

A Study to Assess Burden of Care and Coping Mechanism of Family Members of Schizophrenia Patients

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ABSTRACT

The persons with schizophrenia undergo altered behaviour in their lifespan. The near relatives have to experience many crisis conditions while caring for them. The family members suffer high levels of emotional exhaustion while caring for a mentally ill patient. The study was conducted with the aim to assess the burden of care and coping of family members of a patient with schizophrenia in the Psychiatry department of Gauhati Medical College Hospital, Guwahati, Assam, India. The interview schedules the standardize tool Burden Assessment Schedule to assess the burden and Brief COPE Inventory to assess the coping was selected. The Data was collected from 60 family members of a patient with schizophrenia by using a convenience sampling technique.

The study result revealed that the majority (60%) had moderate and 21.7% had mild and 18.3% had the severe burden of care. Moreover, the majority of the family member (73.3%) had moderate coping followed by 16.7% had inadequate and least (10%) of the study population had an adequate level of coping. There was no significant correlation established between the burdens of care and coping among the respondents.

The study confirms the general impression that there is a considerable amount of burden among the family members of schizophrenic patients. The nursing personnel should plan some burden reduction program and adoption of healthy coping for the family members of schizophrenia patients as a part of nursing care.

Keywords: Burden of Care, Coping, Family Members and Schizophrenia Patients

INTRODUCTION

The number of people with schizophrenia in the world, particularly in developing countries, is increasing and 1 out of 100 people (approx) in the world suffer from schizophrenia (Mental Health Research Association, 2006). Generally, their behaviours are odd and sometimes harmful for themselves, such as committing suicide or violence to others. In addition, the disease may relapse during treatment and recovery. Therefore, patients with schizophrenia are frequently hospitalized and usually need long term care and

treatment in order to reduce negative impacts. [1] The family remains the major source of care for the mentally ill. The sufferer's family has a profound effect on their illness. People engaged for caring those with schizophrenia include parents, spouses, siblings and offspring. Family with schizophrenic patient faces lots of burdens which include care burden, fear, and embarrassment about illness signs and symptoms, uncertainty about the course of the disease, lack of social support, and stigma. [2]

Schizophrenia is most likely responsible for lengthier hospitalization among all mental illness which causes suffering in society, greater chaos in the family life, more exorbitant costs to individuals and governments, and more fears than any other. Because it is an enormous threat to life and happiness and its causes are an unsolved puzzle. [3] The increasing demands to assist patients in daily activities, to maintain their medications and supervise their problematic behaviours contribute to disruptions in the caregivers social, professional and family, causing feeling of burden. [4] Caregiver burden refers to the negative feelings and subsequent strain experienced as a result of caring for a chronically sick person. [5] The caregivers of schizophrenia patients are likely to face increasing levels of burden and stress. The burden of care does not only include the subjective dimension comprising of impact and consequences on the mental health of the caregivers, but also the objective dimension which includes dealing with patient's symptoms and behaviour, and changes in the household routine and family relations. [6]

Families are usually on the front lines of taking care of persons with dementia praecox. They need support to best assist their ill family member and to cope with the stress associated with schizophrenia. [6] As a mental health nurse it is our responsibility to identify the level of burden, coping and quality of life of the caregivers of schizophrenia patient and help them to adopt healthy coping mechanism and use of community resources, support services provided to them.

Significance of the Study

Schizophrenia is the most common of all psychiatric disorders and is prevalent in all cultures across the world. About 15 % of new admission in mental hospitals is schizophrenic patients. It has been estimated that patients diagnosed as having schizophrenia occupy 50% of all mental hospital beds. About three-four / a thousand in each community suffer from dementia

praecox. About 1% of the general population stands the risk of developing this disease in their lifetime. Schizophrenia has a global prevalence of 0.3-0.7%. In India, the prevalence rate of schizophrenia is high. The epidemiological study concludes that prevalence rate was 2.62 cases per 1000 population. [8]

It is one of the major mental disorders characterized by abnormalities in perception or expression of reality. The onset of symptoms usually happens in young adulthood. Even with available treatments, most people with Schizophrenia continue to experience symptoms throughout their lives. This will create a profound burden in the lives of their family members. Families touched by mental illness are often faced with significant financial burdens that arise from healthcare costs and job loss. A study done in India showed that the antipsychotics are affordable to the family, but the treatment expenditure of comorbidity, side effects and cost of consultation including travel add to the burden for the family. [9]

The consent was obtained from the participants. The Data was collected from 60 family members of a patient with schizophrenia by using a convenience sampling technique from 13th March to 20th April 2017 who fulfils the following inclusion criteria. The Family members whose patient's duration of illness was less than six months were excluded from the study.

