

Assessment of Caregiver Burden in Psychiatric Patients

Dr. Surabhi Agarwal¹, Dr. Nilesh Naphade², Dr. Jyoti Shetty³

¹Resident, Department of Psychiatry, Bharati Vidyapeeth Deemed University Medical College, Pune

²Professor, Department of Psychiatry, Bharati Vidyapeeth Deemed University Medical College, Pune

³Professor, Department of Psychiatry, Bharati Vidyapeeth Deemed University Medical College, Pune

Abstract: *This study aims to assess the prevalence of caregiver burden in psychiatric illnesses, assessing gender differences in caregiver burden, correlating the duration of psychiatric symptoms & relationship of caregiver with patient, to the severity of burden. 45 caregivers of patients with psychiatric illness were assessed on Zarit caregiver Burden interview scale & DASS 42 scale. Caregiver burden was prevalent in all patients, with greater burden perceived by females than by males. Longer duration of illnesses were associated with greater burden perceived. Parents of patients and spouses experienced greater burden followed by the children & siblings respectively.*

Keywords: caregiver, burden, psychiatric illness.

1. Introduction

Recent years have seen increasing awareness of the role of caregivers in the long-term management of psychiatric patients, and there is growing body of literature on the caregiver burden, poor caregiver outcomes, lack of caregiver support, and equivocal success, with interventions aimed at alleviating the care-giving burden. It has also become clear that the emphasis in psychiatric rehabilitation needs to shift from a patient-focused approach to a combined patient and caregiver- focused approach.

Caregiving is a dynamic process which includes patient, and a person who is involved in long term care of the patient. In disabling mental disorders such as schizophrenia and bipolar disorder, long term care is involved. This long term care very often leads to experience of burden in the caregivers.

2. Literature Review

Hoeing and Hamilton¹ were the first researchers to make a distinction between objective and subjective dimensions of burden. Objective burden (OB) refers to the negative effects of the illness on the household and the caregiving demands placed on the family members. Subjective burden (SB) refers to the caregivers' or family members' personal appraisals of the situation and the extent to which the individuals perceive they are carrying a heavy load.²

Caregiver burden can include physical, psychological, social, and financial problems.³ embarrassment; overload; and resentment.⁴ Caregiver responses vary with their relationship to the recipient. Spouses are at risk because of their own physical frailties and loss of support.⁵ Alternatively, caring for a spouse may be viewed as a marriage commitment, but caring for a parent may produce conflicts with a spouse and/or children.⁶ Gallagher and associates¹¹ found that 36% of caregivers who were not seeking help had clinical depression, compared with 68% of self-referred caregivers.⁷ Several studies have shown that female caregivers experience more distress than their male counterparts and

that this finding persists even after controlling for the influence of other variables such as income and education.^{8-10.}

Greater burden was predicted by more severe patient negative symptoms (stressor), greater anger control (vulnerability), and decreased tangible social support (resource).

In a study, Trivedi and colleagues¹¹ found that the parents and siblings of schizophrenic patients experienced more burden in comparison to spouses. They also stated that young relatives and those having the age of above 45 experienced more burden than the middle age group relatives. There is a positive correlation of family burden and duration of illness.¹²

The onset of Bipolar disorder in an adolescent presents potentially lifelong care giving challenges for the parents. Parents may provide decades of extended care giving challenges for the adult son or daughter who is suffering from BPAD when debilitating symptoms produce ongoing obstacles to social and occupational functioning and independent living. This chronic care giving role may cause stress for parents and threaten their physical and mental health. Bipolar disorder is associated with a high degree of chronicity and disability, and caregivers experience a significant burden, which is, in turn, associated with poorer clinical outcomes for the patients. The burden experienced by caregivers for BPAD patients is independently predicted by patients' depression, even after taking into account the chronicity of symptoms.

