

Caregiver Burden in Medical versus Psychiatric Patients: A Cross-sectional Comparative Study

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ABSTRACT


Background: An informal care-giver is generally an unpaid individual who looks after the personal and medical needs of the patient. India being a country of traditions and family values, this informal care-giver is usually a family member. These care-givers, being untrained in this job undergo tremendous stress. Available research studies the burden individually in the relatives of chronically medically ill patients and those of psychiatrically ill patients. Furthermore the previous research targets the burden in individual diseases. This study stands out as it makes a comparison between the two broad groups, taking into account almost all possible chronic diseases in each group. **Methods:** This is a cross-sectional analytical descriptive study that was conducted on the family caregivers of chronically medically ill and psychiatrically ill patients, using the Caregiver's Burden Scale. Data were analyzed by SPSS 20 statistical software and Pearson correlation coefficient tests. Significant difference between area of caregiver burden of medicine and psychiatric patients was tested using relative deviate "Z" of SEDM test at 5% level of significance. **Result:** There is a significant difference between each category of Caregiver's Burden Scale among chronically medically ill and psychiatrically ill patients. ($P < 0.05$). **Conclusion:** The outcome of this study may help the health care providers in designing stress relief programs for primary care-givers. Overall this study may help better delivery systems of care for both the chronically medically ill as well as psychiatrically ill patients, by proper specific framing and psycho education programs for the caregivers of specific chronic illnesses.

Key words: Burden, caregiver, Caregiver's Burden scale, chronically medically ill, psychiatrically ill

INTRODUCTION

A caregiver is a person who provides direct care to a patient. In this study, the caregiver denotes a first-degree relative-spouse, child, parent, sibling, or an extended family member who may or may not be a professional caregiver. Families are the primary source of home care

and support for chronically ill patients, contributing services that would otherwise cost large amount of money if they were supposed to be outsourced.^[1,2] In India, care giving is usually by the family because of limited resources as compared to other countries, and more over due to the fact that we Indians value our

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family ties. However, the changing scenarios such as urbanization and nuclear families has led to a decreased social support. This decrease in social support especially from the other family members, as is the case in a nuclear family increases the burden on the caregiver. Also in case of urbanization where everyone is busy in their lives it is difficult to outsource the duty of care giving.

The role of family caregivers is very demanding. They have to look after the day-to-day needs of the patient, keep a track on the progression of his illness, supervise treatment, and provide emotional support to the patient in addition to their regular family duties. A full-time caregiver (especially in cases of psychiatrically ill patients and patients requiring palliative care) has to give up on his sleeping hours, leisure time, neglect his own health, ignore the other family members, undergo financial constraints, and in extreme cases leave his job to be with the patient. The concept was first introduced by Treudley in 1946 as the negative impact of care giving on caregiver's mental health and quality of life.^[4] In India, the first ever concept of including a family care giver in the treatment of the patient was introduced by Dr. Vidyasagar Rao in the 1950s.^[3] The chief stressors for the caregiver include extent of the patient's disabilities; his perception of the patient's suffering as well as quality and quantity of care to be provided. These stressors cause psychological strain and impaired health in caregivers which may have a potential to culminate into severe illness and mortality. These stressors are further moderated by factors such as age and gender of both the patient and his caregiver; marital status and literacy of the caregiver, social support received by the caregiver, socioeconomic status of the family, and the attitude of the attending doctor.^[5,6] Many a times, the caregiver becomes the recipient of the patient's frustration and misbehavior. Due to the lack of training, insignificant knowledge about the disease and the mental trauma of seeing their once so healthy and active relative now bed ridden these family caregivers undergo a lot of stress and strain, now commonly known as caregiver burden in literature. The negative effects of caregiving include frank deterioration of the caregivers health, disturbed family routines, increased expenses while the subjective effects include a feeling of depression by the entire family and feelings of isolation, loss, anxiety, anger, and frustration by the caregiver.^[7]

The scenario changes when the patient is psychiatrically ill, in part due to the social stigma attached with the illness. In such a case, the caregiver may feel shameful to socialize in the presence of the patient thus isolating himself and further contributing toward his own depression. These people later adapt one or more of the

coping mechanisms such as acceptance of the situation or complete denial, taking refuge in spirituality, and seeking social support.^[6]

METHODOLOGY

This is a cross-sectional analytical descriptive study that was conducted on the primary caregivers of chronically medically and psychiatrically ill patients. A total of hundred caregivers of patients on regular follow-up were included in the study; fifty each from the medicine and psychiatry Departments of a Tertiary Municipal Medical College. Selection of the caregivers was based only on the criteria that their respective patients are chronically ill for more than 2 years. The care givers were recruited in the study after informed consent was obtained from them as well as their respective patients. The process of consent involved detailed explanation about the study and its objectives. The permission for the project was granted by the Institutional Clinical Ethics Committee of the medical college (Rajiv Gandhi Medical College). The caregivers ranged across age, gender, marital and socioeconomic status, and literacy and their relation with the patient. In addition, a variety of chronic diseases from each department was included in the study.

