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Strategizes for Parents of Mentally Retarded Children's

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Abstract: ***Families which are capable of coping with having a mentally retarded child are able to mobilise their internal and external means of support to deal effectively with special needs of their child. The ability of the family to cope with any situation will often depend on their strengths and resources. In this study the coping strategies and mediating factors studied were awareness about the child's problem, expectations and attitudes, child rearing practices, social support, and global family adaptation. Family coping was measured using a pretested self-administered questionnaire. 74% families were seen to have adequately adapted to having a mentally retarded child in their family, as measured on the global adaptation scale. The remaining 26% families had inadequately adapted, of which 7% showed poor coping.***

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INTRODUCTION

Family is the basic unit of social security for every family member; old or young, male or female, healthy or sick, able-bodied or disabled. In families having persons with a disability (physical or mental), the needs and responsibilities of the family are definitely increased manifold. In the past, parents were advised to institutionalize their mentally retarded child. This is not the practice anymore. Now the goal envisaged for the child with mental retardation is to stay in the family and take part in community life.

The present study was undertaken keeping in view the fact that an increasing number of children are being diagnosed with mental retardation. Social, cultural and educational components in the society are helping to increase awareness of this disability, and subsequent to diagnosis, its acceptance by the affected family. More and more families thus have to face the stressors that this disability brings along and, in consequence, have to be able to mediate the stress and cope up in a better way. Caregivers will need to identify the problem, obtain evaluation, and handle the situation in such a way that the mentally retarded child as well as his family adjust well in the society, and make optimum use of their abilities.

MATERIAL AND METHOD

Study Sample: One hundred families with 102 children (age<18 years), out of all listed (370) students with presence of any degree of mental retardation, who were enrolled in special schools in Indore city, were selected using random sampling. In the 100 families, 98 fathers (2 had expired) and 100 mothers were interviewed.

Study Period: The study was carried out between Aug-2002 to Aug 2003

Study Tool: The family assessment schedule developed for the 'Family Interview for Stress and Coping in Mental Retardation, (FISC-MR), a semistructured interview, developed at NIMHANS Bangalore1 was used.

The tool consists of 2 sections:

Measuring Stress (Daily care, emotional stress, social stress and financial stress) and

Measuring mediators of stress or coping strategies (awareness, attitudes& expectations, child rearing practices, social support and global adaptation).

Section one has 4 areas and 11 subscales, and section two has 5 areas and 9 subscales. A 5-point rating scale for section one and a 4-point rating scale for section two is provided.

At administration, this instrument provides for:

Quantification of perceived stress, in the family as a whole under different areas.

Quantification of different mediating influences which are likely to alter the perceived stress.

Coping scores were measured on Likert scale. Percentage of families on various score grades was calculated.

RESULTS AND DISCUSSION

General awareness regarding the child's condition took into account the nature of the problem, its cause, its prognosis and treatment. 34% parents were highly knowledgeable about the cause, prognosis and treatment of their child's condition while 7% of the families showed very poor knowledge in all the areas. In the sub scale misconceptions about treatment, 45% families had no misconception while 3% had wide misconception regarding investigations and treatment of their child's condition. In a similar study conducted by Peshwaria et-al2, one of the most important inhibitors in coping was the lack of professional support. In other words it implied the failure of the professional dealing with the child's condition to provide information about him/her and even wrong advice about the child's condition. It was also found that professional support and training management were reported by parents with mentally retarded children as facilitators in coping.

In the area of "Attitude towards the mentally retarded child and expectations from her/ him", 35% families had largely appropriate expectations from their child while 9% had highly inappropriate expectations. 37% families had most favourable attitude towards the child as a person and a family member, while 4% families had most unfavourable attitude. Some 43% families had most favourable attitude and 3% most unfavourable attitude towards child management. In a study conducted by Nihira et-al in 1986 it was concluded that the quality of parenting, educational expectations and aspirations were the two salient environmental variables associated with the subject's development.