Statistical Analysis:

Analysis for the present study is based on the objectives. After obtaining the data were organised, tabulated and interpreted using descriptive and inferential statistics. The statistical package for the social sciences (SPSS) was utilized to analyse the data. The master sheet was prepared from the raw data before entering the data to SPSS version 20. The level of significance was set at 0.05 levels to interpret the findings. The statistical analyses used were frequency, percentage, mean, and standard deviation, Chi - square

test to determine the association and Pearson correlation-coefficient test to determine relation Patients families are expected to make an unprecedented decision and deal with many stressful situations. In turn, they may have experience of the burden of caring the patient such as the financial need of the patients, physical and mental health of caregivers, disruption of family stability. Hence studying the burden of care and coping styles of family members of a patient with schizophrenia could be a useful way of generating information. There is a paucity of published studies conducted in Assam which signifies the burden and level of adjustment among family members of schizophrenia patients and hence inspire the researcher to take up a study on the assessment of the burden of care and coping mechanism of family members of schizophrenia patients. It is also helpful to plan an intervention program that addresses their specific needs. The study was undertaken with the following objectives:

1. To assess the burden of care among family members of patient with schizophrenia.
2. To assess the coping among family members of patient with schizophrenia.
3. To find out the correlation between burden of care and coping mechanism among family members of patient with schizophrenia

MATERIALS & METHODS

A descriptive study was undertaken with the aim to assess of the burden of care and coping mechanism of family members of schizophrenia patients Psychiatry department of Gauhati Medical College Hospital (GMCH), Guwahati, Assam, India. The psychiatry inpatient department consists of 50 beds with weekly outpatient clinic attendance of approximately 360 per month. The interview schedule standardizes tool Burden Assessment Schedule (Thara et al, 1998) [10] to assess the burden and Brief COPE Inventory (Carver, C. S. (1997). [11] to assess the coping was selected for the study. The reliability of the Burden

Assessment Schedule by Thara et al, (1998) was kappa 0.80 published in the Indian journal of psychiatry. [10] The reliability of Brief COPE inventory was developed by Yusoff N, Low WY, Yip CH with the reliability of Intraclass Correlation Coefficient (ICC) ranged from 0.05 to 1.00. [12]

Prior to data collection administrative approval, ethical committee clearance was obtained and consent between burden and coping.

ANALYSIS AND INTERPRETATION

The present study was conducted to assess the burden of care and coping among the family members of schizophrenic patients in the psychiatry department at Guwahati Medical College and Hospital, Assam. The study is based on the concept of having a mental illness patient is a stressful situation for the family members. Having a patient with schizophrenia is a stressful event for family members who often experience a burden for caring for the patient and fail to cope with the situation. The present study was carried out to assess the burden of care and coping of family members of schizophrenia patients.

It has been found that the majority of the family members i.e. 33(55%) of the population under study were female and 27(45%) were male. Among 60 participants most of the family members (40%) were parents. which can be well understood that the parents were the main members of the family to take care of their sick person. Majority of the respondents i.e. 24(40%) were parents of the patients, 17(28.3%) were spouse, 16(26.7%) were a sibling and 3(5%) were relatives and others.

Table 1: Distribution of family members according to their age

| Age | Frequency(f) | Percentage (%) |
|---------------|--------------|----------------|
| < 25 Years | 7 | 11.7 |
| 25 – 35 Years | 18 | 30.0 |
| 35 – 45 Years | 16 | 26.7 |
| >45 Years | 19 | 31.6 |
| Total | 60 | 100.0 |

Among the respondents, the majority of them i.e. 19 (31.6%) were in the age

group of more than 45 years, followed by 18(30%) were of age 25-35 years and the least comprise of 7(11.7%) were of age < 25 years.

Assessment of the burden of family members

The burden of the family members has been categorized into three categories, namely 'mild', 'Moderate' and 'severe' as per the formula Mean±Standard Deviation (SD) (78.13±7.87).

Table 2: Distribution of the respondents according to their level of burden

| Level of burden | Frequency(f) | Percentage(%) |
|--------------------|--------------|---------------|
| Mild (0 – 70) | 13 | 21.7 |
| Moderate (71 - 86) | 36 | 60.0 |
| Severe (> 86) | 11 | 18.3 |
| Total | 60 | 100.0 |

The majority of the study population 36(60%) had moderate and 13(21.7%) had mild and 11(18.3%) had a severe burden. The overall mean is 78.133 which imply that the subjects had a moderate burden on average.

Assessment of coping of the family members

The overall coping of the family members has been classified according to Mean±Standard Deviation (SD) (78.65±5.47).

Table 3: distribution of among family members according to the level of coping

| Coping | Frequency(f) | Percentage(%) |
|------------|--------------|---------------|
| Inadequate | 10 | 16.7 |
| Moderate | 44 | 73.3 |
| Adequate | 6 | 10.0 |
| Total | 60 | 100.0 |

It has been revealed that the distribution of the respondents according to their level of coping, majority of the study population 44(73.3%) had moderate and 10(16.7%) had inadequate and 6(10%) had adequate coping. The overall mean is 78.65 which imply that the subjects had moderate coping on average.

Table 4: Correlation between Burden and Coping

| Variables | Mean | SD | Correlation | P – value | Remark |
|-----------|-------|------|-------------|-----------|--------|
| Burden | 78.13 | 7.87 | -0.033 | .802 | NS |
| Coping | 78.65 | 5.47 | | | |

In the present study among the 60 family members caring for a schizophrenia patient, there was no correlation between burden and coping. It was found to be $r = -0.033$ which is not significant at 5% level ($p = 0.802 > 0.05$). Thus we can conclude that both the variables are independent. However, the 'r' value was in a negative direction. This means that if the burden of care increases the coping levels go down although there was no statistical significance for the present study.

