ABSTRACT

The family is a major source of support for the mentally ill in India. Although Indian families show tremendous resilience in caring for their ill relatives, they experience a lot of physical and emotional distress. The burden assessment schedule (BAS) aims to assess both objective and subjective burden experienced by the primary care givers of chronic mentally ill patients. Step-wise ethnographic exploration has been used in the development of this 40 item instrument. Reliability exercises have been carried out throughout the development of this schedule. Criterion validity has been established by comparing with another standardized instrument to assess burden, which has been developed in India.

Key Words: Burden assessment, subjective, objective, caregivers, chronic mentally ill

The subject of burden has become significant with the emergence of de-institutionalisation and the practice of community psychiatry. Several descriptions of the concept have been attempted. Treudley (1946) has referred to burden as the consequences for those in close contact with a severely ill psychiatric patient. Platt (1985) has presented a more elaborate definition which states that, "burden refers to the presence of problems, difficulties or adverse events that affect the lives of psychiatric patients". Although the entire family experiences the burden of the illness, the responsibility of caring is often shouldered by one "primary care giver" who experiences physical and emotional burden.

The seminal work of Grad & Sainsbury (1963) provided the distinction between "objective" and "subjective" burden. Objective burden is used in reference to the physical burden of care consequent to behavioral changes of the mentally ill individual and the social effect on the caregiver's daily life, such as changes in family relations, employment and health. Subjective burden refers to the emotional reaction of the caregivers, including perception of strain, reduced morale, anxiety and depression (Rabins et al., 1982). Several systematic efforts to assess the extent and nature of burden experienced by families have been extensively reviewed (Platt, 1985, Schene, 1990).

In his critical review of instruments measuring burden, Platt (1985) while differentiating between objective and subjective burden noted that one aspect of objective burden was based on subjective feelings of the respondent which were judged better by the investigators. While most scales rate each area of burden in terms of its objective dimensions, subjective burden was often measured by means of one global scale (Hoenig & Hamilton, 1986, Pai & Kapur.)
In many cases, the items of the various instrument were not ethnographically derived. Although Pai & Kapur's scale had items from some unstructured interviews, its' measurement of subjective burden is not extensive and confined to one or two questions. Also, many of the burden instruments developed in the west are not culturally suited to the Indian population.

Indian studies on this subject have been spread out over the last two to three decades. Pai & Kapur (1981) observed that in schizophrenic patients living at home, social dysfunction, psychopathology and burden were positively correlated. Nijhawan et al. (1985) reported a higher burden in the areas of family routine family interaction and health of family members in the families of schizophrenic patients. Chandrasekar et al. (1991) reported higher scores in the areas of family activities and family interaction in an urban sample as compared to a rural sample.

The Schizophrenia Research Foundation has been involved in the rehabilitation of chronic schizophrenic patients with emphasis on including caregivers in the treatment programme. Our experience in working with families have revealed the impact of the family’s emotion on the quality of care giving. Perceptions of caregivers have also reflected the subjectively felt burden in caring for the mentally ill relative. We therefore felt it necessary to develop an instrument to assess subjective burden using the process of "stepwise ethnographic exploration" (Sell & Nagpal, 1992). This paper reports on the development and standardisation of the Burden Assessment Schedule (BAS).

MATERIAL AND METHOD

DEVELOPMENT OF THE INSTRUMENT

First Phase: Qualitative Phase

Study locale: The study was undertaken at two psychiatric facilities. The out patient facility at the Department of Psychiatry, Government General Hospital, Chennai, caters to all varieties of mental disorders. The Schizophrenia Research Foundation, Chennai, provides outpatient treatment and rehabilitation services to patients suffering from schizophrenia.

Study sample: Chronic mentally ill patients attending the out patients services at the two facilities were chosen for the study. They were suffering from schizophrenia or mood disorders (Major depression) according to DSM -III R criteria (APA, 1982), with a mean duration of illness of 9.04 years (sd 6.5). They were included if their principal caregivers fulfilled the following criteria: (i) continuous caregiving for the last two years and (ii) spending a lot of time and emotion in the care of the patient.

Stepwise ethnographic exploration: Is a qualitative technique that was used in the development of the BAS. Ethnography is a branch of anthropology that deals with the study of, description of a culture. Its primary goal as stated by Malinowski (1922) is to "grasp the native's point of view, his relation to life, to realise his vision of his world". Over the years, a new appreciation for this unique approach to understand human behaviour has emerged resulting in its application and adaptation in diverse naturalistic setting by professionals from different disciplines.

Our goal was to develop an instrument that would assess subjective burden as perceived by caregivers of chronic mentally ill patients. Stepwise ethnographic exploration is an iterative process that enabled us to derive items (questions) that were contextual and reflected not the opinions of the researchers but that of the caregivers themselves.

