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The Burden on the Family of a Psychiatric Patient: Development of an Interview Schedule

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Summary: This paper describes the construction of a semi-structured interview schedule to assess the burden placed on families of psychiatric patients living in the community. The Indian population studied found their sick relatives most burdensome in respect of the effect of the illness on family finances, the disruption of normal family activities and the production of stress symptoms in family members other than the patient. The inter-investigator reliability of the interview schedule proved to be high.

During the last decade or so there has been an increasing trend all over the world towards treating psychiatric patients in their family settings and in their own community, rather than in mental hospitals. Even where the patient needs to be in hospital in the acute phase of his illness, the tendency today is to discharge him into the community as soon as possible

While the policy of treating mental patients at home reduces the load on hospitals, and may help early recovery and prevent chronic handicap (Tooth and Brooke, 1961), it perhaps increases the burden on the family and the community. However, most countries have launched large-scale community mental health programmes without assessing the burden families may have to face and the possible damage to family members. In this context Carstairs (1968) has aptly pointed out that "objective evaluations of the effectiveness of new procedures have seldom, if ever, preceded their gaining currency in psychiatric practice".

So far very few systematic attempts have been made to assess the type and degree of burden placed on the families of patients treated at home. Earlier workers, studying the discharge of chronic patients into the community, attempted to assess social burden by readmission of the patient or relapse in his symptoms. Mandelbrote and Folkard (1961a; b) and Wing *et al* (1964) pointed out that the stress caused to families by patients' disturbing behaviour was an important factor in determining the patients' acceptance by the families, or alternatively their readmission to mental hospital. Subsequent workers such as Grad and Sainsbury (1963) and Hoenig and Hamilton (1966) tried to assess this aspect in greater detail. Grad and Sainsbury (1963) made headway in assessing the burden felt by patients' families on a three-point scale. They tested the scale for reliability and reported 75 per cent agreement between three interviewers. Hoenig and Hamilton (1966) added another dimension to this assessment by trying to differentiate between the objective and subjective burdens felt by family members.

No such work has been reported in an Indian setting. The economic and cultural conditions in India being vastly different from those of the Western world, the areas of family burden and the pattern of accepting or rejecting patients may be entirely different. We have therefore attempted to develop a standardized method of assessing the burden on the family.

Method of Construction

As a first step a free unstructured interview was conducted with one relative of each of 40 patients coming to the out-patient clinic. The interview focussed on various areas of burden the families might have experienced due to the patients' illness. They were encouraged to be objective and concrete in their responses. For instance, if they said they had experienced financial burdens they were asked to give details of expenses on drugs and travel, of loss of pay and so on. If they said their leisure was curtailed, they were asked how they had spent it previously, and in what manner and to what extent a particular leisure activity was now curtailed. These interviews were recorded verbatim. Subsequently their content was analysed in terms of the various categories of burden experienced.

Twenty-four new interviews were then recorded, and the records distributed among six colleagues

working in the psychiatric field. These six people were asked to pick out items of burden and to group them into general categories identified by themselves. The categorization thus collected was compared with the categorization prepared by the investigator earlier. It was found that both categorizations were broadly similar, although different terms were used—e.g. the area of financial burden was variously termed 'economic difficulties', 'expenses' and 'financial burden'. Similarly, the area of burden in leisure activities was termed 'recreational handicap', 'leisure time curtailment', etc. Apart from such terminological differences, three colleagues had defined some items of burdensome behaviour which were not noted by the investigator or by the other three colleagues.

