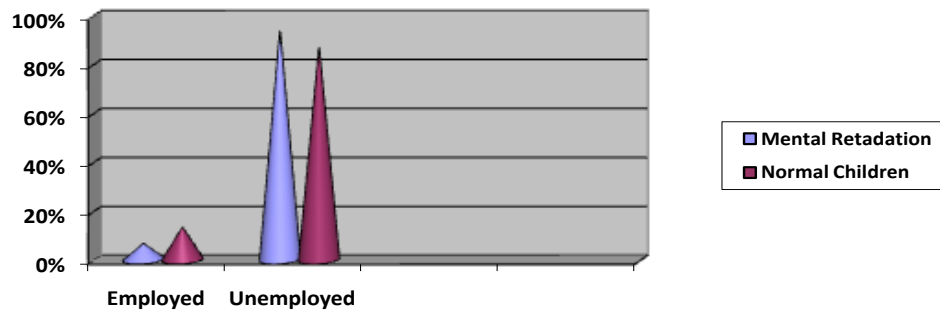
are 53.3% and 46.6% respectively. In both the groups male children are more than female children.

Graph -2: Gives mean(\pm SD) age of mother and children with mental retardation and normal children.



Graph 2 shows the mean(\pm SD) age of mother and mean(\pm SD) age of children with mental retardation and normal children. The mean(\pm SD) age of the children with mental retardation is 8.23(\pm 2.77) and for normal children is 9.6(\pm 4.2). The mean age of the mothers of children with mental retardation is 32(\pm 6.00) and mothers of normal children is 33.83(\pm 6.71).

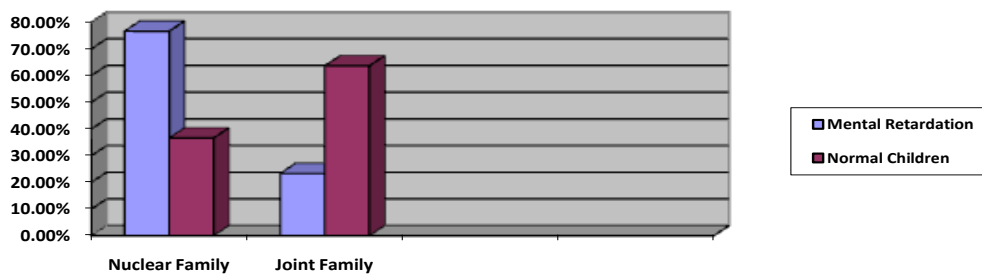
Graph -3: Gives employment of the mothers of children with mental retardation and normal children.



Graph -3 shows the employment of mothers of children with mental retardation and normal children. 6.6% Mothers of children with mental retardation are employed and 13.3% of mothers of normal children are employed. The unemployed

mothers of children with mental retardation are 93.3% and 86.6% mothers of normal children are unemployed. In both groups unemployed mothers are more than employed mothers.

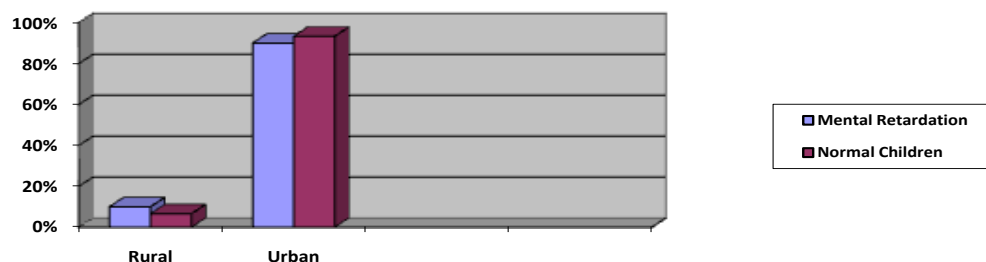
Graph-4: Gives family type of population



Graph -4 shows the family type of mothers of children with mental retardation and normal children. In the group of mothers of children with mental retardation 23.3% belonged to joint family background and 76.6% have nuclear family background. In the group of mothers of normal children; 63.6% belonged to joint family background and 36.6% belonged to nuclear family

background. In mental retardation group most of the mothers belong to nuclear family background than joint family background and in the group of normal children belong to joint family background than nuclear family background.

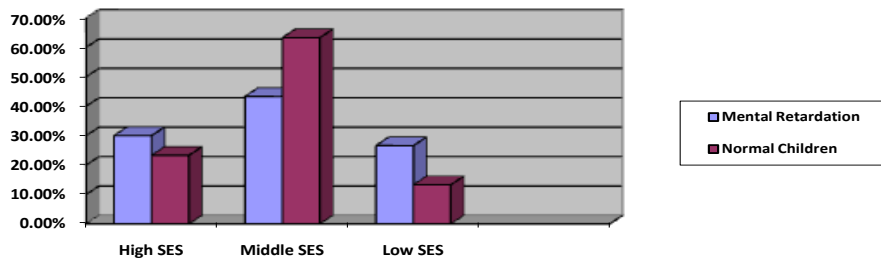
Graph-5: Gives Domicile of population



Graph -5 gives the domicile of the population. About 10% of mothers of children with autism are belongs to rural background and the remaining 90% mothers are belongs to urban background. In the group of mothers of children with mental retardation 6.6% mothers are belong rural background and 93.3%

belongs to urban area background. In both groups most of the mothers are belongs to urban background.