The process (fig. 1) to start with involved conducting unstructured interviews on the subject of burden with caregivers of chronic schizophrenic patients. Care was taken to allow issues to emerge from the respondent during the interview. Thirty such interviews were initially carried out. All interviews were carried out in the local language, Tamil. We (i.e. all the authors) then met regularly and exchanged our
experiences with the aim of arriving at a consensus on the various domains of subjective burden like finance, occupation, physical problems, emotional and psychosocial aspects, social relations, family, marriage and sexual relations, leisure etc. Based on these unstructured interviews, a semistructured interview guide was prepared which enabled the interviews to be more focused this time. With the help of this interview guide, semistructured interview, were conducted on a fresh sample of 75 caregivers of chronic schizophrenic patients. At the end of this stage we once again met to discuss our findings. When we each found that our information was, becoming repetitive, no new issues were emerging and that the respondents had all endorsed the domains of burden, we decided to stop doing further interviews. This endorsement during successive interviews helped establish the relevance of these domains to the assessment of subjective burden.

To further counteract threats to the validity of the information obtained, focus groups were held with caregivers of chronic mentally ill patients on the subject of burden. These were carefully moderated group discussions that were used to examine the meaningfulness and comprehensiveness of the domains of burden that had emerged during the interviewing stage. The number of participants in each group ranged between 8-10 and comprised a mix of both men and women who were all primary caregivers of schizophrenic patients. Four focus groups were conducted and the data from them were largely confirming of these domains thereby validating their relevance to the assessment of burden.

This iterative process of conducting several interviews followed by focus group discussions provided considerable endorsement of the burden domains. Then began the process of itemization or framing the questions that would constitute the instrument. The focus group transcript and the interview notes contained many valuable suggestions that helped in framing the questions. The draft instrument thus established was then subjected to the assessment of its psychometric properties.

**Second Phase: Development of the Structured Instrument**

The written transcripts of the interviews and the focus group discussions were carefully studied for framing items reflecting the views of caregivers. Care was taken to use simple language that could be easily understood by the common man. About 100 such questions were initially generated. The deletion of ambiguously worded, repetitive and irrelevant questions resulted in a 65-item questionnaire.

**Third Phase: Qualitative Phase**

Factorial configuration: The 65-item draft questionnaire was administered on 250 caregivers, fulfilling the inclusion criteria. The data obtained was subjected to factor analysis with varimax rotation. Items with loadings below 0.4 were discarded. The questionnaire was reduced
| Factors                      | Items                                                                 | Loadings |
|-----------------------------|----------------------------------------------------------------------|----------|
| I. Spouse related           | Spouse helps with family responsibilities                            | .93692  |
|                             | Spouse satisfies sexual needs                                        | .91211  |
|                             | Spouse affection                                                      | .86435  |
|                             | Quality of marital relationship                                       | .72431  |
|                             | Help from health professionals                                       | .49669  |
| II. Physical and mental     | Caregiver anxious, depressed                                         | .88741  |
| Health                      | Caregiver feels tired, exhausted                                      | .76354  |
|                             | Caregiver feels frustrated                                            | .66946  |
|                             | Caregiver's health affected                                           | .65715  |
|                             | Caregiver feels isolated, lonely                                      | .58531  |
|                             | Increase in work load                                                 | .50421  |
| III. External support       | Family appreciates caregiver's effort                                 | .79257  |
|                             | Relatives appreciates caregiver's effort                              | .73361  |
|                             | Caregiver able to care for others                                     | .68149  |
|                             | Support from family                                                   | .64442  |
|                             | Friends appreciate                                                   | .60712  |
| IV. Caregiver's routines    | Caregiver has time to look after his health                           | .85556  |
|                             | Caregiver has sleep disturbances                                      | .65148  |
|                             | Caregiver able to relax                                               | .56185  |
|                             | Satisfied with patient looking after himself                          | .54430  |
| V. Support of patient       | Current financial resources to care for patients                      | .79306  |
|                             | Reduce time spent with patient                                        | .69561  |
|                             | Caregiver forced to work to support the patient                       | .49680  |
| VI. Taking responsibility   | Care giver meets patients financial needs                            | .73557  |
|                             | Concern about future finances                                        | .71382  |
|                             | Sharing problems with others                                          | .61787  |
|                             | Caregiver responsible for all needs of patient                        | .41420  |
| VII. Other relations        | Relationship with other family affected                               | .79775  |
|                             | Disruption of family stability                                        | .79956  |
|                             | Relationship with friends affected                                    | .56125  |
| VIII. Patient's behaviour   | Care giver feels there is no solution                                 | .75802  |
|                             | Patient causes disturbances at home                                   | .73132  |
|                             | Patients unpredictable behaviour                                       | .73526  |
|                             | Caregiver unable to take up a job                                     | .69680  |
| IX. Care giver's strategy   | Support from friends                                                  | .76153  |
|                             | Care giver compensates for patient's shortcomings                     | .74559  |
|                             | Care giver done more than patient to improve situation                | .40284  |
|                             | Care giver seeks temporary separation                                 | .38676  |
to a 40-item instrument, which was administered on a sample of 200 caregivers. The data from these respondents was again subjected to the same factorial analysis. This time the analysis yielded 9 factors (table 1). Almost all the items that loaded high on each of the retained factors showed a good degree of common content thereby, permitting a meaningful interpretation. Based on their item content the factors were named; spouse-related, physical & mental health, external support, caregiver's routines, support to patients, taking responsibility, other relationship, patients behaviour and caregiver's strategies.