The research instrument was a questionnaire which consisted of two parts – one part including the demographic data (age and gender of both the patient and the relative, disease the patient has been suffering and since how many years, number of family members in the household, and the family income) and the second part consisting of The Caregiver's Burden Scale (CBS) [Appendix 1].^[8-10] The CBS is a 22-item scale with four options for each question (not at all, seldom, sometimes, often) scoring 1–4, respectively. The questions are divided into five factors –general strain, isolation, disappointment, emotional involvement, and environment. Each caregiver was personally interviewed by the author, with absolute noninterference by any third party. Any personal information asked was purely for the research purpose and the identity of each subject was always protected.

Data were analyzed by SPSS20 (Statistical Package for the Social Sciences) a software currently owned by UNICOM Systems, Inc., a division of UNICOM Global, under the UNICOM Intelligence brand, Mission Hills, California and Pearson correlation coefficient tests. In addition, significant difference between the area of caregiver burden of medicine and psychiatric patients was tested using relative deviate "Z" of SEDM test. Statistical significance was considered at $P < 0.05$. Karl Pearson's correlation and Chi-square test were used to determine the relationship between

demographic variables and the caregiver burden score.

RESULTS

From the medicine department of 50 caregivers, 32 (64%) were female, and 18 (36%) were male (for 36 of female and 14 of male patients). From the psychiatry department of 50 caregivers, 31 (62%) were female, and 19 (38%) were male (for 26 of female and 24 of male patients) [Tables 1 and 2].

Of 50 caregivers, 14 (28%) in the psychiatry department were taking care of the patients for more than 10 years as against only 7 of 50 caregivers (14%) of their counterparts in the medicine department [Table 3].

Table 1: Gender wise frequency distribution of medicine and psychiatry patients

Gender	Medicine	Psychiatry
Male	14	24
Female	36	26

Total patients=100

Table 2: Caregiver's gender wise frequency distribution for medicine and psychiatry patients

Gender	Medicine	Psychiatry
Male	18	19
Female	32	31

Total caregivers=100

Table 3: Frequency distribution of medicine and psychiatry patients with respect to disease duration

Disease duration	Medicine	Psychiatry
Up to 5 years	32	27
5-10 years	11	9
Above 10 years	7	14

Table 4: Caregiver burden scores

Caregiver burden score	Medicine	Psychiatry
Low	27	11
Average	20	30
Severe	3	9

Table 5: Testing of significance with respect to Caregiver Burden Scale score

Factors in CBS	Medicine		Psychiatry		P
	Mean	SD	Mean	SD	
General strain	2.17	0.68	2.58	0.67	0.000021
Isolation	1.7	0.67	2.48	0.81	<0.00001
Disappointment	2.14	0.54	2.37	0.62	<0.00001
Emotional involvement	1.51	0.56	2.15	0.85	<0.00001
Environment	1.82	0.62	2.01	0.76	<0.00001

CBS – Caregiver's Burden Scale; SD – Standard deviation

Of 50 caregivers, 23 (46%) from medicine department reported average to severe caregiver burden whereas of 50 caregivers, 39 (78%) from the psychiatry department reported average to severe caregiver burden [Table 4].

In this study, of 100 caregivers, 62 (62%) reported moderate-to-severe levels of caregiver burden [Table 5].

There is a significant difference between each category of caregiver burden score among medicine and psychiatrically ill patients [Table 5].

In the care givers of chronically medically ill patients, there was a significant association between the relative gender and disappointment category of CBS ($P = 0.0278$); the disease duration and isolation category of CBS ($P = 0.0028$); number of family members and emotional involvement category of CBS ($P = 0.0101$); with no significant association at the corresponding levels in the caregivers of psychiatrically ill patients.

DISCUSSION

This study used the CBS to make a comparison between the burden that is faced by the family caregivers of chronically and psychiatrically ill patients; the reliability and validity of which were verified by the research team at Kerman Razi School of Nursing to be used in a thesis entitled as “Investigating the relationship between social support and caregiver burden feeling in mothers with premature babies hospitalized in NICU.”^[11] This scale has been used in the past for various chronic illnesses.^[11-15]

Difference in the stress of caregivers of chronically medically and psychiatrically ill patients

It is seen in this study that there is a significant difference between each category of caregiver burden score among medicine and psychiatrically ill patients [Table 5]. Although a slight contradiction was found in a remote study,^[16] the possible explanation could be as following factors.