The 24 possible items thus picked out were arranged in six different categories, making use of the common item wording noted in the interview records. Each item was then converted into a question for the definitive interview schedule. Guidelines for assess-

TABLE I

Category and extent of burden and inter-rater reliability

Category of burden	Items included and number out of 20 interviewees rating burden as severe, moderate, nil	Inter-rater reliability coefficient (d.f. = 2 throughout)
1. Financial	Loss of patient's income (7, 0, 13)	0.99
	Loss of income of other family members (7, 5, 8)	0.99
	Expenses of patient's illness (12, 6, 2)	0.99
	Expenses due to other necessary changes in arrangements (4, 10, 6)	0.94
	Loans taken (14, 4, 2)	0.97
	Any other planned activity needing finance, postponed (2, 3, 15)	0.95
2. Effect on family routine	Patient not attending work, school, etc. (9, 3, 8)	0.95
	Patient unable to help in household duties (14, 4, 2)	0.91
	Disruption of activities due to patient's illness and care (12, 8, 0)	0.88
	Disruption of activities due to patient's irrational demands (10, 5, 5)	0.96
	Other family members missing school, meals, etc. (2, 4, 14)	0.97
3. Effect on family leisure	Stopping of normal recreational activities (5, 7, 8)	0.87
	Absorption of another member's holiday and leisure time (9, 9, 2)	0.93
	Lack of participation by patient in leisure activity (7, 4, 9)	0.93
	Planned leisure activity abandoned (1, 1, 18)	0.89
4. Effect on family interaction	Ill effect on general family atmosphere (6, 11, 3)	0.94
	Other members arguing over the patient (2, 4, 14)	0.99
	Reduction or cessation of interaction with friends and neighbours (5, 2, 13)	0.97
	Family becoming secluded or withdrawn (6, 3, 11)	0.95
	Any other effect on family or neighbourhood relationships (5, 3, 12)	0.96
5. Effect on physical health of other family members	Physical illness in any family member (3, 5, 12)	0.98
	Any other adverse effect on others (0, 3, 17)	0.90
6. Effect on mental health of other family members	Any member seeking professional help for psychological illness (1, 2, 17)	0.87
	Any member becoming depressed, weepy, irritable (10, 8, 2)	0.94

Details of interview questions are shown in the Appendix.

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ment of the level of burden for that particular item were provided. Each item could be recorded as absent (scored zero), moderate (scored 1) or severe (scored 2). This constituted the structured interview schedule.

Reliability of the Interview Schedule

The reliability of the interview schedule was examined by the following method. One relative of each of 20 patients was interviewed by three raters, who sat together with one of them putting the questions to the relative. Each rater scored every answer individually without consulting the others, making his or her own assessment of the burden felt by the relative. The ratings were then compared and the differences were examined for statistical significance by determining a reliability coefficient, the method being based on two-way analysis of variance (Winer, 1962).

The reliability score was above 90 per cent for 20 items, and between 87 per cent and 89 per cent for the other four. As can be seen, this is extremely high. The details of scores obtained on individual items are shown in the table below.

It will be noted that our sample of relatives found their heaviest burdens were financial loss, disruption of normal family activities and the production of stress symptoms in family members, in that order.

Validation: In order to test the validity of the instrument, the subjective burden as reported by each relative was scored on a similar three-point scale. It was considered that if the overall objective burden assessed by the raters was highly correlated with the subjective burden as reported by the relative, it would be an indirect, though not an absolute, method of measuring the validity of the instrument. In fact, the correlation coefficient between the mean total scores on each item as assessed by the professional raters and by the relatives was 0.72 (d.f. = 1), which we considered sufficiently high.

The Uses of the Interview Schedule

The semi-structured interview schedule can be used in a variety of studies, e.g. in comparing different treatment situations for similar illness, or in comparing the effect on the family of different types of illness. It was originally designed to be used in a study comparing home treatment with hospital admission for schizophrenic patients. This study has now been completed. The schedule has given consistent results, and has also been found to have a high correlation with the social functioning of the patients. The data are under preparation.

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Appendix

The Interview Schedule

Instructions to relative: We are trying to assess the various difficulties felt by the family of a psychiatric patient, and will ask you a few questions about these. Please do not hesitate to express your true feelings.

Instructions to raters: Please interview the relative on the following guidelines. You may probe further in order to assess a particular item if you feel it necessary. During the interview note your rating for each general category, as well as for each individual item, on a three-point scale, viz

Severe burden —2
Moderate burden—1
No burden —0

After completing the interview please assess the burden on the family as a whole, and give the rating on a similar three-point scale.

