



ORIGINAL RESEARCH PAPER

Psychiatry

TO STUDY THE BURDEN AND ATTITUDE OF CAREGIVERS OF SCHIZOPHRENIC PATIENTS

KEY WORDS: Expressed emotion, caregiver burden, schizophrenia, diabetes.

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ABSTRACT

Background: Schizophrenia is a dark shadow in an individual's life. The patients with schizophrenia are frequently hospitalized and usually need long term care and treatment in order to reduce negative impacts. Families in India are involved in most aspects of care for person with several mental illnesses. Families not only provide practical help and personal care but also provide emotional support to their relatives.
Methods: Two groups, one of 100 caregivers of schizophrenia and another one of 50 caregivers of diabetes mellitus were selected. The structured self-report tools including Burden Assessment Schedule (BAS) a rating scale to assess caregiver burden and The Family Attitude Scale (FAS) a rating scale to assess expressed emotion were administered to both the groups. Appropriate statistics was applied to compare both groups.
Results: Caregiver of schizophrenic patients have higher BAS score and FAS score compare with caregivers of Diabetic.

Introduction-

As per WHO estimates, around 450 million people are suffering from a mental or behavioural disorder worldwide.^[1] Neuropsychiatric disorders including schizophrenia, depression, bipolar disorder and alcohol-use disorders constitute of the leading causes of years lived with disability.^[1,2] Schizophrenia has a global prevalence of 0.3-0.7 %, with 3 million Indians suffering from the same.^[3] Schizophrenia is a chronic psychiatric disorder, and its effects can be classified at three levels like the patient who undergoes personal suffering, the caregiver and/families for the burden of care, financial and psychosocial support.^[4] Patient's relatives experience a large range of emotions like- loss and grief to guilt, anger, isolated and stigmatized.^[5,6] Caregivers are often bound by kinship obligations to adopt certain duties and responsibilities.^[7-9] If caregiving is prolonged, problems can be exacerbated, things may not get better with time. A further difficulty is that caregivers find that they have no choice.^[10] Historically and in contrast to their Western counterparts, Indian caregivers always have been included in the treatment of people with mental illness. A large part of the mental health care had thus always taken place in the community with the family as the primary care provider. This is due to the social and cultural milieu as well as the inadequate existing mental health infrastructure.^[11] Families in India are involved in most aspects of care for persons with several mental illnesses. They are recognized as having a prominent role in-decisions regarding engagement or disengagement in the process of treatment, supervision of medication, providing day-to-day care and emotional support to the patients.^[12,13] Burden of family caregivers leads to negative consequences for themselves, patients, family members, and health care system. For caregivers, burden negatively affects caregiver's-physical, emotional, economic status, poor caring, mistreatment or behaving violently to the patients can cause patients relapse.^[14]

Expressed emotion is a measure of the family environment that is based on how the relatives of a psychiatric patient spontaneously talk about the patient.^[15] A high level of expressed emotion in the home can worsen the prognosis in patients with mental illness such as schizophrenia and act as a potential risk factor for the development of psychiatric diseases.^[16-18]

It is important to understand caregivers' coping mechanisms for tackling burden, because it affects caregivers' day-to-day functioning. The burden is a constant source of stress, and how the caregivers cope with it, affects the course of illness. The burden and the coping methods also influence the physical and mental health of the caregiver and hence their further efficacy as a caregiver.

The emotion focused coping has been reported to be associated with perception of higher burden, whereas predominantly

problem focused and fewer emotion focused coping strategies lead to reduced perception of burden. Caregiver's positive evaluation of their coping strategies is associated with reduced distress levels and positive attitude toward the patient (independent of symptoms and levels of burden). Problem solving coping has been reported to be associated with better functioning.^[19]

Aim of the study – There is high burden for caregivers and attitude towards psychiatric patients so present study was conducted to find out caregivers burden and expressed emotion in caregivers of schizophrenic patients.

Methodology- An approval was obtained from the Institutional ethics committee of SMS Medical College, Jaipur before the commencement of the study. A cross sectional, descriptive study was done at department of psychiatry and endocrinology , SMS Medical college Jaipur.100 caregivers of schizophrenic patients who were diagnosed by ICD-10 criteria and 50 caregivers of diabetic patients as a control group.

Inclusion Criteria-

- Caregivers age 18-60 of either sex.
- Primary caregiver (adult relative) was living with a patient, in the same environment, for at least 12 months and was involved directly in giving care to the patient and most supportive either emotionally or financially, i.e. felt most responsible for the patient.
- Caregivers of patients with continuous illness since last 2 years.

