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Perceived Burden and Coping Styles of the mothers of Mentally Handicapped Children

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Eveline M Sequeira ,

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- *Department of Psychiatry, St. Agnes College, Mangalore, India*

P Madhu Rao, - *Department of Clinical Psychology, National Institute of Mental Health & Neuro Sciences, Bangalore 560 029, India*

D K Subbakrishna, - *Department of Biostatistics, National Institute of Mental Health & Neuro Sciences, Bangalore 560 029, India*

G G Prabhu, - *Department of Clinical Psychology, National Institute of Mental Health & Neuro Sciences, Bangalore 560 029, India*

Abstract

A group of 55 mothers, of male (N=30) and female (N=25) mentally handicapped children in the age range of 5-12 years with moderate (N=30) and severe (N=25) degree of retardation, were studied to assess the extent of the burden perceived and the coping styles utilised by the mothers in relation to the sex and the degree of retardation in their handicapped child. Results indicated that there were no significant differences in the perceived burden with reference to the sex of the child. Significant differences were found by way of disruption of routine family activities when degree of retardation was taken into account. Denial, rehearsal of outcome, finding a purpose and seeking emotional support were the commonly utilised coping styles by the mothers of the mentally handicapped children.

Key words -

Burden,
Coping Styles,
Moderate and several mental retardation

The presence of a mentally handicapped child in the family, is known to place constraints on its normal functioning and be a source of stress [1], [2], [3], [4]. It is also perceived as a burden on the family as a whole making demands on its coping resources. It is evident from the literature that the impact of the mentally retarded individual in the family is on the entire family and the burden is experienced in various sphere of family functioning. Reports indicate parental tension concerning their own roles and family relationships [5], frequent quarrels [6], lack of opportunity for social contacts, sense of rejection, social isolation [1], [3], [7], [8], marital disharmony [3], [9], [10], [11] and the health of the mother [12]-especially in the psychological sphere in the form of feelings of depression, anxiety and reduced self esteem [13]. Studies have also revealed that the presence of a mentally handicapped child affects the normal development of other siblings [7], [14], [15].

The present study is an attempt to assess the burden, as perceived by the mothers of the mentally handicapped children in relation to the degree of retardation and the sex of their handicapped child. It also aims to study the, coping styles used by the mothers of handicapped children as they experience the ongoing stress which demands continuous coping.

Material and Methods

Sample

The sample was purposive and consisted of mothers of male and female mentally handicapped children, in the age range of 5-12 years seeking consultation for the first time, at the mental retardation clinic, NIMHANS. Mothers with more than one mentally handicapped child and mothers who had undergone or who were undergoing psychiatric treatment at the time of screening were excluded, as it may affect their perception of the burden on the family. Degree of retardation in the child was determined on the basis of the clinical diagnosis made by the clinical psychology consultant and the social age of the child assessed by using the 'Vineland Social Maturity Scale'. The final sample consisted of 55 mothers and was divided into 4 groups as shown in Table I.

Table I - Number, sex and the degree of retardation among the children in the four groups

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Male=Gr. I & II=30.
Female=Gr. III & IV=25
ICD 9 318.0 (moderate)=Gr. I & III=30
ICD 9 318.1 (severe)=Gr. II & IV=25.

The age range of mothers included in the sample was between 21 to 55 years (Mdn age=33 years). Out of 55 mothers, 30 (54.6%) were illiterate; 10 (18.2%) had 1 to 5 years of schooling; 13 had 6-10 years of schooling and just 2 had college education. Most of the mothers (83.6%) were housewives. Nine (16.4%) mothers were working outside the house, of whom 2 were teachers and 7 were daily wage earners. The presenting complaints in the child highlighted by the mothers at the time of consultation are given in Table II.

Table I - Nature and frequency of presenting complaints

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Tools

The following tools were used:

1. A socio-demographic data
2. Pai and Kapur's [16] schedule to assess the perceived burden. This scale was originally constructed to assess the burden, in six areas, on families of psychiatric patients living in the community. For the present study, this was modified to assess burden in 4 areas-financial, disruption of routine family activities, disruption of family interaction and family health-of families with a handicapped child.
3. A coping check list, adapted for the present study, consisted of 7 coping styles as given by Moos [17].The items under each of the coping categories were pooled together during the pilot study.