Patients with disorders such as schizophrenia and bipolar affective disorder are more likely to relapse when there is high expressed emotion present in their living environment. The stress from the remarks and attitudes of the family is overwhelming because they feel like the cause of the problems. The patient then falls into the cycle of relapse. The only way to escape this vortex is for the family to go through therapy together to prevent the criticism and relapse. But

before that it becomes necessary to understand that what is the reason behind such attitude towards a family member who is mentally ill, what is the cause of burden and what all changes the caregivers' and the patients' quality of life come across.

3. Method

This was a Cross Sectional , analytical study conducted among patients attending the Psychiatric OPD/IPD at BharatiVidyapeeth Deemed Univeristy Medical College and Research Centre; a private tertiary care hospital in Pune , India . A total of 45 caregivers, all above the age of 18 years, of patients with psychiatric diagnosis of schizophrenia, mood disorders, substance use disorders as per International Classification of Diseases and Health Related Problems- 10 (ICD-10) were included. Caregivers having pre-existing psychiatric illnesses and other co-existing medical or surgical illnesses as well as Caregivers of patients having co-existing medical or surgical illnesses and having other diagnosed psychiatric conditions other than schizophrenia, substance use disorders, mood disorders were excluded.A written informed consent was taken from all participants.

After Obtaining Sociodemographic details of the participants like age, gender , education, occupation, relation with patient , family type , marital status , etc., the perceived burden of the caregivers was measured using the Zarit Burden Interview Scale , a popular caregiver self-report measure used by many aging agencies, originated as a 29-item questionnaire (Zarit, Reever& Bach-Peterson, 1980).The revised version contains 22 items. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always).

The DASS 42 is a set of three self –report Scales designed to measure the negative emotional states of depression, anxiety and stress. Based on a dimensional rather than categorical conception of a psychological disorder , the development of DASS was based on the assumption that the depression , the anxiety and the stress experienced by the normal and the clinically disturbed , are essentially differences in degree. The DASS is available in English, Hindi and Marathi , translation there of has been done by a team at KEM hospital , Pune. Psychological disturbances in participants were assessed on the scores obtained on DASS 42. Chi-Square test, Fischer's Exact- test were used to obtain the results.

4. Results

Out of a total of 45 participants , 19 were females and 26 were males. A certain degree of burden along with varying degrees of stress, anxiety and burden was perceived by all participants. 56% of caregivers displayed moderate burden , 9% mild burden and around 35% of patients having severe burden . However, females perceived a great level of burden compared to men (p=0.322). They also had a marginally greater amount of anxiety (p<0.001), stress (p=0.018) and depressive features (p=0.056) compared to men.

22 participants had their patients with duration of illness of less than 1 year, 13 had between 1-5 years, while 10

caregivers had their patients with duration of illness of more than 5 years. The duration of illness showed a directly proportionally relation with respect to the burden perceived by the caregivers. Caregivers of patients with longer duration of illness, showed a great amount of burden (p=0.162). They also perceived a greater amount of depressive features (p=0.811) and stress (p=0.932). Anxiety (p=0.955)however was seen more among caregivers of patients with comparatively shorter duration of illnesses

The Caregivers were the parents, the siblings, the children or the spouses of the patients. With respect to the relationship of the caregiver with the patient, parents of patients and spouses experienced greater burden followed by the children and siblings respectively (p<0.001). Depressive and stress symptoms (p<0.001) were greatest in the spouse , followed by the parents , and then children and siblings respectively. The parents and spouse have equal levels of anxiety (p=0.005,) followed by the children and then lastly the siblings of the patients.

