FAMILY INTERVIEW FOR STRESS AND COPING IN MENTAL RETARDATION (FISC-MR) : A TOOL TO STUDY STRESS AND COPING IN FAMILIES OF CHILDREN WITH MENTAL RETARDATION

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ABSTRACT

Stress and coping in the families caring for their member with mental retardation has recently received worldwide research attention. There is no comprehensive instrument to study these issues in India. This study reports on development and standardization of a new instrument to fill this lacuna. Family Interview for Stress and Coping in Mental Retardation (FISC-MR), a semi-structured interview schedule, was developed as a part of two years prospective study of efficacy of brief family intervention for 157 children with mental retardation (funded by ICMR). The tool consists of 2 sections - one measuring stress (daily care, emotional, social and financial) and the other measuring mediators of stress or coping strategies (awareness, attitudes, expectations, rearing practices and social support). Results indicate moderate to high reliability (internal consistency, inter-rater reliability and test-retest reliability) and validity (factorial, criterion and construct) of the instrument. It is concluded that FISC-MR is a useful, reliable and valid instrument for both clinical and research purposes.

Key words: Mental retardation, families, stress and coping, interview schedule

The response of society to its individuals with disabilities, especially those with mental retardation, has varied a great deal over the human history. In recent times, all over the world, there has been a movement away from institutional care and towards family based care of individuals with mental retardation (Shearer, 1977). In India, an overwhelming majority of persons with mental retardation have traditionally been cared for in their families. A recent document of Government of India, the National Policy on Mental Handicap (Govt. of India, 1988), has emphasised the importance of home-based care with parents as partners in the care process.

The consequences of this home based care approach for the family has received a good deal of research attention from the professionals in the last two decades. One major concern of the researchers has been to study the processes of stress, coping and adaptation in these families (Crnic et al., 1983; Gallagher et al., 1983; Byrne & Cunningham, 1985). The recent research evidence from India and abroad has evaluated the types, degree and determinants of the stress faced by the families in caring for their disabled member (Seshadri, 1983; Wig et al., 1985; Sethi & Sitholey, 1986; Crnic, 1983; Tunali & Power, 1993; reviewed by Byrne & Cunningham, 1985). The literature is uniform in reporting that families do experience high levels of stress. However, the research has also shown that stress is not an inevitable consequence in these families (Koller et al., 1992; Beresford, 1994). The nature of stress has been shown to span over several aspects of family life such as daily care demands, emotional distress (such as maternal depression), interpersonal difficulties (such as parental discord), financial problems and adverse social
consequences (such as social isolation).

What are the variables which influence or determine the extent of stress experienced by the families? Studies indicate 3 sets of variables. These are (i) child specific variables such as age, sex and severity of retardation, (ii) socio-demographic variables such as social class, family income and domicile and (iii) family coping resources and strategies. It is interesting to note that studies have consistently shown that coping by the families has a more decisive effect on the stress experienced by them than the other 2 sets of variables (Byrne & Cunningham, 1985; Beresford, 1994). Though it is clear that coping plays a key role in family adaptation, it has been a difficult research question to study. Several theoretical models have been utilised for examining this intricate process of family stress, coping and adaptation, such as the stress and coping theory of Folkman & Lazarus (1984), the ABCX model of McCubbin (Orr et al., 1991) and eco-cultural model (Gallimore et al., 1993).

What are the coping strategies employed by the families to deal with the stress? Researchers have been able to identify many such coping strategies. For instance, in their review, Gallagher and colleagues (1983) identified the following as important mediator variables (or coping strategies) which influence the stress felt by the families: expectations, attributions, parents' view of the causation of the handicap, nature and quality of daily interactions with the child, parents' notions about their own efficacy as 'change agents' in facilitating child's development, attitudes and social support. Other such mediating factors which have been identified include family beliefs and perceptions, religious and moral beliefs, overall philosophies and ideologies held by the families, family lifestyles and extent of harmony in the family (Byrne & Cunningham, 1985; Beresford, 1994). The role of these issues in the family focussed intervention in mental retardation is evidently of crucial importance and has been reviewed elsewhere (Cunningham, 1985; Davis & Rushton, 1991; Girimaji, 1993; Beresford, 1994).

