

A preliminary study of the impact of long term psychotic disorder on patients' families

D de Silva¹ and S de Silva²

(Index words: Burden assessment scale, carers, emotional, physical and financial well-being)

Abstract

Objective To assess impact of long term psychotic disorders on caregivers.

Design A questionnaire based, interviewer administered, cross-sectional survey using the translated version of a Burden Assessment scale (BAS).

Setting Outpatient clinic of the University Psychiatry Unit, National Hospital, Sri Lanka.

Sample SO caregivers of patients suffering from psychotic disorders for more than 2 years

Measurements The BAS was administered to SO caregivers to assess degree of distress and domains of concerns.

Results 60% of caregivers felt very anxious and depressed. 54% experienced a financial decline, and 82% felt responsible for meeting the entire financial needs of the patient. 54% felt that their workload increased due to the illness. 58% of the caregivers were parents.

Conclusions Caregivers of patients with long term psychotic disorders are distressed, and have several concerns. Interventions focused on these will relieve the distress of caregivers and help patients. A majority of caregivers are parents. This has future implications, as many patients are not capable of independent living.

Introduction

Several mental illnesses need long term treatment and care. In developing countries, such as Sri Lanka, most patients with long term mental illness are cared for in their homes by their families, because of a dearth of community based and institutional psychiatric services.

Thus planning comprehensive care for these patients requires us to recognise the critical role played by families, and be sensitive to their needs. Family members of patients who bear the burden when caring for these patients should be considered as partners in providing care, and as an important support system for patients. Such an approach would help improve compliance with care plans, and thereby prevent relapses and reduce hospitalisation. The objective of this study was to quantify the impact of long term psychotic disorder on caregivers and assess the domains that cause the greatest impact.

Burden can be defined as the presence of problems, difficulties or adverse effects which affect the lives of psychiatric patients' carers eg. members of household of family (1). Scales have been developed to measure this burden (1). Of the scales, those developed in India were chosen because of the cultural similarity between Sri Lanka and India (2,3). From these the Burden Assessment Scale (BAS) was selected, because it measures both subjective and objective burden on the carers (2,4). BAS is a 40-item questionnaire. It measures the degree of distress in several important domains such as emotional and physical distress, impact on relationships with others, finances, and distress related to coping mechanisms and support provided by others. It uses a 3-point scale for distress and scores 1 for 'not at all', 2 for 'some extent' and 3 for 'very much'.

Methods

BAS was translated into Sinhalese by bilingual translators taking the semantic meanings and translated back to English to check validity. The outpatients' clinic of the University Psychiatry Unit at the National Hospital Sri Lanka formed the setting for this study. Fifty consecutive outpatients with psychotic disorders for more than two years who were accompanied by a caregiver were studied. The questionnaires were administered to the caregivers by the researchers and analysed using standard statistical techniques.

Results

Of the caregiver sample 38 (76%) were women. 29 (58%) were parents of patients. 11 (22%) were siblings, and 37 (74%) of carers were married. 46 (92%) were educated up to secondary level, and 13 (26%) were in full time employment.

The 40 items were divided into 10 factors for descriptive purposes. The items related to marital satisfaction were not analysed, as the sample was inadequate (6 spouses). Only the items where more than 50% of caregivers were affected "very much", and the total of "to some extent" and "very much" was more than 75% of affected caregivers are given in the Table (Complete table available with authors).

¹Senior Lecturer, Department of Psychological Medicine, Faculty of Medicine, University of Colombo and ²Senior Registrar, University Psychiatry Unit, National Hospital, Sri Lanka. (Accepted 21 July 2001. Corresponding author D de S, e-mail: damani@srilanka.net)

Table. Burden assessment schedule (BAS - selected items)