RELIABILITY

Inter-rater reliability exercises were conducted on a sample of primary caregivers of chronic mentally ill patients before commencement of the quantitative phase. The inter-rater reliability between the interviewers was good (Kappa, 0.80). Reliability exercises were also done for every 10th interview throughout the process of instrument development and standardisation to ensure that reliability was maintained.

VALIDITY

Face validity: The draft instrument was given to a team of mental health professionals and their opinions were sought whether at face value the instrument appeared to be assessing the desired qualities. All the mental health professionals agreed with respect to the relevance of the items in measuring burden.

Content validity of the instrument was established through a logical process wherein we first defined burden in terms of domains that were arrived at consequent to the qualitative work. Items were drafted so as to ensure that the instrument sampled information from these domains.

Criterion validity was established by comparing the new instrument with the family burden schedule (FBS) (Pai & Kapur, 1981). Both the FBS and the newly developed burden instrument were administered on a sample of 60 primary caregivers of chronic mentally ill person independently by two raters. Correlation between the two instruments was found to be good for most of the items and ranged between .71 and .82. There were a few subjective items in the instrument which had no corresponding items in the FBS and so could not be correlated.

The final instrument, therefore, has 40 items rated on a 3-point scale, marked 1-3. The responses would be "not at all, to some extent or very much". Depending on the way the questions are framed, the point for each of these responses would vary.

DISCUSSION

Burden as a research construct has been examined in diverse samples and conceptualised in several ways (Stephens & Kinney, 1989). The need to tap the subjective component of burden in addition to the objective, has assumed importance because of the tremendous impact it exerts on the quality of life of the individual. Little is known about the subjective levels of burden perceived by Indian families caring for a chronic mentally ill person. The development of the BAS is significant, as it has helped interpret and understand burden in the cultural context. The distinctive feature in the development of the BAS is the use of a combination of qualitative and quantitative methods. The "stepwise ethnographic exploration" (Sell & Nagpal, 1992) involves a thorough conceptual mapping of the subject under study before establishing individual items. The qualitative techniques of indepth interviews and focus group discussion have provided a rich source of information, entirely reflecting the perceptions of the study population and not that of the researchers. The indepth interviews gave valuable insights into the functioning of the Indian family support system and important clues into the way the items needed to be worded so as to be most
pertinent. The focus groups that were conducted subsequent to the indepth interviews helped to validate the comprehensiveness and applicability of the broad domains of burden that were derived from the interview. We were therefore able to assure its relevance to the cultural milieu. Use of this method, ensured a thorough discussion into the subject of burden thereby enhancing its content validity.

During the course of the ethnographic exploration we discovered that even though many families were finding it extremely difficult and stressful to look after the patient, most refused to consider the idea of a separation, involving sending the ill member to an institution or a home. A strong sense of hurt and responsibility particularly among women, coupled with the fear of rejection by society, appeared to act as a powerful deterrent.

The BAS has been developed from the perspective of the chronic mentally ill and consequently would be most applicable to this group. It could be conceptualised that this instrument may be able to predict burnout in persons caring for a chronically mentally ill person. With nuclear families rapidly replacing joint families, especially in urban areas and with increasing number of women in the work force, caring for the mentally disabled member is often shouldered by a single caregiver. This naturally increases the possibilities of burn out, which have to be recognised early for effective intervention. We believe that, by measuring both subjective and objective burden, the BAS will be sensitive enough to detect early symptoms of burnout.

While the BAS may be relevant and applicable to measuring burden in other chronic illness groups, a good deal more research will need to be carried out before this could be established with certainty.