| | | Gender | | Total | p-value |
|----------------|----------|--------|----|-------|---------|
| | | F | M | | |
| zarit severity | mild | 11 | 5 | 16 | 0.322 |
| | moderate | 14 | 11 | 25 | |
| | severe | 3 | 1 | 4 | |
| Total | | 19 | 26 | 45 | |

| | | Gender | | Total | p-value |
|--------------------|------------------|--------|----|-------|---------|
| | | F | M | | |
| dass anxiety grade | Extremely severe | 1 | 0 | 1 | < 0.001 |
| | mild | 9 | 9 | 18 | |
| | moderate | 8 | 3 | 11 | |
| | severe | 1 | 0 | 14 | |
| | normal | 0 | 14 | 1 | |
| Total | | 19 | 26 | 45 | |

| | | Gender | | Total | p-value |
|----------------|----------|--------|----|-------|---------|
| | | F | M | | |
| zarit severity | Mild | 11 | 5 | 16 | 0.322 |
| | Moderate | 14 | 11 | 25 | |
| | Severe | 3 | 1 | 4 | |
| Total | | 19 | 26 | 45 | |

| | | Gender | | Total | p-value |
|--------------------|------------------|--------|----|-------|---------|
| | | F | M | | |
| dass anxiety grade | Extremely severe | 1 | 0 | 1 | < 0.001 |
| | mild | 9 | 9 | 18 | |
| | moderate | 8 | 3 | 11 | |
| | severe | 1 | 0 | 14 | |
| | normal | 0 | 14 | 1 | |
| Total | | 19 | 26 | 45 | |

| | | Gender | | Total | p-value |
|---------------|------------------|--------|----|-------|---------|
| | | F | M | | |
| dassdep grade | extremely severe | 1 | 0 | 1 | 0.056 |
| | mild | 11 | 6 | 17 | |
| | moderate | 7 | 6 | 13 | |
| | normal | 1 | 7 | 8 | |
| Total | | 19 | 26 | 45 | |

| | | Gender | | Total | p-value |
|-------------------|------------------|--------|----|-------|---------|
| | | F | M | | |
| dass stress score | extremely severe | 1 | 0 | 1 | 0.018 |
| | mild | 6 | 11 | 17 | |
| | moderate | 6 | 6 | 12 | |
| | normal | 0 | 7 | 7 | |
| | severe | 6 | 2 | 8 | |
| Total | | 19 | 26 | 45 | |

| | | Relation | | | | Total | p-value |
|----------------|----------|----------|----------|----------|--------|-------|---------|
| | | parents | siblings | children | spouse | | |
| zarit severity | mild | 3 | 8 | 3 | 2 | 16 | < 0.001 |
| | moderate | 10 | 0 | 5 | 10 | 25 | |
| | severe | 0 | 0 | 0 | 4 | 4 | |
| Total | | 13 | 8 | 8 | 16 | 45 | |

| | | Duration_Group | | | Total | p-value |
|----------------|----------|----------------|-----------|-----------|-------|---------|
| | | <1 year | 1-5 years | > 5 years | | |
| Zarit severity | mild | 1 | 4 | 11 | 16 | 0.162 |
| | moderate | 7 | 8 | 10 | 25 | |
| | severe | 1 | 1 | 2 | 4 | |
| Total | | 22 | 13 | 10 | 45 | |

| | | Relation | | | | Total | p-value |
|--------------------|------------------|----------|----------|----------|--------|-------|---------|
| | | Parents | Siblings | Children | Spouse | | |
| dass anxiety grade | Extremely severe | 0 | 0 | 0 | 1 | 1 | 0.005 |
| | mild | 6 | 2 | 4 | 6 | 18 | |
| | moderate | 2 | 0 | 1 | 8 | 11 | |
| | normal | 5 | 6 | 3 | 0 | 14 | |
| Total | | 13 | 8 | 8 | 16 | 45 | |

| | | Duration_Group | | | Total | p-value |
|--------------------|------------------|----------------|-----------|-----------|-------|---------|
| | | <1 year | 1-5 years | > 5 years | | |
| dass anxiety grade | Extremely severe | 1 | 0 | 0 | 1 | 0.955 |
| | mild | 10 | 5 | 3 | 18 | |
| | moderate | 5 | 3 | 3 | 11 | |
| | normal | 5 | 5 | 4 | 14 | |
| | Severe | 1 | 0 | 0 | 1 | |
| Total | | 22 | 13 | 10 | 45 | |