Exclusion criteria-

- Caregivers who are not willing to participate.
- Caregivers with psychiatric problems.

Tools of the study-

- Informed consent form (Hindi)
- Semi structured socio-demographic profile sheet
- Detailed clinical data sheet
- BAS(Burden Assessment Schedule)
- FAS (Family Attitude Scale)

Brief Description about Tools-

- BAS
- FAS

BAS (Burden Assessment Schedule)-developed at the Schizophrenia Research Foundation (SCARF), India, to assess the burden on family caregivers of patient with chronic mental illness. This is a semi-quantitative, 40-item scale measuring 9 different areas of objective and subjective caregiver burden. Each item is rated on a 3-point scale. The responses are 'not at all', 'to some

extent', and 'very much'. Some of the items are reverse coded. Scores range from 40 to 120 with higher scores indicating greater burden i.e. mild burden (0-40), moderate burden (41-80) and severe burden (81-120).^[20]

FAS (Family Attitude Scale)- Respondents reported how often each statement was true at the moment, on a scale from 'Every Day'(4) to 'Never'(0). Ten items were reverse scored. Responses were summed to give a score ranging from 0 to 120, with higher scores indicating higher levels of burden or criticism.^[21]

Statistical Analysis- Data were analysed using Statistical Package of Social Sciences (SPSS) version 23.0. Appropriate statistic, both parametric and non-parametric tests, were applied as below.

OUTCOME ANALYSIS:

- Qualitative data will be expressed in percentage and proportion.
- Quantitative data will be expressed in mean and standard deviation
- Significance of difference in proportion will be inferred by student t-test.

For significance P 0.05 will be considered significant.

Results- 100 caregivers of schizophrenic patients and 50 caregivers of diabetic patients were included in our study. The mean age of caregivers for the both chronic illness was 38 years. 66% of schizophrenic caregivers were female and for diabetic 48%. 72% of schizophrenic caregivers were married while diabetic 92%. Schizophrenic caregivers were belongs to mostly from lower socioeconomic class (63%) while diabetic caregivers 46% from lower socioeconomic class. 56% schizophrenic caregivers were lived in joint family and on other hand 60% diabetic caregivers in nuclear family. In both groups caregivers were from urban areas. The kinship in the caregivers of schizophrenic patients were spouse, father, mother, and child but for the diabetic patients mostly spouse followed by others.

The burden and attitude of schizophrenic patients caregivers were statistical significant (p<0.001).They faced moderate to severe burden in caring of schizophrenic patient and also the attitude score were high towards patients. The mean of burden assessment score in schizophrenic patient caregivers group was 82.40 and for diabetic 40.84. The mean of family attitude scale was 58.20 for the caregivers of schizophrenia while in diabetic 7.36.

Table [1] Socio-demographic characteristics of caregivers of schizophrenic and diabetic patients (control group)

Variables	caregivers of schizophrenic patients (n=100)	caregivers of diabetic patients (n=50)
Age	38.98± 5.85	38±10.2
Gender		
Male	44(44%)	26(52%)
Female	66(66%)	24(48%)
Marital status		
Single	20 (20%)	8 (16%)
Married	72 (72%)	40 (80%)
Widowed	8 (8%)	2 (4%)
Educational Level		
Illiterate	18 (18%)	3 (6%)
Upto middle	38 (38%)	7 (14%)
Middle to Sr.sec	20 (20%)	10 (20%)
Graduate/PG	24 (24%)	20 (40%)
Employed		
Yes	78 (78%)	30 (60%)
No	32 (32%)	20 (40%)
Socioeconomic class		
upper	1 (1%)	2 (4%)
middle	36 (36%)	25 (50%)
lower	63 (63%)	23 (46%)
Family type		
nuclear	44 (44%)	30 (60%)
joint	56 (56%)	20 (40%)

Locality		
Urban	52 (52%)	31 (62%)
Rural	48 (48%)	19 (38%)
Kinship with the patient		
father	20 (20%)	8 (16%)
mother	18 (18%)	8 (16%)
spouse	32 (32%)	19 (38%)
child	16 (16%)	10 (20%)
brother	12 (12%)	4 (8%)
Sister	2 (2%)	1 (2%)

Table[2] FAS and BAS for the caregivers of schizophrenic and diabetic patients (control group)

Variables	for caregivers of schizophrenic patients Mean ± SD	for caregivers of diabetic patients Mean ± SD	P Value
FAS	58.20 ± 25.28	7.36 ± 1.87	0.001
BAS	82.40 ± 16.15	40.84 ± 2.01	0.001

Discussion-

In our study Burden assessment schedule (BAS) total score mean for the caregivers of schizophrenic patients 82.40 which was statistically significant (p=0.001) and having the moderate to severe burden and The family attitude scale (FAS) total score mean for the caregivers of schizophrenic patients was 58.20 statistically significant (p=0.001). Most of the caregivers were females. The caregivers were observed to have moderate and high levels of burden. Burden on caregivers was depending on their overall quality of life, by the levels of coping and extrovert type of personality and also with the environmental health of the caregivers. Caregivers who were not able to use effective coping styles have heavier burdens. So who were using non-functional coping styles, should be helped to change their attitudes.

