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The BURDEN ASSESSMENT Schedule (BAS)



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H. Sell, R. Thara
R. Padmavati and S. Kumar



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Contents

	Page
<i>Abstract</i>	v
<i>Preface</i>	vii
1. Introduction	1
2. Methods and Results	4
3. Discussion	9
<i>Bibliography</i>	11
Annexes	
1. Factorial Configuration of the 20-Item Questionnaire	13
2. Burden Assessment Schedule	15

Abstract

THIS PAPER describes the process of developing an instrument to quantify the subjective burden as perceived by care-givers to a chronic psychotic person. The methodology applied was qualitative-quantitative where extensive ethnographic work was followed by quantification of the concepts which emerged during the qualitative field work. As expected, some of these concepts were statistically confirmed in factor analysis, others merged or split up.

The result is a 20-item questionnaire representing five factors or concerns which reflect care-givers' main feelings about their care-giving role.

Preface

THE FAMILY constitutes a major support system in the continuing care of the chronic mentally ill in the community. Although many families show tremendous resilience in caring for an ill relative, their share of physical and emotional distress cannot be ignored. It is crucial for mental health professionals to be sensitive to the distress and burden experienced by families, in order to plan and implement a comprehensive treatment programme. This would also facilitate enhancing the quality of life of both – the mentally ill and their families.

The Schizophrenia Research Foundation (SCARF), a voluntary organization devoted to the care of the chronic mentally disabled for over a decade, has effectively integrated the role of the family in the management of the mentally ill. To further this objective, SCARF, in collaboration with the Regional Office for South-East Asia of WHO (SEARO), took up the development of an instrument to measure the subjective components of burden in families (Thara et al, 1995). We hope that the Burden Assessment Schedule (BAS) will facilitate a greater understanding of this subject and will facilitate and encourage studies to develop interventions of support to families, or of the relative contribution of specific features of pathology to this burden, thereby benefiting, in the long term, patients, their families, and health professionals engaged in work with the chronic mentally ill.

Introduction

RECENT TRENDS towards deinstitutionalization and an emphasis on community-based psychiatric care have resulted in the recognition of families as critical partners in the care for the mentally ill. However, in most developing countries, the ratio of psychiatric beds per population continues to be so low, (e.g. an estimated 1/30 000 in India) that institutional care has always been accessible only to a small and desperate minority of the mentally ill. In such instances, community-based management aims to bring care to patients for whom psychiatric care was hardly accessible at all earlier.

Considering the substantial decrease in psychiatric beds in industrialized countries over the last three decades, and the corresponding increase in out-patient and home care, surprisingly little research has been done on the burden this increase in home care places on patients' families and care-givers. In a comprehensive review, Kreisman and Joy (1974) concluded that the impact of mental illness on the family has not been adequately assessed, that mental illness severely affected the family, and that mental health professionals have not responded sufficiently to the needs of the family. The emergence of self-help and advocacy groups of affected families, and the pressure towards involving consumer groups in service planning during the last two decades, has certainly

The Burden Assessment Schedule

helped to bring the needs of care-giving families into increasing focus. Lefley (1987) and many others have pointed to the lack of adequate preparation for care-giving which families receive, and Winefield and Harvey (1994) have described the critical attitude of many affected families towards the mental health care system.

Platt (1985) has critically reviewed several instruments aiming to quantify burden ('potentially harmful effects ['burden] upon the patient's care-givers'; 'the impact [or burden] of his/her behaviour upon the patient's family, household and significant others'). He differentiates between *objective* burden (meaning any disruption to family/household life which is potentially verifiable and observable) and *subjective* burden (i.e. personal feelings of carrying a burden; being distressed, unhappy, upset, etc.). Whereas he points out that 'it would be theoretically and practically useful to assess the informant's distress in relation to each particular problem or difficulty associated with the patient's illness, this distress is invariably to be rated by the interviewer'. 'One aspect of objective burden is in fact based on a subjective experience ('distress') whose presence or absence is commonsensically assumed by the investigator'. Thus, the investigator is consistently considered a better judge of care-givers' feelings than they themselves are. A more recent review of 12 burden assessment instruments (Schene, 1990) adds little to Platt's earlier suggestions. The items contained in the reviewed instruments seem to have been drawn up by experts. Only the instrument developed by Pai and Kapur (1981) included some unstructured interviews with care-givers as the first step in instrument development, although the content of the interviews seems