<i>Burden</i>	<i>To some extent</i>	<i>Very much</i>
Impact on emotional well being		
Are you able to relax some time of the day?	27(56%)	16(32%)
Do you sometimes feel depressed and anxious because of the patient?	17(34%)	*30 (60%)
Have you started to feel lonely and isolated since patient's illness?	26(52%)	12(24%)
Do you feel frustrated that the patient's improvement is slow?	23(46%)	24(48%)
Impact on physical well being		
Does looking after patient make you feel easily tired and exhausted?	20(40%)	18(36%)
Do you think your health is affected because of patient's illness?	28(56%)	15(30%)
Do you find time to look after your health?	27(54%)	11(22%)
Has your sleep been affected since the patient took ill?	23(46%)	16(32%)
Appreciation for caring		
Are you able to care for others in your family?	27(54%)	13(26%)
Do you think your family appreciates the way you handle the patient?	13(30%)	•31 (62%)
Do you think friends appreciate the way you handle the patient?	17(34%)	*27 (54%)
Do you have the feeling that patient understands and appreciates your effort to help?	20(40%)	23(46%)
Impact on relations with others. Help from others		
Does support from your family help in caring for the patient?	23(46%)	21(42%)
Does sharing your problems with others make you feel better?	29(58%)	13(26%)
Are you satisfied with the amount of help received from health professionals regarding illness?	14(28%)	•38 (72%)
Effect on finance/income		
Is current financial situation adequate to look after patient?	22(44%)	19(38%)
Does patient's future financial situation worry you?	18(36%)	*27(54%)
Has family financial situation worsened after illness?	13(26%)	•31 (62%)
Responsibility for caring		
Are you concerned that you are largely responsible to meet financial needs of patient?	9(18%)	•41 (82%)
Do you feel you have to take the responsibility of ensuring that patient has everything needed?	11(22%)	*39 (78%)
Do you think you have to compensate for the patient's shortcomings?	18(36%)	22(44%)
Do you feel you are doing more than the patient to improve* situation?	19(38%)	21(42%)
Impact/effect on work/employment		
Has your workload increased after the patient's illness?	6(32%)	*26 (52%)
Does reducing the time spent with patient help you?	21(42%)	14(28%)
Perceived severity of disease		
Are you satisfied with the way patient looks after himself/herself?	25(50%)	13(26%)
Does the patient's unpredictable behaviour disturb you?	26(52%)	14(28%)
Do you sometimes feel there is no solution to your problems?	23(46%)	20(40%)

Selected BAS items were where > 75% are somewhat distressed or very distressed
> 50 of sample are very distressed. (*)

Discussion

The study shows that the well-being of caregivers is affected in 3 main aspects as given below.

1). The illness is a heavy emotional burden to the family, who often feel unable to relax, and are depressed, anxious, isolated and frustrated. 60% of caregivers felt very anxious and depressed. Interventions such as formation and networking of patient groups and their families will relieve some of this burden. Presently there are a few such support groups, and these need to be extended and linked to families.

2). 62% felt that the family financial situation deteriorated very much after illness, and 54% are very worried about the future financial situation of the patient. 82% of caregivers felt they were largely responsible for meeting financial needs of the patient. Financial burden is a problem for these families because of the impact on employment, and rising cost of care. The fear of future financial security caused a great deal of distress. Steps to provide some degree of financial security include recognition of mental illness as a category to qualify for social welfare, provision of low interest loans to assist these families, and vocational training to caregivers and patients to supplement income.

3). 54% felt their work load increased very much after the patient's illness. 78% felt they were responsible for meeting all needs of the patient. Ways of distributing the duty of care among the extended family and friends should be addressed. Other organisations also could provide such support. For example, a day care centre to look after patients (run by the community or a nongovernmental organisation) would enable caregivers to attend to some of their personal needs.

Most family members felt that their efforts in caring were appreciated by patient, family and friends respectively (46%, 54%, 62%). Interventions to sensitise others to express appreciation of care can be achieved without much cost. These positive factors need reinforcement, and services to provide support to caregivers should target these aspects.

The support provided by professionals was considered very satisfactory by 72%. This may be because the relatives were interviewed by the health care team. Another factor might be the low expectations of these persons who are satisfied with whatever is delivered to them by the system.

A majority of caregivers are parents. This has implications for the future care of these patients as most of them are unable to care for themselves and live independently.

References

1. Thara R, Padmavati R, Kumar S, Srini vasan L. Burden Assessment Schedule. Imminent to assess burden on caregivers of the chronically mentally ill. *Indian Journal of Psychiatry* 1998; 40: 21-9.
2. Piatt S. Measuring the burden of psychiatric illness on the family: an evaluation of some rating scales. *Psychological Medicine* 1985;15:383-93.
3. Pai S, Kapur RL. The burden on the family of a psychiatric patient: development of an interview schedule. *British Journal of Psychiatry* 1981; **138**: 331-5.
4. Compilation of research instruments. Developed by the schizophrenia research foundation (Scarf) India. Scarf publication, 1997.

Correction

The article titled "Prospective study of congenital heart disease in children" by Pujitha Wickramasingha, Sanath P Lamabadusuriya and S Narenthiran, which was published in the *Ceylon Medical Journal* 2001; **46**: 96-98, was not listed on the contents page under "Papers" by inadvertant error.