

CAREGIVER BURDEN IN A COMMUNITY MENTAL HEALTH PROGRAM — A CROSS SECTIONAL STUDY

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ABSTRACT

Background: As mental health services in the community are ill-developed, in India, the care of individuals with mental illness lies mostly with the family. Studies elsewhere have shown that families of patients with mental illness have significant levels of caregiver burden, and that such burden has negative consequences on both the patients and the caregivers.

Methods: A cross sectional study assessed 46 randomly selected individuals with mental illness registered in a community mental health program and their caregivers. Burden Assessment Schedule and WHO Disability Assessment Scale were employed, and socio-demographic and clinical variables were assessed.

Results: The most common diagnosis was psychosis (28.3%), and the caregiver was most commonly the mother (32.6%). The mean score on the WHODAS was 26.48 ± 7.48 . The mean levels of caregiver burden on the BAS were — impact on wellbeing: 7.28 ± 2.66 , impact on marital relations: 8.10 ± 3.07 , appreciation for caregiving: 6.09 ± 1.88 , impact on relations with others: 6.67 ± 2.42 , and perceived severity of disease: 7.26 ± 2.51 . The female and illiterate caregivers reported significantly more burden. Levels of caregiver burden were not associated with any other clinical or sociodemographic variables.

Conclusion: Significant levels of caregiver burden were present in the sample of predominantly female caregivers. The resources within mental health services of this country need to be improved to address this aspect. The possible benefits of community-based services in this context are discussed.

Keywords: Caregiver burden, community, mental illness

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INTRODUCTION

In India, the ratio of mental health professionals to patients is very low. The responsibility for day-to-day care of patients usually rests with the family.¹ In a scenario where it is taken for granted that one should be caring for one's ill relatives, caregiver distress, both physical and emotional, is often ill addressed. Perceived burden can have a serious impact on the caregiver's health and social relationships, and expression of negative emotions like frustration and anger could possibly negatively influence the patient too.

Defining caregiver burden: Caregiving is defined as the act of providing unpaid assistance and support to family members or acquaintances with physical, psychological or developmental needs. Caring for others generally takes three forms: instrumental caring, emotional caring, and informational caring.³ The World Health Organization (WHO) defines caregiver burden as “the emotional, physical, and financial demands and responsibilities of an individual's illness that are placed on the family members, friends or other individuals involved with the individual outside the health care system”.⁴

Implications of Caregiver burden: Caregivers have reported effects of burden in different areas like family functioning, social function, financial issues and health.^{5,6} The most common mental health consequences of caregiver burden identified are depression, anxiety and burn out. Caring for individuals with psychiatric illness has been shown to be associated with a higher levels of stress than caring for someone with functional impairment from other chronic medical illnesses.^{6,7} Previous

studies have reported that the level of disturbed behaviour, and not diagnosis, has a more important role in determining the level of burden on caregivers.⁸

Caregiver burden in mental illness can either be objective or subjective. Objective burden is defined as readily verifiable behavioral phenomena like disruption of the caregiver's domestic routine and social activities, and difficulties encountered in areas like finances and employment. Subjective burden refers to emotional reactions of the caregivers, including perception of strain, reduced morale, anxiety and depression.⁹ For many carers, frustration, anger and despair are common.^{10,11,12} This is further compounded by them being subjected to the same stigma as their patients.¹³ The addition of the caregiving role to the already existing family role may become psychologically and economically stressful.¹⁴

This investigation was planned because there are very few studies examining caregiver burden in mental illness in rural community care settings in our country.

AIMS AND OBJECTIVES

1. To assess the levels of subjective caregiver burden within the community outreach program
2. To determine the sociodemographic and clinical correlates of caregivers' burden

MATERIALS AND METHODS

Study design: A cross sectional study design was employed.

Study setting and participants: The setting of the study was a community outreach program named Community Mental Health Program (CMHP). It is part of a multi-disability community based rehabilitation program attached to the Dr. S.M.C.S.I.