to have been drawn from earlier published work. But it inquires about the subjective component only in one overall question of "suffering owing to the patient's illness." In this context, it is important to realize that care-givers often find it difficult to articulate what help they wanted and are unlikely to complain (MacCarthy *et al*, 1989). We found a similar situation in Northern India and Sri Lanka where 100% and 75% respectively of rural mothers of mentally retarded children did not, without probing, mention any need for help in caring for their disabled children (Sell, unpublished). Interviewing, in such a situation, may resemble asking a series of lead questions more than the extraction of "true" feelings. For the latter, ethnography beyond interviewing will be the only method of exploration. The need for a very thorough ethnographic exploration of the concepts involved in the perception of burden is even more strongly underlined by the finding that the 'objective burden', as quantified, using the instrument developed by Pai and Kapur (1981), correlates very highly with the negative items of the Subjective Well-Being Inventory (SUBI) (Sell and Nagpal, 1992) but not with the positive items (Roy Chaudhuri *et al*, 1995). Their finding not only corroborates the finding that positive and negative outlook on life are evaluated largely independently from each other, but also that positive factors are more stable over time and less affected by life circumstances (Nagpal and Sell, 1985; Sell and Nagpal, 1992).

Methods and Results

THE FIRST phase of the study followed the technique of 'stepwise ethnographic exploration' as developed during exploratory work on subjective well-being (Sell and Nagpal, 1992). This technique involves multiple ethnography, i.e. ethnographic work by a number of ethnographers/interviewers and a process of stepwise consensus building amongst them on concepts underlying/representing/being causally related to the topic under exploration. In the beginning, this ethnographic work was more of a 'living in' experience with participatory observation and in-depth interviewing, a deeply gratifying experience for field workers. Upon reaching a consensus on a list of these concepts, this list is discussed in focus groups of care-givers (qualitative validation). After finalization, these concepts are itemized into a first draft of a questionnaire-like quantitative instrument. The usual psychometric procedures of item reduction etc. then follow. There is a concern for reliability, but not for validity. We believe that the issue of validity does not arise in the process of stepwise ethnographic exploration since the multiplicity of ethnographic enquiry is a sufficient substitute for triangulation and related efforts to follow the validity paradigms of purely quantitative research (Sell and Nagpal, 1992). This process resulted in a draft questionnaire of 65 items. We applied a 3-point scale ('not at all', 'to some extent', 'very much') for reasons described elsewhere (Sell and Nagpal, 1992). Inter-rater reliability was established by verbally administering the draft questionnaire to 50 care-givers with the responses independently being coded by two field workers listening to the interview. This yielded a Kappa

of 0.80. Furthermore, in the following questionnaire administration, reliability was checked with every tenth interview to ensure that reliability was maintained.

The 65-item questionnaire was administered to 250 caregivers of chronic mentally-ill persons. No specific sampling procedure was adopted except efforts to ensure that all socioeconomic strata were represented in sufficient numbers to have their feelings reflected in the analysis. The returns were subjected to factor analysis. We would like to point out here that we consider factor analysis (FA) in this context a merely descriptive and not an analytical tool, describing similarities in a rather loose way, as do the correlation coefficients the FA is based on, especially since the data are non-parametric. We are, therefore, not concerned with Platts (1985) reservations about FA in terms of replicability, the amount of unexplained variance and the potential omission of too many items. The FA yielded, as expected, a number of clearly spurious and three equally clearly meaningful factors. The first factor was composed of items reflecting a general discomfort and malaise, depression, emotional instability, social disruption, health impact, and hopelessness. The second reflects effects on intimacy and emotional relations within the primary family group. The third factor was positive, reflecting positive feelings in the care-giver from appreciation for his/her caring by the patient, the family, and family friends. The findings were used to discard items with low loadings on any meaningful factor. This resulted in a 40-item questionnaire. This modified questionnaire was administered to a further 200 care-givers and the returns again subjected to FA.

The Burden Assessment Schedule

In this second FA, the three meaningful factors of the first FA emerged again. However, the first factor of the first FA split into three, with the separation of items of family disruption forming an independent factor, as did items relating to the perceived severity of the illness. This led to the retention of five factors or concerns (see Annex 1).