General strain

Psychiatric illness is still viewed as a taboo, a curse, or a social stigma in the Indian society. This becomes an additional burden on the caregiver of such a patient. Caregivers in this case have to put in extra effort in terms of physical strength as the patient is physically, mentally, and at times emotionally dependent on them. In extreme cases, these caregivers also have to endure the patient's noncooperative attitude. Things are quite different for the caregivers of chronically medically ill patients. First of all, their patient is mentally sound and aware of the efforts

that the caregiver is putting, and second in the absence of any kind of stigma, these caregivers tend to get a large amount of social support in terms of a helping hand or a few encouraging and positive words that the patient will get better soon. This signifies the higher general strain in the caregivers of psychiatrically ill patients.

Isolation

Given the social stigma attached, the psychiatrically ill patient is isolated from the society and so is his caregiver. Some even complained of “boycott” by their neighbors. People whose spouses were patients complained of “loneliness” in life while some confessed they would either like to run away from their current situation or keep the patient in a professional care institute. In extreme cases, caregivers of psychiatrically ill patients said they avoided inviting people to their homes due to the fear of untoward behavior from their patient, thus accounting for higher isolation among the caregivers of psychiatrically ill patients.

Disappointment

The caregivers from the psychiatry department also complained of a greater economic sacrifice and the physical strain that was required to take care of their patient. The caregivers said that most of the times they could not keep their patient alone at home thereby increasing the time that they spend with the patient which further added to their burden. One problem which the spouses faced was making sure that their children do not get influenced by the illness of the patient. These were seldom seen with the caregivers of chronically medically ill patients amounting to greater disappointment in their counterparts from the psychiatry department.

Emotional involvement

Caregivers from the Department of Psychiatry showed emotional involvement as compared to their counterparts from the Department of Medicine. This is because during the survey most of them confessed that they felt “embarrassed” of their relative to the extent that they avoided going to any social gatherings. All this added to their frustration which was ultimately vented out on the patients. However, at the same time, an excessive emotional involvement meant that the caregivers neglected their other family members in the process of care giving. It is known that high expressed emotional involvement in caregivers is a known factor both in cause and altered prognosis in psychiatrically ill patients.^[17,18]

Environment

The caregivers of the psychiatrically ill patients were more influenced by their environment or more precisely the physical environment. This was because

most of the subjects involved in the came from a poor socioeconomic class who only had the option of getting their patient treated at tertiary care municipal hospital instead of a private setup with sophisticated technology. For some of them either the municipal hospital was not easily accessible or the caregivers had to go out of their way like taking a day’s leave from their job to get the patient for a checkup to the psychiatrist. When the illness prolonged, the caregivers generally had a notion that it was because they were not taking good care of their respective patients. In the case of chronically medically ill patients, this was not so prominent because they even had an option of getting regular checkups done even at the nearest accessible general practitioner.

Serendipitous findings

Role of gender

There is a significant relationship between the relative’s gender with disappointment category of caregiver burden score ($P = 0.0278$) in medicine patients; however, there is no significant relationship between the relative’s gender and all categories of caregiver burden score of psychiatrically ill patients. Burden is generally on the higher sides in case of female caregivers^[19] (not always^[20]) due to the fact that a lot of other household duties apart from caregiving are expected from females. In case if the parents of a married female are chronically ill, she is expected to fulfill all the duties of a mother, a wife, and a daughter in law in addition to her care giving duties toward her parents. Sometimes the situation is further worsened for the female if she is working. In addition, in most cases, females being uneducated and unemployed in the lower socioeconomic classes or due to the fact that females do not receive equal pay for equal work as their male counterparts, females tend to experience more economic crunch as compared to males, while carrying out the role of a caregiver.

Disease duration and isolation as stressors

There is a significant relationship between the disease duration with isolation category of caregiver burden score ($P = 0.0028$) in medicine patients; however, there is no significant relationship between disease duration and all categories of caregiver burden score of psychiatrically ill patients. This is consistent with the previous findings.^[21-23] In case of chronic illness as the duration of caregiving increases, the severity of the disease also increases. For example, a Parkinson’s patient may become bed ridden or a patient of brain-tumor may become vegetative. This demands additional care from the caregiver, who in the process gives up on his social life thereby adding to the burden. On the contrary, the severity of the psychiatric illness may remain constant over the same duration (though there are episodes of exacerbations) and so does the

burden. Thus, the duration and of the illness are more stress inducers in the medically ill.

Other significant findings

Though this wasn't a primary aim of our study yet we found a significant relationship between the degree of physical dependence of the patient on his caregiver with general strain, isolation, emotional involvement and environment category of caregiver burden score in chronically medically patients however there is no such finding in case of psychiatrically ill patients. It is obvious for the caregiver of a person to experience more burdens if his patient is completely dependent on him as compared to his counterpart whose patient is independent.^[24] The burden here is due to two reasons. Firstly the caregiver's job becomes more physically demanding, and in the absence of any help, the situation worsens. It is more prominent if the patient is a male and the caregiver is a female of the same or lesser age. Also, things may become awkward if the situation is vice versa. Secondly seeing your once so healthy and fit relative now bed-ridden and dependent is mentally traumatizing. But this finding calls for a further study and intervention in this topic.