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Appendix: Burden Assessment Schedule

1. Is the current financial position adequate to look after the patient?
   Not at all 3
   To some extent 2
   Very much 1

2. Are you concerned that you are largely responsible to meet the patient's financial need?
   Not at all 1
   To some extent 2
   Very much 3

3. Does the patient's future financial situation worry you?
   Not at all 1
   To some extent 2
   Very much 3

4. Has your family's financial situation worsened since the patient's illness?
   Not at all 1
   To some extent 2
   Very much 3

5. Is the patient's illness preventing you from looking for a job?
   Not at all 1
   To some extent 2
   Very much 3

6. Do you feel forced into going to work to support the patient?
   Not at all 1
   To some extent 2
   Very much 3

7. Does the patient's illness affect your efficiency at work (at home/at work place)?
   Not at all 1
   To some extent 2
   Very much 3

8. Are you satisfied with the way the patient looks after himself?
   Not at all 3
   To some extent 2
   Very much 1

9. Do you feel you have to take the responsibility of ensuring that the patient has everything he needs?
   Not at all 1
   To some extent 2
   Very much 3

10. Do you think you have to compensate the patient's shortcomings, in general?
    Not at all 1
    To some extent 2
    Very much 3

11. Does support from your family help in caring for the patient?
    Not at all 1
    To some extent 2
    Very much 3

12. Does the patient cause disturbances in the home?
    Not at all 1
    To some extent 2
    Very much 3

13. Are you able to care for others in your family?
    Not at all 1
    To some extent 2
    Very much 3

14. Has your family stability been disrupted by your relative's illness (frequent quarrels, break-up)?
    Not at all 1
    To some extent 2
    Very much 3

15. Do you think that your family appreciates the way you handle the patient?
    Not at all 1
    To some extent 2
    Very much 3

16. Does the patient's illness prevent you from having satisfying relationship with the rest of your family?
    Not at all 1
    To some extent 2
    Very much 3

*(If the spouse is the ill member in your family, please answer the next 4 questions)*
17. Does your spouse help with family responsibility?

- Not at all (3)
- To some extent (2)
- Very much (1)

18. Is your spouse able to satisfy your sexual needs?

- Not at all (3)
- To some extent (2)
- Very much (1)

19. Is your spouse still affectionate towards you?

- Not at all (1)
- To some extent (2)
- Very much (3)

20. Has the quality of your marital relationship declined since your spouse's illness?

- Not at all (1)
- To some extent (2)
- Very much (3)

21. Does caring for the patient make you feel easily tired and exhausted?

- Not at all (1)
- To some extent (2)
- Very much (3)

22. Has your workload increased after the patient's illness?

- Not at all (1)
- To some extent (2)
- Very much (3)

23. Do you think that your health has been affected because of the patient's illness?

- Not at all (1)
- To some extent (2)
- Very much (3)

24. Do you find time to look after your health?

- Not at all (3)
- To some extent (2)
- Very much (1)

25. Are you able to relax for sometime during the day?

- Not at all (3)
- To some extent (2)
- Very much (1)

26. Do you sometimes feel depressed and anxious because of the patient?

- Not at all (1)
- To some extent (2)
- Very much (3)

27. Do you sometimes feel that there is no solution to your problems?

- Not at all (3)
- To some extent (2)
- Very much (1)

28. Do you feel sometimes the need for temporary separation from the patient?

- Not at all (1)
- To some extent (2)
- Very much (3)

29. Does reducing the time spent with the patient (work/other activities) help you?

- Not at all (3)
- To some extent (2)
- Very much (1)

30. Does the patient's unpredictable behaviour disturb you?

- Not at all (1)
- To some extent (2)
- Very much (3)

31. Has your sleep been affected since the patient took ill?

- To some extent (2)
- Very much (3)

32. Does your relative's illness prevent you from having satisfying relationships with the friends?

- Not at all (1)
- To some extent (2)
- Very much (3)

33. Have you started feeling lonely and isolated since the patient's illness?

- Not at all (1)
- To some extent (2)
- Very much (3)

34. Does support from friends help in caring for the patient?

- Not at all (3)
- To some extent (2)
- Very much (1)

35. Does sharing your problems with others make you feel better?

- Not at all (3)
- To some extent (2)
- Very much (1)

36. Do you feel that your friends appreciate the way you handle the patient?

- Not at all (3)
- To some extent (2)
- Very much (1)

37. Do you often feel frustrated that the improvement of the patient is slow?

- Not at all (1)
- To some extent (2)
- Very much (3)
38. Do you feel that you are doing more than the patient to improve his/her situation?

- Not at all: 1
- To some extent: 2
- Very much: 3

39. Do you have the feeling that your relative understands and appreciates your effort to help him/her?

- Not at all: 3
- To some extent: 2
- Very much: 1

40. Are you satisfied with the amount of help that you are getting from health professionals regarding your relative's illness?

- Not at all: 3
- To some extent: 2
- Very much: 1