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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 the 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 in family	Daily care stress	Extra inputs for care
		Decreased leisure time
		Neglect of others
		Disturbed behaviour
	Family emotional stress	Personal distress
		Marital problems
		Other interpersonal problems
		Effects on sibs & other worries
	Social stress	Altered social life
		Social embarrassment
	Financial stress	Financial implications
Mediators of stress or Coping strategies	Awareness	General awareness
		Misconceptions
	Attitudes and expectations	Expectations from child
		General attitude towards child
		Attitude towards management
	Rearing practices	General rearing practices
		Practices specific to training
	Social support	Social support
	Global	Global family adaptation

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

Sub-scale 1: Extra inputs for care Scoring key : 0 - Nil 1 - Low 2 - Moderate : significant time or enegy 3 - High : significant time and energy 4 - Very high : care felt to be highly demanding throughout the day	Sub-scale 2: Decreased leisure time Scoring key . 0 - Nil : not affected at all 1 - Minimal : minimally affected 2 - Somewhat . somewhat affected 3 - Definitely ; definitely affected 4 - Totally : All leisure time totally affected	Sub-scale 3: Neglect of others Scoring key : 0 - Nil: not at all 1 - Minimal : minimally affected 2 - Somewhat : one or more family member marginally affected 3 - Definitely . at least care of one family member definitely affected 4 - Totally : several family members definitely affected in terms of amount of care provided
Sub-scale 4 : Disturbed behaviour Scoring key : 0 - Nil : not at all 1 - Mild : minimal disturbed behaviour 2 - Moderate : occasional disturbance and needs extra inputs 3 - Severe : frequent disturbances and severity is marked 4 - Very high : very severely disturbed behaviour, persistent almost throughout the day needing extra input/care/ vigilance; constant interference with family routines	Sub-scale 5 : Personal distress Scoring key : 0 - Nil : no personal distress 1 - Mild : occasional or transient periods of distress 2 - Moderate : significant personal distress but lasting for a short duration 3 - Severe : persistent dysphoria for long periods with significant intensity 4 - Very severe : very severe personal distress (depression, hopelessness, shamefulness anger, or guilt present almost everyday).	Sub-scale 6 : Marital problems Scoring key : 0 - Nil: no marital difficulties attributable to child's condition 1 - Mild : slight differences of opinion 2 - Moderate . differences of opinion with tiffs between the couple at times concerning/arising out of child's condition 3 - Severe : frequent fights between the couple directly/indirectly attributable to child's condition 4 - Very high: threat to marital relationship impending divorce/separation
Sub-scale 7 : Other interpersonal problems Scoring key : 0 - Nil : no interpersonal problems 1 - Mild : differences of opinion/slight non-cooperation 2 - Moderate :non-cooperativeness and quarrels between family members at times 3 - Severe : disagreements in and fights over more than 2 areas 4 - Very high : severe disagreements in all aspects with threat to family integrity	Sub-scale 8 : Effects on sibs and other family worries Scoring key : 0 - Nil : no demonstrable effect 1 - Mild : slight apprehension and worry regarding others 2 - Moderate : definite apprehensions and worry regarding others' future/welfare 3 - Severe : difficulty regarding others' future, at least on two occasions 4 - Very high : experienced more than two instances of threats regarding other members' future (marriage, education, job etc.)	Sub-scale 9 : Altered social life Scoring key : 0 - Nil : social life not altered at all 1 - Mild :slightly altered in terms of going out 2 - Moderate : social contacts cut in 1 or 2 areas 3 - Severe : all social contacts cut down except those of importance 4 - Very high : all social contacts cut down
Sub-scale 10 : Social embarrassment Scoring key : 0 - Nil : no social embarrassment 1 - Mild : anticipated apprehension regarding stigma 2 - Moderate : apprehension about others' comments, stares, queries etc.; prevents the child being taken out 3 - Severe . persistent, significant apprehension leading to child being frequently being kept away from social situations 4 - Very high . active efforts to keep the child constantly away from public eye in all instances	Sub-scale 11 : Financial implications Scoring key : 0 - Nil : no financial implications 1 - Mild 2 - Moderate 3 - Severe 4 - Very high	