Factor 1: Impact on well-being

This factor contains items describing the impact of the presence of the chronic psychotic on the care-giver in terms of feelings of exhaustion, frustration, depression, and impact on health in general.

Factor 2: Impact on marital relationships

(Note: this factor can be elicited only if the care-giver is the spouse of the patient).

The items reflect the ability of the mentally-ill patient to give adequate attention and affection to other members of the family and to satisfy the emotional needs of her/his partner.

Factor 3: Appreciation for caring

This is a positive factor which reflects the satisfaction care-givers receive from the appreciation and acknowledgement

of their good care from friends and family members, and the pride of still being able to take good care of the rest of the family. This factor seems to be of particular importance to us because it hints at a very important component of support to care-giving families. Winefield and Harvey (1994) report on 'intrinsic enjoyment of the patient as a person'. But they asked only in a very general manner about 'good points for them when patients lived at home'. This obviously stretched the imagination of the interviewees too far.

Factor 4: Impact on relations with others

This factor includes items which refer to the disruption of family and other social relations as a consequence of the presence of the mentally ill person.

Factor 5: Perceived severity of the disease

In this factor converged items which represent the severity of the disorder, such as disturbing or unpredictable behaviour rendering the care giver unable to hold or take up a regular job.

Some items did not load highly on any of these factors and yet the interviewees had very strong feelings about their meaningfulness for the care-givers, and that they should not be left out for the simple reason of a descriptive and semi-quantitative statistical procedure. They may of course also have dropped out because sufficiently related items were not

included to form a statistically identifiable cluster. They were, therefore, included into the factors on which they loaded highest, although other items not retained did in fact have higher loadings.

These items include 'time out' or the possibility to simply relax for some time (indicating, of course, the importance of the availability of respite care), and the issue of meeting the financial needs of the patient (reflecting the worries of the care-givers about what may happen to the person if they are no more). Interestingly, the financial needs of the family did not cluster although several items addressed this issue. It is obvious that the presence of a chronic psychotic can cause financial hardship to the care-giving family in a variety of ways, and it may be important to inquire about these. However, we have dropped these items not only for the reason that they do not seem to be perceived as a rather homogeneous cluster or concern, but also because they seem to add a somewhat 'objective' component. Furthermore, their inclusion would have incurred the risk of influencing the perception of the inquiry in terms of possible expectations. If such questions are added, they should probably be asked verbally after the questionnaire is completed.

The proposed final version of the instrument is annexed. We have not annexed details of the outcome of the FAs in this paper. They can be found in the publication by Thara *et al* (1995). We believe that the outcome of qualitative and semi-quantitative research is more important than its quasi-quantitative description: what care-giving to a chronic psychotic "means" to a care-giver may be more important

than what numbers epidemiologists may extract from this. The final instrument is annexed (Annex 2).

Discussion

THE PRESENT paper describes the development of an instrument to quantify the burden perceived by care-givers to a chronic psychotic person, and the reasons for doing this. The instrument is based on extensive ethnographic work with affected families in an effort to gauge the "meaning" of giving care to a chronic psychotic person, i.e. an effort to quantify the subjective perceptions of care-givers.

In a process of 'stepwise ethnographic exploration', multiple ethnography was followed by focus group discussions (qualitative validation) and itemization of the concepts which had emerged. The resulting draft questionnaire was finalized in two waves of interviews and factor analyses.

Five factors or concerns emerged: impact on well-being, on marital relationships, on relationships with others; appreciation for caring; and perceived severity of the disease.

Interestingly, the financial needs of the family as affected by the presence of a disabled family member, did not emerge as a factor, although inquired about in various facets. The financial needs of the patient, reflecting worries of the care-givers about his/her fate when they will be no

The Burden Assessment Schedule

more, and the issue of respite care or 'time out' were included in the final version of the questionnaire because they were perceived as high priorities for care-givers by the interviewers, although their factor loadings were lower than those of some other items.

It is expected that the instrument, the Burden Assessment Schedule (BAS), will serve a number of purposes. The most immediate will be the evaluation of the impact of various support measures to care-giving families on perceived burden. A second will be the correlation between various aspects of psychopathology and perceived burden. This will, hopefully, permit the establishment of treatment plans which will not only aim at reducing symptoms in the patient, but also aim at reducing the burden in care-givers. Furthermore, the instrument can rather easily be adapted to quantify burden in care-givers to otherwise disabled or incurably-ill persons.