Medical College, Karakonam, Kerala; and is funded in part by CBM (Christoffel Blinden Mission), an international non-governmental organization. It evolved out of the crisis brought about by the December 2004 Indian ocean tsunami that devastated communities on the south western coast of India.² Though the hospital's catchment area covers Trivandrum district of Kerala and Kanyakumari district of Tamil Nadu, the CMHP covers a much smaller area with a population of 100,000. The program maintains offices in Colachel, Pozhiyoor and Thuthoor; with monthly clinics in the first two. Appropriate patients are routinely referred to our own inpatient psychiatry unit.

In addition to professionals, the program also employs 10 community-based workers. They visit the homes of the patients twice a month and implement interventions aimed at improving adherence to treatment, activities of daily living and social functioning. They also use informal counselling techniques like listening, relaxation techniques, and support for caregivers. Self-Help Groups, referred to as Family Support Groups, are also organized.

123 patients were registered in the program at the time of the study. 46 caregivers of patients with mental illness were selected using systematic simple random sampling from the registry of the mental health community program in Colachel and Pozhiyoor villages. These are both coastal villages with fishing being the predominant means of livelihood.

Caregivers of patients with an ICD 10 diagnosis of mental disorder, with an illness duration of at least one year, and who gave written informed consent were included in the study. The person identified by the

patient or the family as playing the primary caregiving role was considered as the caregiver and assessed for levels of burden.

Caregivers of patients with known physical or sensory disability, and those who had needed inpatient treatment in the last one month prior to assessment were excluded. Patients with substance use disorders were not included as they had been treated primarily in the hospital setting.

ASSESSMENT TOOLS

1. *A semistructured sociodemographic questionnaire*: This covered the following details about the caregiver: age, socioeconomic status, gender, address, level of education, occupation, and relationship with the patient. Clinical data such as diagnosis (as per ICD 10 criteria) and duration of illness were collected from the case records maintained in the program. For the purposes of this study, the diagnoses were grouped into "Psychosis" (schizophrenia, psychosis NOS and delusional disorder), "BPAD" (bipolar affective disorder), "Depression" (depressive disorders, dysthymia), "Organic" (mental retardation, autism, attention deficit hyperactivity disorder, seizure disorder), and "Others" (anxiety, stress related disorders, etc.).

2. *The WHO DAS (World Health Organization Disability Assessment Schedule) 2.0*: This is a generic assessment instrument for health and disability employed across a range of diseases; including mental, neurological and addictive disorders. It is short, simple and easy to administer (5 to 20 minutes); and can be used in both clinical and general population settings. It has 12 questions, and answers are on a Likert score from none to extreme (1 to 5).¹⁵

3. *The Burden Assessment Schedule:*

This is a 20-item interviewer-rated tool. It was developed by Sell et al. in association with SCARF (Schizophrenia Research Foundation) and Regional Office for South-East Asia of WHO (SEARO). It is a measure of subjective caregiver burden. Questions are rated on a three-point scale from 1 to 3. The available responses are “not at all”, “to some extent” and “very much”. The maximum score in each area of burden is 12, with higher scores indicating higher degree of burden. The scale has the following domains:

- a) Impact on wellbeing: Any psychological distress or adverse impact on health due to caring for the patient.
- b) Impact on marital relationships: This domain is assessed only if the spouse is the caregiver. This reflects the ability of the mentally ill person to give adequate attention and affection to other members of the family and to satisfy the emotional needs of his/her partner.
- c) Appreciation for caregiving: A positive factor. This reflects the satisfaction obtained from the acknowledgement received for caregiving.
- d) Impact on relations with others: This refers to disruption in family and other social relations.
- e) Perceived severity of the disease: This measures the caregiver’s opinion of the severity of the patient’s illness.