| | | Relation | | | | Total | p-value |
|---------------|-------------------|----------|-----------|-----------|---------|-------|---------|
| | | Parent s | Sibling s | Childre n | Spous e | | |
| dassdep grade | Extremel y severe | 0 | 0 | 0 | 1 | 1 | < 0.001 |
| | mild | 7 | 2 | 8 | 0 | 17 | |
| | moderate | 4 | 0 | 0 | 9 | 13 | |
| | normal | 2 | 6 | 0 | 0 | 8 | |
| | severe | 0 | 0 | 0 | 6 | 6 | |
| Total | | 13 | 8 | 8 | 16 | 45 | |

| | | Duration_Group | | | Total | p-value |
|---------------|------------------|----------------|-----------|-----------|-------|---------|
| | | < 1 year | 1-5 years | > 5 years | | |
| Dassdep grade | extremely severe | 1 | 0 | 0 | 1 | 0.811 |
| | mild | 3 | 6 | 8 | 17 | |
| | moderate | 4 | 4 | 5 | 13 | |
| | normal | 1 | 1 | 6 | 8 | |
| | severe | 1 | 2 | 3 | 6 | |
| Total | | 22 | 13 | 10 | 45 | |

| | | Relation | | | | Total | p-value |
|-------------------|------------------|----------|----------|----------|--------|-------|---------|
| | | Parents | Siblings | Children | Spouse | | |
| Dass stress score | extremely severe | 0 | 0 | 0 | 1 | 1 | < 0.001 |
| | mild | 5 | 3 | 8 | 1 | 17 | |
| | moderate | 6 | 0 | 0 | 6 | 12 | |
| | normal | 2 | 5 | 0 | 0 | 7 | |
| | severe | 0 | 0 | 0 | 8 | 8 | |
| Total | | 13 | 8 | 8 | 16 | 45 | |

| | | Duration_Group | | | Total | p-value |
|-------------------|------------------|----------------|-----------|-----------|-------|---------|
| | | < 1 year | 1-5 years | > 5 years | | |
| Dass stress score | Extremely severe | 0 | 0 | 1 | 1 | 0.932 |
| | mild | 4 | 5 | 8 | 17 | |
| | moderate | 3 | 4 | 5 | 12 | |
| | normal | 5 | 1 | 1 | 7 | |
| | severe | 2 | 2 | 4 | 8 | |
| Total | | 22 | 13 | 10 | 45 | |

| | | diagnosis of primary pt | | | | Total | p-value |
|--------------------|------------------|-------------------------|------------------------------|----------------------|----------------------|-------|---------|
| | | ADS (n=15) | Mood disorder with psy (n=4) | Mood disorder (n=11) | schizophrenia (n=15) | | |
| zarit severity | mild | 3 | 2 | 8 | 3 | 16 | 0.079 |
| | moderate | 10 | 2 | 3 | 10 | 25 | |
| | severe | 2 | 0 | 0 | 2 | 4 | |
| dass anxiety grade | mild | 4 | 2 | 4 | 8 | 18 | 0.228 |
| | moderate | 4 | 1 | 2 | 4 | 11 | |
| | Severe | 0 | 1 | 0 | 0 | 1 | |
| | extremelysevre | 0 | 0 | 0 | 1 | 1 | |
| | normal | 7 | 0 | 5 | 2 | 14 | |
| dassdep grade | mild | 6 | 2 | 4 | 5 | 17 | 0.262 |
| | moderate | 5 | 1 | 1 | 6 | 13 | |
| | severe | 2 | 0 | 1 | 3 | 6 | |
| | extremely severe | 0 | 0 | 0 | 1 | 1 | |

| | | | | | | | |
|-------------------|------------------|---|---|---|---|----|-------|
| | normal | 2 | 1 | 5 | 0 | 8 | |
| dass stress score | mild | 7 | 2 | 4 | 4 | 17 | 0.118 |
| | moderate | 4 | 1 | 2 | 5 | 12 | |
| | severe | 2 | 1 | 0 | 5 | 8 | |
| | extremely severe | 0 | 0 | 0 | 1 | 1 | |
| | moderate | 4 | 1 | 2 | 5 | 12 | |