A variety of approaches have been adapted by the researchers to study stress and coping in the families and include questionnaires (Fiedrich et al., 1983; Knussen & Cunningham, 1988; Dyson et al., 1993), interviews (Frey et al., 1989; Narayan et al., 1993), rating scales (Bhatti et al., 1985; Peterson, 1984) and ethnographic methods (Gallimore et al., 1993). The focus of these methods has varied and included areas such as mothers' well-being, marital adjustment among parents, stress of parenting, parental attitudes, care-taking demands, perceptions and expectations. However, there is no one standardized instrument to study the variety of stresses experienced by the families and coping strategies available to them. Such an instrument is required not only for research purposes but also to facilitate family focussed intervention.

Keeping this lacuna in mind, the authors developed a new instrument to evaluate stress and its mediators in the families of children with mental retardation. This work was carried out as a part of the initial preparation for two years prospective study funded by Indian Council of Medical Research, titled 'a study of the evaluation of the effectiveness of brief inpatient family intervention versus outpatient intervention for mentally retarded children'. For this study, stress was defined as those aspects of the family's response to its member with mental retardation that are experienced as distressful. Mediators of stress, or coping strategies were defined as those aspects of family's beliefs, attributions, expectations, resources and practices that are likely to influence the stress experienced by the family. These definitions were adapted along the lines suggested by Gallagher et al. (1983).

This paper describes the development and standardization of this instrument, which has been named Family Interview for Stress and Coping in Mental Retardation (FISC - MR).

**MATERIAL AND METHOD**

**Description of the main study:** In the project funded by Indian Council of Medical Research
and carried out at the child and adolescent psychiatry unit of the Department of Psychiatry of NIMHANS, two comprehensive models of brief, intensive, family-focused intervention in mental retardation were developed, crystallized and prospectively evaluated. One was the outpatient group and the other was the inpatient group. The components of intervention included (i) family orientation, (ii) medical measures, (iii) general parenting measures, and (iv) parent training. In all, 75 and 82 subjects were recruited for inpatient and outpatient group respectively.

Many instruments were used to collect data at intake and follow-up. These included Detailed Evaluation Schedule (DES), Vineland Social Maturity Scale (VSMS - Malin’s Indian Adaptation), Gessel’s Developmental Schedule (GDS), Problem Behaviour Rating Scale (PBRS), Questionnaire on Resources and Stress (QRS-SF; Friedrich et al., 1983), FISC-MR, Intervention Sheet (IS) and Follow-up Sheet. The efficacy of intervention was studied in terms of (a) impact on child variables (adaptive functioning and problem behaviours) and (b) impact on families (observer rated and self report of family stress and coping strategies).

The subjects and their families were prospectively followed up every three months for a period of two years. Instruments measuring outcome were repeatedly administered at the time of follow-up visits.

**Development and description of the FISC-MR:** An in-depth survey of all the available instruments were made. Authors also drew heavily from their clinical experience in the field. Following this, sections, areas and sub-scales were decided upon and questions were prepared to cover the sub-scales. This instrument has been developed not only for recording the perceived stress and its mediators (or coping strategies) in the family, but also to help in the formulation of family based intervention.