The scale has previously been used in Indian populations to assess caregivers of individuals with mental illness.¹⁶

DATA COLLECTION

The data was collected, ensuring both privacy and confidentiality, by two Psychiatry residents and a Social Worker, in

September 2013. To avoid bias, any two investigators separately assessed burden and the sociodemographic and clinical measures. The community volunteers visited the patients and caregivers a day before the data collection, informed them about the study, sought their permission, and fixed a mutually convenient time.

ANALYSIS

Descriptive Statistics were employed, with frequency and percentages calculated for categorical data, and means and standard deviations calculated for continuous variables. The Mann Whitney U test was employed to look for associations between categorical independent variables and domains of caregiving burden, while Spearman Rank correlation was used to examine the relationship between WHO DAS scores and domains of burden. Data was analyzed using the Statistical Package for the Social Sciences, version 16.00 (SPSS Inc).

RESULTS

46 caregivers were assessed in the community. Their mean age was 43.5(\pm 15.9) years. Only 13 (28.3%) had obtained a matric level of education, while 9 (19.6%) were illiterate. 76.1% of the caregivers were female (Table 1). 32.6% of the caregivers were mothers, forming the most common group of caregivers; followed by daughters and wives at 17.4% and 15.2% each. The most frequent diagnosis of the patients was psychosis (28.3 %), followed by depression for 21.7% (Table 1). The mean duration of illness was 15.6(\pm 9.9) years. The mean WHO DAS score of the patients was 26.48(\pm 7.48).

The scores on the various domains of caregiver burden on Burden Assessment Schedule are given in Table 2.

Variable	Categories	n (%)
Gender of caregiver	Male	11 (23.9)
	Female	35 (76.1)
Education of caregiver	Matriculation	13 (28.3)
	Below matriculation	33 (71.7)
Employment status of caregiver	Employed	15 (32.6)
	Unemployed	31 (67.4)
Relationship with patient	Spouse	10 (21.7)
	Parent	19 (41.3)
	Children	11 (23.9)
	Others	6 (13)
Diagnosis*	Psychosis	13 (28.3)
	BPAD	6 (13)
	Depression	10 (21.7)
	Organic	11 (23.9)
	Others	6 (13)
Duration of illness	<5 years	6 (13)
	5-10 years	15 (32.6)
	>10 years	25 (54.3)

Table 1: Sociodemographic and clinical variables of caregivers and patients (n=46).
*Diagnostic break up explained in method section

	Impact on wellbeing	Impact on marital relations*	Appreciation for caregiving	Relationship with others	Perceived severity of illness
Mean	7.28	8.10	6.09	6.67	7.26
SD	2.66	3.07	1.88	2.42	2.51

Table 2: Scores of domains of Caregiver Burden on Burden Assessment Schedule
*Calculated for caregivers who were spouses (n=10)

Variables	n (%)	Score*	p value**
Male	11 (23.9%)	5 (4-7)	p = 0.038
Female	35 (76.1)	7 (5-9)	
Literate	37 (80.4)	6 (4-8)	p= 0.029
Illiterate	9 (19.6)	9 (5.5-11.5)	

Table 3: Caregiver variables significantly associated with Impact on Relations with others on BAS. *Mean (interquartile range) **Mann Whitney U Test

An analysis employing the Mann Whitney U test demonstrated that being female (p=0.038) and illiteracy (p=0.029) were significantly associated with greater impact

on relations with others (Table 3). Females were also significantly more likely to report receiving more appreciation for caregiving (p=0.031), while illiteracy was significantly

	Impact on wellbeing	Impact on marital relations	Appreciation for caregiving	Relationship with others	Perceived severity of illness
Spearman's rho	-0.053	0.455	0.069	-0.033	-0.072
p value	0.728	0.186	0.648	0.829	0.636

Table 4: Correlation between WHO DAS scores and BAS domains

associated with having higher levels of burden in the domain of perceived severity of illness ($p=0.002$). There was no association between relationship of caregiver, employment status of caregiver, caregiver having a medical illness, illness being of more than 10 years duration or patient having a psychotic disorder and any of the domains of caregiver burden.