5. Discussion

These findings demonstrate that almost all the caregivers of patients with psychiatric illnesses experience some form of burden and also display symptoms of anxiety, depression and stress in varying levels. Also females displayed a greater burden compared to males. The duration of the illness was directly proportional to the severity of the burden. Anxiety however was seen more in illnesses with shorter duration, unlike depressive and stress symptoms. Spouse and parents of patients experienced greatest burden and psychological symptoms, followed by children and lastly siblings.

6. Future Scope

Chronic caregiving role may cause stress for the caregivers and threaten their physical and mental health, which go unaddressed leading to worsening of their own health as well as the health of the primary patients.

Patients with psychiatric disorders are more likely to relapse when there is high expressed emotion present in their living environment. The stress from the remarks and attitudes of the family is overwhelming because they feel like the cause of the problems. The patient then falls into the cycle of relapse. The only way to escape this vortex is family counseling and psychoeducation to prevent this relapse. It is also imperative to identify and address caregiver burden and stress and thus prevent a psychological breakdown in the caregivers themselves.

References

- [1] P.J. Wang, "Fundamentals of erbium-doped fiber amplifiers arrays (Periodical style—Submitted for publication)," *IEEE J. Quantum Electron.*, submitted for publication. Hoening J, Hamilton MW. The schizophrenic patient in the community and his effect on the household. *International J Soc Psychiatry*, 1966; 12 : 165-176. 0
- [2] Maurin JT, Boyd CB. Burden of mental illness on the family: A critical review. *Arch Psychiatr Nursing* 1990; 6 : 99-107.
- [3] George LK, Gwyther LP. Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *Gerontologist*. 1986;26:253-259). Gupta, M.A. and Gupta, A.K. (1998) Depression and Suicidal Ideation in Dermatology Patients with Acne, Alopecia areata, Atopic Dermatitis and Psoriasis. *British Journal of Dermatology*, **139**, 846-850.
- [4] (Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*. 1980;20:649-655).
- [5] Cohen CA, Gold DP, Shulman KI, et al. Factors determining the decision to institutionalize dementing individuals: a prospective study. *Gerontologist*.

- 1993;33:714-720.). Wysowski, D.K., Pitts, M. and Beitz, J. (2001)
- [6] Brody EM. "Women in the middle" and family help to "older people. *Gerontologist*. 1981;21:471-480.
- [7] Gallagher D, Rose J, Rivera P, et al. Prevalence of depression in family caregivers. *Gerontologist*. 1989;29:449-456
- [8] Cook JA. Who 'mothers' the chronically mentally ill? *Family Relations* 1988; 37 : 42- 49.
- [9] Noh S, Turner RJ. Living with psychiatric patients: Implications for the mental health of family members. *Soc Sci Med* 1987; 25 : 263- 271.
- [10] Noh S, Avison WR. Spouses of discharged psychiatric patients: Factors associated with their experience of burden. *J Marriage Family* 1988; 50 : 337-389.
- [11] Trivedi JK, Dalal PK, Kalra H. Family burden and coping strategy in relatives of schizophrenic patients. *Indian J Psychiatry Supplement* 2003; 106.
- [12] Vohra AK, Garg S, Gaur DR. A study of burden on families of schizophrenia and depressive disorders. *Indian J Psychiatry, Suppl* 2002; 33.

Author Profile

Dr. Surabhi Agarwal Resident, Bharati Vidyapeeth Deemed University Medical College, Pune

Dr. Nilesh Naphade ,Professor, Department of Psychiatry, Bharati Vidyapeeth Deemed University Medical College, Pune

Dr. Surabhi Agarwal, Professor, Department of Psychiatry, Bharati Vidyapeeth Deemed University Medical College, Pune