The final prepared version of the instrument is an observer rated, semi-structured interview schedule and attempts to systematically elicit and quantify (i) the stress experienced (perceived) by families caring for a child with mental retardation and (ii) certain key coping strategies specific to disability employed by the families that are likely to modify the perceived stress (mediators). Accordingly, FISC-MR has 2 major Sections: Section-I is meant for elicitation of perceived stress in different area and Section-II for exploration of certain mediating factors or coping strategies. The structure of these two Section is laid out in Table 1. In short, Section-I has 4 areas and a total of 11 sub-scales, whereas Section-II has 5 areas and a total of 9 sub-scales. A four or five point rating scale with scoring instructions are provided for each sub-scale. The sub-scales on stress are rated on a 5 point scale (no or minimal stress to very high level) and those in the Section-II are rated on a 4 point scale (most favourable to most unfavourable). Table 2 and 3 give details of the scoring patterns for Section I and II respectively. The approximate time required for the administration of the instrument was around 45 minutes.

**PROCEDURE**

Once the instruments was developed, the

**TABLE 1**

**STRUCTURE OF FISC-MR**

| SECTION           | AREA                    | SUB-SCALES                                      |
|-------------------|-------------------------|-------------------------------------------------|
| Perceived stress  | Daily care stress       | Extra inputs for care                           |
| in family         |                         | Decreased leisure time                          |
|                   | Family emotional        | Neglect of others                               |
|                   | stress                  | Disturbed behaviour                             |
|                   |                         | Personal distress                               |
|                   |                         | Mental problems                                 |
|                   | Social stress           | Other inter-personal problems                   |
|                   |                         | Effects on sibs & other women                   |
|                   | Financial stress        | Allered social life                             |
|                   |                         | Social embarrassment                            |
|                   |                         | Financial implications                          |
| Mediators of stress | Awareness              | General awareness                              |
| or Coping         |                         | Misconceptions                                 |
| strategies        |                         | Expectations from child                        |
| Attitudes         |                         | General attitude towards child                  |
| and expectations  |                         | Attitude towards management                    |
| Rearing practices |                         | General rearing practices                      |
| Social support    |                         | Practices specific to training                  |
| Global            |                         | Global family adaptation                       |

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### TABLE 2
SCORING KEYS FOR SUB-SCALES OF SECTION-I (PERCEIVED STRESS IN FAMILIES) OF FISC - MR

| Sub-scale 1: Extra inputs for care | Sub-scale 2: Decreased leisure time | Sub-scale 3: Neglect of others |
|-----------------------------------|-------------------------------------|-------------------------------|
| Scoring key:                      | Scoring key:                        | Scoring key:                  |
| 0 - Nil                           | 0 - Nil: not affected at all         | 0 - Nil: not at all           |
| 1 - Low                           | 1 - Minimal: minimally affected      | 1 - Minimal: minimally affected|
| 2 - Moderate: significant time or energy | 2 - Somewhat, somewhat affected | 2 - Somewhat: one or more family member marginally affected |
| 3 - High: significant time and energy | 3 - Definitely: definitely affected | 3 - Definitely: at least care of one family member definitely affected |
| 4 - Very high: care felt to be highly demanding throughout the day | 4 - Totally: All leisure time totally affected | 4 - Totally: several family members definitely affected in terms of amount of care provided |

| Sub-scale 4: Disturbed behaviour | Sub-scale 5: Personal distress | Sub-scale 6: Marital problems |
|----------------------------------|--------------------------------|-------------------------------|
| Scoring key:                    | Scoring key:                    | Scoring key:                  |
| 0 - Nil: not at all             | 0 - Nil: no personal distress    | 0 - Nil: no marital difficulties |
| 1 - Mild: minimal disturbed behaviour | 1 - Mild: occasional or transient periods of distress | 1 - Mild: slight differences of opinion |
| 2 - Moderate: occasional disturbance and needs extra inputs | 2 - Moderate: significant personal distress but lasting for a short duration | 2 - Moderate: differences of opinion with tiffs between the couple at times concerning/answering out of child's condition |
| 3 - Severe: frequent disturbances and severity is marked | 3 - Severe: persistent dysphoria for long periods with significant intensity | 3 - Severe: frequent fights between the couple directly/indirectly attributable to child's condition |
| 4 - Very high: very severely disturbed behaviour, persistent almost throughout the day needing extra input/care/ vigilance, constant interference with family routines | 4 - Very severe: very severe personal distress (depression, hopelessness, shamefulness anger, or guilt present almost everyday) | 4 - Very high: threat to marital relationship impending divorce/separation |