Graph-6: Gives Socio economic status of mothers of children with autism and mothers of children with mental retardation



Graph -6 gives the socio economic status of mothers of children with mental retardation and normal children. The percentage value of mothers of children with mental retardation belongs to high, middle and low socio economic status are 30%, 43.3%, and 26.6%; respectively. In the group of mothers of

normal children belongs to high, middle and low socio economic status are 23.3%, 63.3%, and 13.3% respectively. In both groups most of the mothers are belongs to middle socio economic status.

Table -2 Mean (\pm SD) Score on (CBS) Caregiver’s Burden Scale for mothers of Mental Retardation and Normal children (N=30/group)

Items Mean (\pm SD)	MR	NORMAL	“t”	“p”
CBS	43.43(\pm 12.07)	34.96(\pm 9.53)	3.01	.004
Gen. strain	15.96 (\pm 5.48)	12.96(\pm 4.35)	2.34	.022
Isolation	5.83 (\pm 2.30)	7.36(\pm 17.36)	-.479	.633
Disap.	9.83 (\pm 3.48)	7.93 (\pm 3.38)	2.143	.036
Emo-involvement	6.20 (\pm 2.49)	5.03 (\pm 1.80)	2.072	.043
Environment	4.93 (\pm 2.08)	4.73 (\pm 1.98)	.381	.705

In the table 2; there is a significant difference between the mothers of children with mental retardation and mothers of normal children on Caregiver’s Burden Scale and the subscales are General Strain, Disappointment, and Emotional Involvement. There are significant 0.05 level.

There is a significant difference on caregiver burden scale; the Mean (\pm SD) scores of mothers of children with MR is 32.0(\pm 6.00) and Mean (\pm SD) of mothers of normal children is 33.8(\pm 6.71). The “t” value is -.750 and it is significant at 0.05 level. It shows that the mothers with mental retarded children have a higher burden levels than the mothers with normal children. There is a significant difference in the following subscales General Strain; the Mean (\pm SD) scores of mothers of children with MR are 15.96(\pm 5.48)where as Mean (\pm SD) of mothers of normal children are 12.96(\pm 4.35)The “t” value is 2.34

and it is significant at 0.05 level. It shows that mothers of children with mental retardation are experiencing more general strain than the mothers of normal children.

In the subscale of Disappointment; the mothers of children with MR Mean (\pm SD) is 9.83(\pm 3.48) and mothers of normal children is 7.93(\pm 3.38) respectively. The “t” value is 2.14 and it is significant at 0.05 level. It shows that mothers of children with mental retarded are experiencing more disappointment than mothers of normal children. In the subscale of Emotional Involvement; the mothers of children with MR Mean (\pm SD) is 6.20(\pm 2.49) and mothers of normal children is 5.03(\pm 1.80) respectively. The “t” value is 2.07 and it is significant at 0.05level. It indicates that mothers of children with MR are showing emotional involvement than mothers of normal children.

Table-3 mean (+SD) score on social support scale for mothers of mental retardation and normal children (N+30/group)

BSSS Mean (+SD)	MR	Normal	“t”	“p”
BSSS	1.00(+8.84)	99.43(+11.35)	.520	.605
Perceived Available Support	25.73(+4.68)	1.23(+527.22)	-.960	.341
Need for Support	13.23(+1.90)	13.70(+1.85)	-.960	.341
Support Seeking	13.46(+3.93)	16.16(+3.06)	2.96	.004
Actually Received Support	47.70(+6.41)	1.17(+1.26)	3.003	.004

In table -3 there is a significant difference between the mothers of children with mental retardation and mothers of normal children on social support scale and the subscales are support seeking and actually received support. There are significant 0.05level.

In the subscale of support seeking; the mothers of children with MR Mean (+SD) is 13.46(+3.93) and mothers of normal children is 16.16(+3.06) respectively. The “t” value is 2.96 and it is significant at 0.05level. It indicates that mothers of children with MR are seeking more support than mothers of normal children.

In the subscale of actually received support; the mothers of children with MR Mean (+SD) is 47.70(+6.41) and mothers of normal children is 1.17(+1.26) respectively. The “t” value is 3.003 and it is significant at 0.05 level. It indicates that mothers of children with MR are not receiving support from their spouses than mothers of normal children.

IV. DISSCUSSION

The scales taken for the study was burden assessment schedule. This scale is a 22- item scale, which measures 5 different areas of burden. And the other scale is Berlin Social Support Scale this scale is 32-item scale, a four- point Likert-type scale consisting of 4 subscales. Results suggested mothers of children with Mental Retardation showed significant difference on care givers burden than the mothers of normal children in the areas of General Stain, Disappointment, and Emotional Involvement. And there is also a significant difference in social support for mothers of children with mental retardation and mothers of normal children in the areas of support seeking and actually received support. 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.

V. CONCLUSION

Mothers of children with mental retardation are experiencing more caregiver’s burden and seeking more social support than the mothers of normal children.

VI. IMPLICATION OF THE STUDY

- Assessment of burden and social support helps in counseling the mother to reduce the mother’s burden and to guide her 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.

VII. LIMITATIONS OF THE STUDY

- Presence of any other medical or psychiatric co-morbidity associated with mental retardation 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 Mental Retardation and Normal Children, it would be better to have an additional comparison group such as children with other disabilities and children with behavior problems.

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