Caregivers of schizophrenia experienced significantly higher burden in area of external support, caregivers routine, and other relations. The extent of burden among families of schizophrenic patients was more than other psychiatric disorder. Caregivers considered medical intervention to be the most important, but they also advocated supportive interventions such as counselling and family support. Financial problem was one of the factors that impacted negatively on follow-up of patients. Educational programs for the relatives of patients by developing psycho-educational intervention and sensitization campaigns are needed.

Our findings were supported by Disha et al that most of the caregivers were females of the schizophrenic patients and were observed to have moderate and high levels of burden^[22] and by S Vasudeva et al that the caregivers of schizophrenia group had significantly higher total burden score as compared to caregivers of bipolar disorder. Caregivers of schizophrenia experienced significantly higher burden in area of external support, caregivers routine, and other relations.^[23] Also supported by Koujalgi SR, Patil SR that caregivers of schizophrenic patients in comparison to depressive disorder have significantly high family burden except the effect on physical health of other family members^[24] and in Lorenza Magliano et al study that caregivers of schizophrenic patients having both objective and subjective burden were significantly higher.^[25] One another study by Asli Ozlu et al supported our findings that female caregivers was higher than men. The burden of employed caregivers was higher than unemployed. Statistically significant negative correlation between monthly income and burden was found.^[26]

Examination of differences on subjective burden revealed that there was a significant difference among two groups with more subjective burden in caregivers of schizophrenia group. Subjective burden delineates the personal distress or pain as a result of illness, which are psychological reactions, which caregivers undergo. These include grieving for the ill, feelings of loss, and loss of the person who might have been. The family members of schizophrenia group experience tremendous psychological stress with regard to caring of the ill person, which may precipitate

subjective burden. These family members experiences considerable grief about not enough has been carried out for the ill and may feel that they are the cause or contributed for the patient illness.

Caregivers of schizophrenia patients experience enormous burden and are potential "high risk group" for mental disorders. Thus, they require comprehensive intervention in order to reduce the growing incidence of chronic enduring diseases including mental disorders.

The present study has implications for practice, administration, education, and research. The exploration of burden of family caregivers gives baseline data necessary for decisions taking, further research and generation of coping styles, and tools to promote rehabilitative caring. Psychosocial intervention program has to be planned on the bases of proper assessment by caregivers coping styles, communication skills and community resources of key caregivers.

Conclusion- The present study has shown that family members of patients with schizophrenia experienced considerable high degree of family burden and higher emotional expression compared to other chronic illness. This has an important implication for management of patient with the schizophrenia.

Limitation-

- 1) Compare should be done with chronic mental illness.
- 2) Socio-demographic factors impact on BAS and FAS. So detailed study of these variables required. That will help in understand the caregiver's problems to care patients of chronic mental illness.

References-

[1] Investing in Mental Health Geneva, World Health Organization 2003 http://www.who.int/mental_health/media/en/investing_mnh.pdf (Accessed on: 21st January, 2012)

[2] WHO-Global Burden of Disease 2004 Update; Part 4; 4-5. Geneva, World Health Organization. http://www.who.int/healthinfo/global_burden_disease/2004_report_update/en/ (Accessed on: 21st January, 2012)

[3] Van Os J, Kapur S. Schizophrenia. *Lancet*. 2009;374(9690):635–45.

[4] Awad AG, Voruganti LN. The burden of schizophrenia on caregivers: a review. *Pharmacoeconomics*. 2008;26(2):149–62.

[5] Lefley HP. Aging parents as caregivers of mentally ill adult children: an emerging social problem. *Hosp Commun Psychiatry* 1987;38:1063–70.

[6] Wahl OF, Harman CR. Family views of stigma. *Schizophr Bull* 1989;15:131–9.

[7] Schene AH. Objective and subjective dimensions of family burden: towards an integrative framework for research. *Soc Psychiatry Psychiatr Epidemiol* 1990;25:289–97.