| Sub-scale 7: Other interpersonal problems | Sub-scale 8: Effects on sibs and other family worries | Sub-scale 9: Altered social life |
|-------------------------------------------|------------------------------------------------|-------------------------------|
| Scoring key:                              | Scoring key:                                    | Scoring key:                  |
| 0 - Nil: no interpersonal problems        | 0 - Nil: no demonstrable effect                  | 0 - Nil: social life not altered at all |
| 1 - Mild: differences of opinion/slight non-cooperation | 1 - Mild: slight apprehension and worry regarding others | 1 - Mild: slightly altered in terms of going out |
| 2 - Moderate: non-cooperativeness and quarrels between family members at times | 2 - Moderate: definite apprehensions and worry regarding others' future/welfare | 2 - Moderate: social contacts cut in 1 or 2 areas |
| 3 - Severe: disagreements in and fights over more than 2 areas | 3 - Severe: difficulty regarding others' future, at least on two occasions | 3 - Severe: all social contacts cut down except those of importance |
| 4 - Very high: severe disagreements in all aspects with threat to family integrity | 4 - Very high: experienced more than two instances of threats regarding other members' future (marriage, education, job etc.) | 4 - Very high: all social contacts cut down |

| Sub-scale 10: Social embarrassment | Sub-scale 11: Financial implications |
|-----------------------------------|-------------------------------------|
| Scoring key:                      | Scoring key:                        |
| 0 - Nil: no social embarrassment | 0 - Nil: no financial implications |
| 1 - Mild: anticipated apprehension regarding stigma | 1 - Mild |
| 2 - Moderate: apprehension about others' comments, stares, queries etc.; prevents the child being taken out | 2 - Moderate |
| 3 - Severe: persistent, significant apprehension leading to child being frequently being kept away from social situations | 3 - Severe |
| 4 - Very high: active efforts to keep the child constantly away from public eye in all instances | 4 - Very high |

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research staff of the project were trained in the nature, theoretical background and method of administration of the instrument. Training also consisted of practical demonstration, pilot administration and feedback. They were asked to rate the families for the study purpose following a satisfactory period of training. The families recruited for the study initially underwent a detailed evaluation by the research staff, who familiarized themselves with the nature of child's problems and the background of the families. Following a discussion with one of the authors, they went on to administer FISC-MR to the key family members (both parents in 93% of instances). They were blind to previous rating while administering the instrument during follow-ups.

Sample for standardization: As noted, the sample consisted of families of 157 subjects with mental retardation attending the mental retardation clinic of NIMHANS who fulfilled the criteria for inclusion into the main study. Subjects were of a young age (around 50% under 3 years of age), from a lower socioeconomic background, both rural and urban and with a moderate to profound degree of mental retardation (mean SQ was 24.9 in IP group and 37.3 in OP group) (Table 4).
RESULT

The results of standardization of the instrument are reported below in terms of reliability and validity. The analyses were done using SPSS ver. 6.0.

Reliability Measures: Three measures of reliability were calculated, as follows: Cronbach’s Alpha, a measure of internal consistency, calculated for the whole sample (N=155, data for 2 cases missing) separately for Section-I and Section-II, was 0.9 and 0.67 respectively. Inter-rater reliability of 3 raters for 9 families was computed. The intra-class correlation co-efficient (ICC) for any single rater was 0.81 and average reliability for all 3 raters was 0.93, indicating good inter-rater reliability. Test-retest reliability was calculated for a sub-sample of families who were evaluated at intake and again after a mean duration of 4.5 months (N=110). Pearson’s ‘r’ for Section-I was 0.71 (p<.01) and for Section-II was 0.36 (p<.01), indicating moderate to high test-retest reliability.