Family members a cause for stress

Last but not the least, there is a significant relationship between the number of family members with emotional environment of caregiver burden score in medicine patients; however, there is no significant relationship between number of family members and all categories of caregiver burden score of psychiatrically ill patients. Caregivers receiving social support from family members tend to have lesser burden.^[25] In some cases, it may so happen that for example, a female caregiver has to take care of so many family members in addition to taking care of the patient which makes further add on to her burden. Although it may happen that in process of taking care of the patient, the caregiver tends to ignore or neglect the other family members.

CONCLUSION

It has been observed that care givers whose patients are psychiatrically ill experience more burden as compared their counterparts from the medicine department. This calls for a greater intervention by the attending doctor for the psycho education and motivation of such a caregiver. The burden was more in females as compared to the other sex which too needs a similar intervention by the attending doctor. Further, it was observed that burden is directly proportional to the chronicity of the illness. This exemplifies the need to make professional help, which counsels about the various coping methods be made available to the caregivers as their patient's illness progresses toward bad prognosis.

Limitations

Contradictory to previous research,^[26] there was no significant relationship between the patient's age and gender caregiver's age and annual family income with all categories of caregiver burden score among medicine as well as psychiatrically ill patients. This was in consistence with a previous report "Burden on Caregivers of Patients with Schizophrenia and Related Factors."^[27] A possible explanation for the former the sample being from a tertiary municipal medical college located in a semiurban area, is not representative of the population. Hence, the results of this study cannot be extrapolated to the general population. Further, since we have not evaluated the samples by different categories of mental illness and prognostic formulations, we cannot very well predict the prognosis of the illness and the impact of the same on the care giver. Finally, certain demographic parameters such as marital status, job profile, and availability of professional help to the care giver were not studied.

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Conflicts of interest

There are no conflicts of interest.

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APPENDIX

APPENDIX 1

Questionnaire

I. Personal Information.

1. Details of relative/primary caregiver

Name: _____

Age: _____

Gender: _____

Occupation: _____

Place of residence: _____

No. of members in household: _____

Approximate monthly income: _____

No. of earning members: _____

2. Details of patient

Name: _____

Age: _____

Gender: _____

Patient is suffering from: Since how long has the patient been suffering:

II. Scale (Caregiver's Burden Scale)

1 = Not at all 2 = Seldom

3 = Sometimes 4 = Often

III. Questions

Please, place a tick in the appropriate box.

No 1: Do you feel tired and worn out?

1 2 3 4

No 2: Do you feel lonely and isolated because of your relative's problem?

1 2 3 4

No 3: Do you think you have to shoulder too much responsibility for your relative's welfare?

1 2 3 4

No 4: Do you sometimes feel as if you would like to run away from the entire situation you find yourself in?

1 2 3 4

No 5: Do you find yourself facing purely practical problems in the care of your relative that you think are difficult to solve?

1 2 3 4

No 6: Do you ever feel offended and angry with your relative?

1 2 3 4

No 7: Do you think your own health has suffered because you have been taking care of your relative?

1 2 3 4

No 8: Has your social life, e.g., with family and friends, been lessened?

1 2 3 4

No 9: Does the physical environment make it troublesome for you taking care of your relative?

1 2 3 4

No 10: Do you feel tied down by your relative's problem?

1 2 3 4

No 11: Do you feel embarrassed by your relative's behavior?

1 2 3 4

No 12: Has your relative's problem prevented you from doing what you had planned to do in this phase of your life?

1 2 3 4

No 13: Do you find it physically trying to take care of your relative?

1 2 3 4

No 14: Do you think you spend so much time with your relative that the time for yourself is insufficient?

1 2 3 4

No 15: Do you worry about not taken care of your relative in the proper way?

1 2 3 4

No 16: Do you neglect your other family members because of your patient?

1 2 3 4

No 17: Do you neglect looking after yourself because of your patient?

1 2 3 4

No 18: Have you experienced economic sacrifice because you have been taking care of your relative?

1 2 3 4

No 19: Do you find it mentally trying to take care of your relative?

1 2 3 4

No 20: Can you leave your patient alone in the house to fulfill your other commitments?

1 2 3 4

No 21: How often do you think of keeping your patient in some professional care institute (something like an old age home) or hiring a personal attendant/nurse?

1 2 3 4

No 22: Do you avoid inviting friends and acquaintances home because of your Relative's problem?

1 2 3 4