Prior to the collection of data sufficient rapport was established with the mother. The tests were administered individually in one session.

Results

Two way analysis of variance was used to determine whether the burden experienced by the mothers of mentally handicapped individuals was significantly different in any of the 4 areas studied in relation to the sex of the child and the degree of retardation.

There was no significant difference in the perceived burden in any of the 4 areas with reference to the sex of the child.

A significant difference in burden was observed in the are of disruption of routine family activities in terms of the degree of retardation, (P. =<.05; F value 6.11). Item analysis, using the (2 × 3) chi-square test revealed that 3 items significantly differentiated the 2 groups i.e. the group of mothers of moderately handicapped children from the group of mothers of children with severe mental retardation.

Data on coping styles was analysed using the chi-square test. As there were no significant differences in coping styles between the groups, percentages were computed which indicates the percentage of mothers using a particular coping style.

Discussion

The results of the present study do not indicate any significant difference in the burden perceived by the mothers, with reference to the sex of the handicapped child. However mothers of the male handicapped children reported comparatively greater burden in all the areas.

A significant difference was found in the area of disruption of routine family activities when degree of retardation present in the child was taken into account (Table III). This was perceived more by the mothers of the severely handicapped children who had a larger number of associated problems (Table II) in addition to mental handicap. Similarly disruption in routine activities of the family have been reported by Moroney [2], Narayana [3] and Seth [10].

Table III - Level of perceived burden as seen on each item in the area of disruption of routine family activities

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Mothers of the severely retarded children perceived greater burden when compared to the mothers of the moderately handicapped children in the financial, family interaction, family health as well as the family activities area.

Nearly two thirds of the group of mothers studied (66%) had a score above the mean with regard to the all pervasive burden.

Severe strain on the psychological health of the mother was seen in 70.9% of the mothers.

More than 50% of the mothers reported that the family experienced severe financial burden. Jain

& Sathyavathi [8] had pointed out that 61% of the parents studied by them had severe financial constraints.

Forty-two per cent of the mothers reported disruption in the family interactions. The mothers 52.7% felt that they were steadily getting isolated from the social life, while 25% were of the opinion that there was all pervasive tension in the family due to the presence of a mentally handicapped child. The findings of the present study do not indicate disruption in family interaction to as high a degree as reported by earlier workers like Jain & Sathyavathi [8] and Seth [10].

A vast majority of mothers expressed that it is neither the sex of the child nor the degree of retardation that influenced their perceived burden but mental retardation per se that made a number of demands on them and the whole family.

Analysis of coping styles revealed certain trends (Table IV).

Table IV - Type of coping styles used by the mothers

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Although some of the mothers suspected retardation in their child as early as 6 months and most by the time the child was 5 years, yet they entertained the thought and hoped that their child was a 'slow learner' and (s)he would 'outgrow' the lag (98%). Similar notions were held by the parents studied by Kanner [18]. Its impact can be seen when we find that the median age at which the first consultation was made around 7.5 years of age.

The second most frequently used (96.4%) coping style was, rehearsal of potential alternative outcome. Finding a purpose for the occurrence of mental retardation was seen in 85.5% of the mothers. They felt that their child was mentally retarded either because of their own sins or due to the effect of their 'Karma'.

Problem focussed procedures such as teaching the child simple age appropriate self-help skills were used by only 25.5% of the mothers. Their coping styles were mostly geared towards handling their own emotional turmoil rather than handling the problems of retardation and its consequences experienced by the child and the family.

The findings of the present study draw attention to the fact that it is necessary that the family as a whole is strengthened to take care of their handicapped child at home. Long term support to the family by way of parental counselling to accept and utilize more problem focussed coping styles and organising of self-help groups of parents may be worth considering seriously.

An early diagnosis, imparting of clear knowledge about the assets as well as the liabilities of their handicapped child, providing of social supports and the imparting of knowledge and skills to adopt problem centered coping strategies can be instrumental in bringing down the burden perceived by the mother and the family and make them capable of providing the necessary care for the retarded person at a home. The challenge of the times is to develop methods by which to provide these to the concerned families.

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