Measures of Validity: A factorial validation was attempted to find out whether the scale yields a small number of meaningful factors. A principal components analysis with varimax rotation followed by factor extraction with eigen values more than 1 was carried out separately for Section-I and Section-II. All the sub-scales (11 for Section-I and 9 for Section-II) were included for factor analysis. Section-I yielded two factors. On inspection of the loading, factor 1 has been labelled as socio-emotional stress and factor 2 as stress of daily care demand. Similarly, Section-II yielded 3 factors and have been named as awareness/expectations, attitudes/rearing practices and social support respectively. The loading of sub-scales on these factors have been given in table 5.

Criterion Validity: Since FISC MR is a newly developed instrument, it was decided to concurrently evaluate all the families with another well established instrument. For this purpose, Questionnaire on Resources and Stress - Short Form (QRS-SF) developed by Friedrich and his colleagues (Friedrich et al., 1983) and widely used in USA was chosen. This is a self-report Questionnaire of family stress completed by a key family member and has 52 items. The criterion or concurrent validity, as measured as Pearson’s ‘r’ between Section-I and QRS-SF score for 157 families at intake was 0.63 (p<.01), indicating moderate criterion or concurrent validity.

Construct Validity: It was hypothesized that measure of stress (total score on Section-I) should correlate with measure of mediators (total score on Section-II), which was indeed so, Pearson’s ‘r’ between Section-I total score and Section-II total score was found to be 0.51, (p<.001), indicating a moderate degree of
From the results, it is evident that the new instrument reasonably satisfies the requirements of standardisation in terms of reliability and validity. The coefficients of measures of reliability were between 0.36 to 0.9. Some loss of association may have occurred in test-retest reliability due to the possibility of intervention acting as a confounding variable. The coefficients of validity measures were between 0.51 and 0.63, indicating a reasonable degree of validity. In the factorial study, though there was some overlap of items between the factors, the overall factor loading of items revealed meaningful factors. The emergence of two factors in the Section-I viz., emotional/social and stress of care demand, is in keeping with the findings reported by others (Cmic et al., 1983; Friedrich et al., 1983). Section 2 yielded 3 factors as already mentioned, with sub-scales of awareness and expectations hanging together in the first factor, those of attitudes and rearing practices coming together in the second and social support and global adaptation in the third. These findings shed some light on the process of coping and adaptation in these families. It is also worthwhile to note that total score on Section-II (signifying the extent of coping in the families), correlated significantly with total score on Section-I (signifying the extent of stress in the families), indicating the importance of coping as a determinant of perceived stress in the families. Further refinement of the instrument based on the results of the factor analysis was not attempted in this study. However, it is worth noting that all the sub-scales loaded significantly on one or other factor, indicating that none of the sub-scales were redundant.

During the use of this instrument in the project work, we found it to be of definite value in terms of getting a better understanding of the families, to develop good rapport with them to facilitate further work and in planning targeted intervention, be it in the form of improving their coping skills, relieving their personal distress, enhancing their rearing and training practices, or improving their social life. So, the instrument, to our mind, can not only serve for research purposes but also for planning management. The instrument has already been used, either in the original or modified form in 3 postgraduate dissertations and experience thereof lends additional support to usefulness of the instrument (Gaekwad, 1993; Anand, 1996; Rathnasabapathy, 1996). The training requirements for using this instrument would include (i) experience of having worked with several families of children with mental retardation, (ii) a reasonable understanding of the structure and rationale of the instrument, and (iii) few pilot administrations under an experienced supervisor.