TABLE 3
SCORING KEYS FOR SUB-SCALES OF SECTION-II (MEDIATORS OR COPING STRATEGIES) OF FISC - MR

Sub-scale 12 : General awareness about mental retardation	Sub-scale 13 : Misconceptions	Sub-scale 14 : Expectations from child
Scoring key : 1 - Largely adequate : Highly knowlegeable or reasonable ideas about nature, cause, prognosis and treatment 2 - Adequate : know enough in 2 areas 3 - Slightly inadequate : aware of only one aspect of the problem, but not clearly 4 - Highly inadequate: very poor knowledge in all areas	Scoring key : 1 - No misconceptions 2 - Misconceptions almost absent 3 - Misconceptions present 4 - Misconceptions present to a large extent	Scoring key : 1 - Largely appropriate 2 - Mildly appropriate 3 - Moderately inappropriate 4 - Highly inappropriate
Sub-scale 15 : Attitudes towards child as person and family member	**Sub-scale 16 : Attitudes towards child management**	**Sub-scale 17 : General rearing practices**
Scoring key : 1 - Most favorable 2 - Favorable 3 - Moderately unfavorable 4 - Most unfavorable	Scoring key : 1 - Most favorable 2 - Favorable 3 - Moderately unfavorable 4 - Most unfavorable	Scoring key : 1 - Most favorable 2 - Favorable 3 - Moderately unfavorable 4 - Most unfavorable
Sub-scale 18 : Rearing practices specific to training	**Sub-scale 19 : Social support**	**Sub-scale 20 : Global rating of family adaptation**
Scoring key : 1 - Most favorable 2 - Favorable 3 - Moderately unfavorable 4 - Most unfavorable	Scoring key : 1 - Best or excellent social support : high level social support available utilized maximally 2 - Adequate : Several instances of actual social support 3 - Somewhat inadeuqate : inadeuqate in terms of availability and/or use 4 -Very little or no social support available/utilized	Scoring key : 1 - Extremely well adapted : highly satisfactory coping 2 - Adequate adapted 3 - Inadeuqate adapted 4 - Very poor coping/adaptation

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 moderate to profound degree of mental retardation (mean SQ was 24.9 in IP group and 37.3 in OP group) (Table 4).

TABLE 4
SUMMARY OF SOCIO-DEMOGRAPHIC CHARACTERSTICS OF THE GROUPS

Variables	IP group	OP group
Sample size	75	82
Mean age in months	43.0	41.3
Sex(percent males)	59	60
Residence (percent urban)	21	57
Social class(percent class IV+V)	97	93
Family income (percent less than Rs 500 per month)	75	57

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.

TABLE 5
FACTOR ANALYSIS OF F.I.S.C. - M.R.

A : Factor structure of Section-I (perceived stress)

Factors	Sub-scales	Loading
1. Emotional/social stress (52.6%)[a]	Other interpersonal problems	0.792
	Personal distress	0.758
	Financial stress	0.713
	Marital problems	0.688
	Social embarrassment	0.678
	Altered social life	0.645
	Effect on sibs	0.629
2. Stress of care demand (11.1%)	Disturbed behaviour	0.793
	Extra inputs for care	0.794
	Decreased leisure time	0.781
	Neglect of others	0.757
	Effect on sibs	0.458
	Altered social life	0.423
	Social embarrassment	0.408

B : Factorial structure of Section-II (mediators or coping strategies)

Factors	Sub-scales	Loading
1. Awareness and expectations (31.3%)	General awareness	0.822
	Misconceptions	0.756
	Expectations	0.714
2. Attitudes and rearing practices (21.4%)	Rearing practices-general	0.825
	Rearing practices-specific	0.797
	Attitudes - general	0.63
	Attitudes to management	0.625
3. Social support (11.6%)	Social support	0.767
	Global adaptation	0.685
	Attitudes - general	0.548
	Attitudes to management	0.403

Note : Only those items with a loading of 0.4 or more have been included

a : Numbers in brackets are the percentage of variance explained by the factors.

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

evidence for construct validity.

DISCUSSION

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 (Crnic 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.

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