[8] Schene AH, Van Wijngaarden B, Koeter MWJ. Family caregiving in schizophrenia: domains and distress. *Schizophr Bull* 1998;24:609–18.

[9] Schene AH, Tessler RC, Gamache GM. Caregiving in severe mental illness: conceptualization and measurement. In: *Mental Health Service Evaluation*, Knudsen HC, Thornicroft G (Eds).UK: Cambridge University Press, 1996. . pp. 296–316.

[10] Kuipers E, Paul E, Bebbington PE. Research on burden and coping strategies in families of people with mental disorders: problems and perspectives. In: *Families and Mental Disorders: From Burden to Empowerment*, Sartorius N, Lefly J, Lopez Ibor JJ, Okasha A (Eds). Chichester, UK: John Wiley, 2005. pp. 217–34.

[11] Thara R, Srinivasan TN. Outcome of marriage in schizophrenia. *Soc Psychiatry Psychiatr Epidemiol* 1997;32:416–20.

[12] Nunley M. The involvement of family in Indian psychiatry. *Cult Med Psychiatry* 1998;22:317–53.

[13] Shankar R. Family professional collaboration in India. In: *Family Intervention in Mental Illness: International Perspectives*, Lefley HP, Johnson DL (Eds). Westport, CA: Praeger Publishers, 2002.

[14] Rafiyah Imas, S. Kp, Wandee Sutharangsee. Burden on Family Caregivers Caring for Patients with Schizophrenia and Its Related Factors. *Nurse Media Journal of Nursing* January 2011; 1(1):29–41.

[15] Butzlaff RL, Hooley JM (June 1998). "Expressed emotion and psychiatric relapse: a meta-analysis". *Arch. Gen. Psychiatry*. 55 (6): 547–52.

[16] Brown, G., Birley, J., & Wing, J. (1972). Influence of family life on the course of schizophrenic disorder: a replication. *British Journal of Psychiatry*, 121, 241-258. doi: 10.1192/bjp.121.3.241

[17] Garcia-Lopez, L.J., Muela, J.A. Espinosa-Fernández, L., & Diaz-Castela, M.M. (2009). Exploring the relevance of expressed emotion to the treatment of social anxiety disorder in adolescence. *Journal of Adolescence*, 32, 1371-1376. doi: 10.1016/j.adolescence.2009.08.001

[18] Asarnow JR, Tompson M, Woo S, Cantwell DP (December 2001). "Is expressed emotion a specific risk factor for depression or a nonspecific correlate of psychopathology?". *J Abnorm Child Psychol*. 29 (6): 573–83.

[19] Creado DA, Parkar SR, Kamath RM. A comparison of the level of functioning in chronic schizophrenia with coping and burden in caregivers. *Indian J Psychiatry* 2006;48:27-33.

[20] R. Thara, R. Padmavati, Shuba Kumar & Latha Srinivasan: Burden Assessment Schedule Instrument To Assess Burden On Caregivers Of Chronic Mentally Ill Indian J. Psychiat, 1998, 40(1), 21-29

[21] David J. Kavanagha, U, Paul O'Halloranb, Vijaya Manicavasagar c, Dianne Clark d, Olga Piatkowskiae, Chris Tennant f, Alan Roseng: The family attitude scale:

reliability and validity of a new scale for measuring the emotional climate of families, *Psychiatry Research* 70 1997 185 Ž.]195

[22] Disha Geriani, Kochukarottil Satish Babu Savithry, Seemanthini Shivakumar, and Tanuj Kanchan: Burden of Care on Caregivers of Schizophrenia Patients: A Correlation to Personality and Coping *J Clin Diagn Res*. 2015 Mar; 9(3): VC01–VC04.

[23] S Vasudeva, Chandra K Sekhar, Prasad G Rao: Caregivers burden of patients with schizophrenia and bipolar disorder: A sectional study 2013; 35(4):352-357.

[24] Koujalgi Sateesh R, Patil Shobhadevi :Family burden in patient with schizophrenia and depressive disorder: A comparative study , *Indian J Psychol Med*. 2013 Jul;35(3):251-5. doi: 10.4103/0253-7176.119475

[25] Lorenza Magliano Andrea Fiorillo Corrado De Rosa Claudio Malangone Mario Maj: Family burden in long-term diseases: a comparative study in schizophrenia vs. physical disorders, *Volume 61, Issue 2, July 2005, Pages 313-322*

[26] Asli Ozlu, Mustafa Yildiz, Tamer Aker: Burden and burden-related features in caregivers of schizophrenia patients .*The Journal of Psychiatry and Neurological Sciences*: 2015;28:147-153.