A. *Financial burden*

1. Loss of patient's income: (Has he lost his job? Stopped doing the work which he was doing before? To what extent does it affect the family income?)
2. Loss of income of any other member of the family due to patient's illness: (Has anybody stopped working in order to stay at home, lost pay, lost a job? To what extent are the family finances affected?)
3. Expenditure incurred due to patient's illness and treatment: (Has he spent or lost money irrationally due to his illness? How much has this affected the family finances? How much has been spent on treatment, medicines, transport, accommodation away from home and so on? How much has been spent on other treatments such as temples and native healers? How has this affected family finances?)

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4. Expenditure incurred due to extra arrangements: (For instance, any other relative coming to stay with the patient; appointing a nurse or servant; boarding out children. How have these affected the family finances?)
5. Loans taken or savings spent: (How large a loan? How do they plan to pay it back? How much does it affect the family? Did they spend from savings? Were these used up? How much is the family affected?)
6. Any other planned activity put off because of the financial pressure of the patient's illness: (For instance, postponing a marriage, a journey or a religious rite. How far is the family affected?)

B. *Disruption of routine family activities*
1. Patient not going to work, school, college, etc: How inconvenient is this for the family?
2. Patient not helping in the household work: How much does this affect the family?
3. Disruption of activities of other members of the family: (Has someone to spend time looking after the patient, thus abandoning another routine activity? How inconvenient is this?)
4. Patient's behaviour disrupting activities: (Patient insisting on someone being with him, not allowing that person to go out, etc? Patient becoming violent, breaking things, not sleeping and not allowing others to sleep? How much does it affect the family?)
5. Neglect of the rest of the family due to patient's illness: (Is any other member missing school, meals, etc? How serious is this?)

C. *Disruption of family leisure*
1. Stopping of normal recreational activities: (Completely, partially, not at all? How do the family members react?)
2. Patient's illness using up another person's holiday and leisure time: (How is this person affected by it?)
3. Patient's lack of attention to other members of the family, such as children, and its effect on them.
4. Has any other leisure activity had to be abandoned owing to the patient's illness or incapacity—e.g. a pleasure trip or family gathering? How do the family members feel about it?

D. *Disruption of family interaction*
1. Any ill effect on the general atomsphere in the house: (Has it become dull, quiet? Are there a lot of misunderstandings, etc? How do the family members view this?)
2. Do other members get into arguments over this (for instance over how the patient should be treated, who should do the work, who is to blame, etc)? How are they affected?
3. Have relatives and neighbours stopped visiting the family or reduced the frequency of their visits because of the patient's behaviour or the stigma attached to his illness? How does the family feel about this?
4. Has the family become secluded? Does it avoid mixing with others because of shame or fear of being misunderstood? How do the members feel about this?
5. Has the patient's illness had any other effect on relationships within the family or between the family and neighbours or relatives—e.g. separation of spouses, quarrels between two families, property feuds, police intervention, embarrassment for family members, etc? How does the family feel about it?

E. *Effect on physical health of others*
1. Have any other members of the family suffered physical ill health, injuries, etc due to the patient's behaviour? How has this affected them?
2. Has there been any other adverse effect on health (e.g. someone losing weight or an existing illness being exacerbated)? How severe is it?

F. *Effect on mental health of others*
1. Has any other family member sought help for psychological illness brought on by the patient's behaviour (for instance by the patient's suicide bid, or his disobedience, or worry apout his future)? How severe is this?
2. Has any other member of the family lost sleep, become depressed or weepy, expressed suicidal wishes, become excessively irritable, etc? How severely?

Finally, is there any other burden on the family about which we have not asked you? If so, what is it? How badly does it affect you?

Subjective burden on the family: This is to be assessed by asking the following standard question and scoring the relative's answer: How much would you say you have suffered owing to the patient's illness—severely, a little or not at all?

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