In the area of child rearing practices 43% families showed most favourable attitude in their rearing practices adopted for the mentally retarded child. 4% families showed highly unfavourable rearing practices. 33% families show most favourable attitude to rearing practices specific to training while as high as 18% families had most unfavourable attitude. In the study by R. Peshwaria et al, professional and training management are reported as facilitators in coping by 1.4% parents each while difficulty in admission to school as an inhibitor in coping by 1.8% parents.2

As training is an important component in allowing these children to live a more independent life, such a high percentage of families showing unfavourable attitude towards training of the mentally retarded child does point to some loopholes in the professional guidance being meted to such families.

In the area of social support, 50% families reported best social support available which they utilised maximally. While 1% families alleged that very little or no social support was available. In order to cope better with the situation of having a mentally retarded child in the family, the importance of family involvement has long been emphasized4 .Research in India has indicated that receiving maximum social-emotional support from the spouse, family members, relatives, and friends are facilitators for effective coping. Peswaria et al 19955 concluded that physical support from within and outside the family is one of the greatest facilitators in coping.

The last item for rating is meant for overall global understanding of the degree to which the family has adapted to the predicament of having a child with mental retardation, using the interviewers judgment based on all the information available so far. On the whole, the Global Adaptation score suggested that 18% families were extremely well adapted while 56% families adequately adapted to the presence of a mentally retarded child. Of the remaining 44% families, 7% showed very poor coping, that is poor adaptation. In a Canadian study, it was concluded that families can and do adapt resiliently to high levels of demand; and that the focus should now be on family centred practices of care, natural teaching strategies and cooperative family learning.6 Shin in 2001 studying the informal and professional supports available for families of children with mental retardation in Korea and USA, showed that American mothers received more informal and professional support while Korean mothers experienced more stress . A good support system is required to operationalise support and training for families in our part of the world also.

Theories have suggested that resources such as social support may enable people to gain access to perceptions that reduce feelings of threat or stress associated with an event; for example, comparisons with others may lead a person to perceive his or her problem as less difficult than those faced by others.8

Social support or self-help groups have become increasingly popular forms of family support among families who have children with disabilities9,10 Support groups may be organized by a professional or may arise informally through associations among family members, but their chief characteristic is the provision of support among the peer members of the group11. Support groups may serve a number of functions that enhance cognitive coping strategies. For example, the validation of one's feelings by other group members12 might be seen as an enhancement of self-esteem. Also, family members who meet others in similar situations have opportunities to make comparisons with others, to share positive experiences, and to look at situations with a humorous eye, all of which relate to self-esteem. The sharing of information that often occurs in support groups may also lead to a greater sense of empowerment12. In addition, group leaders may directly explain the use of these coping strategies and encourage the members of the group to share their own effective strategies with one another.

A number of curricula for parent education have been developed that may serve to enhance coping strategies. Behaviour modification training, for example, may enhance parents' sense of control and mastery over their child's behaviour. Similarly, training and/or counseling programs designed to teach problem-solving and communication may increase control as well as self-esteem through increased feelings of competence. Finally, educational programs providing family members with information about participating in decision making for their child's educational or habilitation program may directly enhance a sense of mastery and control through empowering family members. A further question to be considered is whether these coping strategies can be taught directly.

One of the most important aspects of family support is the relationship between the professionals serving a child with a disability and the family. Kupfer, 198413 notes that "a certain amount of animosity between parents and professionals may be endemic, since professionals are unable to fulfill parents' ultimate wish, that their child be cured".

Professionals who understand the function and value of these coping strategies may not only be able to help families enhance their use, but may also gain insights into the family's behaviour that may enhance the professional's ability to respect and collaborate with the family.

Although not much research on coping strategies in Indian context is available, it can be learned from foreign experiences that organised parental support inform of social support groups, parental training by educational and informational services, and better family-professional relationship is essential in bringing about a focal change in the resent situation of children with mental retardation and their families.

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