One limitation of this instrument is that it has been developed primarily for families of children with severe forms of mental retardation and therefore best suited for use in this group. However, the utility with families of older subjects with milder forms of mental retardation is yet to be tested and perhaps some modifications might be needed for this purpose, as the worries and concerns of parents and care-givers in this population could be different, for instance issues concerning family life cycle, sexuality, marriage, guardianship and vocational habilitation. Another limitation of the instrument is that it takes approximately 45 minutes to administer, further refinements may be warranted to prepare a shorter version for wider clinical use.

The recent socio-cultural changes in India appear to have had an adverse influence of increasing the stress faced by the families in caring for individuals with mental retardation, and hence calls for greater professional involvement and support. The availability of this instrument hopefully will be a small step in furthering the services and research in this area.

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NOTE
The instrument is available on request for the interested readers from the first author.

REFERENCES

Anand, J.(1996) Stress and coping among the care givers of the moderately retarded children and young adults. Dissertation submitted to the Dept. of Psychiatric Social Work, NIMHANS. (unpublished)

Beresford,B.A.(1994) Resources and strategies : how parents cope with the care of a disabled child. Journal of Child Psychology & Psychiatry, 35, 171-209.

Bhatti,R.S., Channabasavanna,S.M. & Prabhu,L.R.(1985) A tool to study the attitudes of parents towards the management of mentally retarded children. Child Psychiatry Quarterly, 18, 35-43.

Byrne,E.A. & Cunningham,C.C.(1985) The effects of mentally handicapped children on families - a conceptual review, Journal of Child Psychology and Psychiatry, 26, 846-864.

Crnic, K.A., Friedrich, W.N. & Greenberg, M.T.(1983) Adaptation of families with mentally retarded children : A model of stress, coping and family ecology. American Journal of Mental Deficiency. 88, 125-138.

Cunningham,C.(1985) Training and education approaches for parents of children with special needs. British Journal of Medical Psychology, 58, 285-305.

Davis & Rushton,R.(1991) Counselling and supporting parents of children with developmental delay : A research evaluation. Journal of Mental Deficiency Research, 35, 89-112.
of Life Stress, Cognition and Health, (Eds.) Fisher, S. & Reason, J. John Wiley.

Koller, H., Richardson, S.A. & Katz, M. (1992) Families of children with mental retardation: comprehensive view from an epidemiologic perspective. American Journal of Mental Retardation, 93, 315-332.

Narayan, J., Madhavan, T. & Prakasham, B.B. (1993) Factors influencing the expectations of parents for their mentally retarded children. Journal of Intellectual Disability Research, 37, 161-168.

Orr, R.R., Cameron, S.J. & Day, D.M. (1991) Coping with stress in families with children who have mental retardation: an evaluation of the double ABCX model. American Journal of Mental Retardation, 95, 440-450.

Peterson, P. (1984) Effects of moderator variables in reducing stress outcome in mothers of children with handicaps. Journal of Psychosomatic Research, 28, 337-344.

Rathnasabapathy, B. (1996) Stress and coping of parents with mentally handicapped children. Dissertation submitted to the Dept. of Nursing, NIMHANS. (unpublished)

Seshadri, M. (1983) Impact of the mentally handicapped child on the family. Indian Journal of Clinical Psychology, 10, 473-478.

Sethi, B.B. & Sitholey, P. (1986) A study of the time utilization, perception of burden and help expectation of mothers of urban mentally retarded children. Indian Journal of Social Psychiatry, 2, 25-44.

Shearer, A. (1977) The integration of the mentally retarded individual in society. In: Proceedings of the Third Asian Conference on Mental Retardation, (Ed) Prabhu, G.G., Bangalore, 100-110.

Tunali, B. & Power, T.G. (1993) Creating satisfaction: a psychological perspective on stress and coping in families of handicapped children. Journal of Child Psychology & Psychiatry, 34, 945-957.

Wig, N.N., Mehta, M. & Sahasi, G. (1985) A study of time utilization and perceived burden of mentally handicapped child in joint and nuclear families. Indian Journal of Social Psychiatry, 1, 251-281.

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