Levels of disability of the patients was not significantly correlated with the levels of burden in any of the domains (Table 4).

DISCUSSION

In this study, most of the caregivers were female, and a majority were mothers. This is consistent with the findings of other researchers who reported that the burden of care is most often relegated to women, especially the mothers.^{17,18,19}

The scores we detected on domains of caregiver burden in BAS are slightly higher than those reported by Swaroop et al. who used the same instrument in another community based program in Bangalore, South India.¹⁷ This disparity may possibly be explained by the relatively longer mean duration of illness at 15.6(\pm 9.9) years and higher proportion of individuals with psychosis (28.3%) and organic disorders (21.7%) in our samples compared to the Bangalore sample — 85% of patients in their sample had affective illnesses. Kumar et al. had studied a hospital-based population in Agra employing the 40-item BAS and detected high levels of burden, particularly among the wives.²⁰

It may be speculated that access to community based mental health programs, with delivery of drugs within the community, home visits and self-help groups, could theoretically ameliorate the caregivers' burden. However, research (including this one) has so far been unable to reach any clear conclusions regarding this, owing to the absence of comparative prospective studies.

A cross cultural study that employed BAS to compare the burden among Indian and Malaysian caregivers had found significant differences in the expression of burden across the two cultures — with Indian caregivers perceiving more difficulties in areas such as finance, family relationship, well-being and health; but still perceiving less burden than their Malaysian counterparts.²¹ This demonstrates that the pattern of burden can vary across cultures, even within Asia, underlining the importance of the need to look for patterns and correlates of burden in different kinds of communities.

The significant association between being a female caregiver and experiencing higher levels of impact on relationship with others is similar to the higher levels of perceived caregiver burden reported among female caregivers by studies from western settings and other parts of India.^{19,20} We found that illiteracy increases caregiver burden; researchers from both western and other Asian countries have also reported that lower levels of education predict higher levels of burden.^{19,22}

Unlike this study, other investigators have found an association between disability due to mental illness and the severity of caregiver burden.²³ Most studies demonstrated this relationship in caregivers of individuals with schizophrenia, probably partially explaining the difference in our population which had patients from a range of diagnostic categories. Though duration of illness has been found to determine burden in a few studies, our study did not find such a relationship.²⁴

The high levels of caregiver burden detected by us and other researchers dictate that all mental health professionals be equipped with information on treatment approaches to tackle this issue. A variety of psychosocial and pharmacological interventions have shown mild to modest efficacy in mitigating caregiver burden and associated manifestations of caregiver distress. Psychosocial interventions with proven efficacy in this regard include support groups and psychoeducational interventions for caregivers.²⁵

LIMITATIONS

The sample size was small, raising the possibility that our study is underpowered. The cross-sectional nature of this study limits its ability to postulate on the exact contributory factors of the burden. An assessment of what components of the community services, if any, may have contributed to any possible amelioration of the burden was not done, but this would have been difficult, given the cross-sectional nature of this investigation.

Many individuals in this sample had been exposed to the Asian Tsunami in 2004. The effects of the disaster have probably been mitigated over time, but the possibility that this could have influenced the findings cannot be ruled out entirely.

CONCLUSION

Caregiver burden is a significant clinical issue that unfortunately is not routinely addressed in busy, under-resourced clinical settings. We found significant levels of burden across various domains, and higher levels of burden in caregivers who are female or illiterate. As burden could potentially damage the physical and mental health of the carer and worsen the outcome for the patient, there is a need to routinely assess burden and allocate resources to address this. Interventions will need to be sensitive to locally relevant factors, as this study from a rural coastal society demonstrates. In communities like this, there may be a need to pay more attention to caregivers with gender or educational disadvantage.

The possibility of alleviating caregiver burden by providing accessible and holistic mental health services within the community has implications for future planning and organizing of services within this country, where the family continues to remain the primary source of support for individuals with mental illness.

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