The Subjective Well-Being Inventory (SUBI) explores concerns or feelings which make people feel good or bad about self and their lives in general. Experiences have shown that it can very well be used in the training of counsellors or basic health workers working with disadvantaged families (ICMR, 1994) or with cancer patients (SEA/Ment/106) e.g. by helping counsellors to identify remaining intra- and inter-personal resources in seemingly helpless clients or those without hope. Equally, the BAS, when used in a rather unstructured way, can help counsellors or health workers to identify areas of particular concern and, therefore, of particular need for support to care-givers of chronically mentally ill.

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Annex 1

**Factorial Configuration of the
20-Item Questionnaire**

Factor 1: Impact on well being

CG feels depressed, anxious

CG feels tired, exhausted

CG feels frustrated

CG's health affected

Factor 2: Marital relationships

Spouse helps with family responsibilities

Spouse satisfies needs for intimacy

Spouse affectionate

Quality of marital relationship

Factor 3: Appreciation for caring

- Family appreciates CG's efforts
- Relatives appreciate CG's efforts
- Able to care for others
- Friends appreciate CG's efforts

Factor 4: Impact on relations with others

- Disruption of relations with other family members
- Disruption of family stability
- Disruption of relations with friends
- Need for time to relax (time off)

Factor 5: Perceived severity of the disease

- CG feels that there is no solution
- Patient causes disturbances at home
- Patient's unpredictable behaviour
- CG unable to take up a job

Annex 2

Burden Assessment Schedule

- (1) Do you think that your family appreciates the way you care for the patient?

Not at all ... 3
To some extent ... 2
Very much ... 1

- (2) Does the patient's illness prevent you from having a satisfying relationship with the rest of your family?

Not at all ... 1
To some extent ... 2
Very much ... 3

- * (3) Does your spouse help with family responsibilities?

Not at all ... 3
To some extent ... 2
Very much ... 1

* (4) Is your spouse still affectionate towards you?

Not at all	...	3
To some extent	...	2
Very much	...	1

* (5) Is your spouse able to satisfy your needs for intimacy?

Not at all	...	3
To some extent	...	2
Very much	...	1

* (6) Has the quality of your marital relationship declined since your spouse's illness?

Not at all	...	1
To some extent	...	2
Very much	...	3

(7) Does caring for the patient make you feel tired and exhausted?

Not at all	...	1
To some extent	...	2
Very much	...	3

The Burden Assessment Schedule

(8) 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

(9) Do you sometimes feel depressed and anxious because of the patient?

Not at all	...	1
To some extent	...	2
Very much	...	3

(10) Do you sometimes feel that there is no solution to your problems?

Not at all	...	1
To some extent	...	2
Very much	...	3

(11) Has your family stability been disrupted by the patient's illness (frequent quarrels, break-up)?

Not at all	...	1
To some extent	...	2
Very much	...	3

The Burden Assessment Schedule

(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 enough for others in your family?

Not at all	...	3
To some extent	...	2
Very much	...	1

(14) Have you started to feel lonely and isolated since the patient's illness?

Not at all	...	1
To some extent	...	2
Very much	...	3

(15) Does the patient's unpredictable behaviour disturb you?

Not at all	...	1
To some extent	...	2
Very much	...	3

The Burden Assessment Schedule

(16) Do you feel that your friends appreciate the way you care for the patient?

Not at all	...	3
To some extent	...	2
Very much	...	1

(17) Does the patient's illness prevent you from having satisfying relationship with your friends?

Not at all	...	1
To some extent	...	2
Very much	...	3

(18) Do you often feel frustrated that the improvement of the patient is slow/there is no improvement at all?

Not at all	...	1
To some extent	...	2
Very much	...	3

(19) Do you have the feeling that the patient understands and appreciates your effort to help him/her?

Not at all	...	3
To some extent	...	2
Very much	...	1

The Burden Assessment Schedule

(20) Is the patient's illness preventing you from looking for a job?

Not at all	...	1
To some extent	...	2
Very much	...	3

* These items apply only if the patient is a spouse to the care-giver (CG)



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