DISCUSSION

The present study was conducted to assess the burden of care and coping among the family members of schizophrenic patients in the psychiatry department at Guwahati Medical College and Hospital, Assam. The data was collected from 60 family members of patients from the inpatient and outpatient unit by using an interview schedule. The study results showed that the majority 55% of the study subject were female majority of the family members 31.6% were in the age group of more than 45 years. The distribution of subjects with regard to education level, the maximum number of family member 31.7% was matriculated. The distribution of subjects according to the relationship with patients revealed that the majority of family members 40% were parents of the patients. According to their duration of illness, the majority of the patients 30% were suffering from 1- 3 years.

The burden of care among family members of a patient with schizophrenia:

The finding of the present study revealed that 60% had moderate and 21.7% had mild and 18.3% had the severe burden. Family members feel more burden in the area of burden related to the physical and mental health of family members (mean±SD 16.03±2.32) followed by other relationship and taking responsibility (9.95±1.04, 11.30±1.77).

These findings corroborate with the findings of many scholars. This finding is consistent with the finding of Singh PM and

Prajapati (2012) ^[12] who conducted a study on the burden faced by caregivers of schizophrenic patients at ManouthanSewa Kendra, Nepal. The result shows that the moderate burden seems to higher in caregivers of schizophrenic patients. Most burdens were found in the area of finance and family dynamics and the overall burden was moderate. Similar findings were reported by in the descriptive study conducted by Pun KK, Heb G, Wang XH (2014) ^[14] in Nepal who reported that 69(46.9%) were perceived moderate amount burden and 54(36.7%) experienced mild burden while 17(11.6%) felt little burden and 7(4.8%) were experienced severe burden during caring, their schizophrenic patient.

The coping mechanism among family members of a patient with schizophrenia:

Analysis of the present study showed that among 60 family members majority of the family member 73.3% had moderate, 16.7% inadequate and 10% of the study population had an adequate level of coping and family members use more acceptance as coping strategies (7.81±0.59) followed by religion, planning, the mean ± SD was 7.20 ± 1.08 and 7.45 ± 0.48 respectively. It is seen that mean score was higher with acceptance coping strategy and rare use of denial, behavioural disengagement and substance use (mean± SD was 2.90±1.53, 2.93±1.40, 2.58±1.18)

The similar findings were reported by Gerson R, Wong C, Davidson L, MalaspinaD, Glashan, TM and Corcoran C(2011) ^[15] and Batra BS, Ghildiyal R, Mathews M (2015)⁷. Gerson R, Wong C, Davidson L, Malaspina D, Glashan. Gerson R, Wong C, Davidson L, Malaspina D, Glashan, TM and Corcoran C conducted an exploratory study on coping strategies in families of patients in the early stages of psychotic disorder. The findings discovered that Families reported moderate use of "approach" header (e.g. designing, seeking social support, positive reinterpretation, acceptance, and turning to religion) and rare use of "avoidant" coping strategies

(denial/disengagement and use of alcohol and drugs). ^[15] Batra BS, Ghildiyal R, Mathews M (2015) ^[6] conducted a Descriptive Study on Coping Strategies among Caregivers of Patients with Schizophrenia in Nagpur who reported that "seeking non secular support" has emerged because the strongest header strategy among the caregivers and "mobilizing family to simply accept help" because the weakest header strategy.

The correlation between the burden of care and coping mechanism:

The present study revealed that there is no significant correlation between burden and coping. A similar finding was reported by Geriani D, Savithry SK, Shivakumar S, KanchanT (2015). ^[16] They conducted a cross-sectional study in the Department of Psychiatry, Kasturba Medical College, Mangalore, India on the burden of care on caregivers of schizophrenia Patients who reported that there is no significant correlation (p=0.258) between the coping mechanisms and the levels of burden experienced by the caregivers. Hassan WN, Mohamed II, Elnaser AE, and Sayed NE (2011) ^[17] conducted a descriptive study on Burden and coping strategies in caregivers of schizophrenic patients to explore burden and coping strategies in caregivers of schizophrenic patients and establish the connection between burden and header ways among them.

CONCLUSION

The findings of the study conclude that the majority (60%) family members expressed a moderate burden of care and the majority (73.3%) of the family member had a moderate level of coping. The conclusion could be drawn from the present study that there is a necessity to identify the level of burden of care and common areas of burden among family members of schizophrenia patients. It is also essential to identify the coping mechanism of family members and also help to plan intervention for the adoption of healthy coping during this stressful situation. It is suggested that to

plan intervention module and practice to increase satisfaction, coping of patient's families. It could possibly reduce the family member's burden of caring for a person with schizophrenia. The nursing personnel can develop a supportive relationship with family members by assessing the members need and by showing compassion and respect for the members and the member's decision. This supportive relationship has been linked to an increase in the satisfaction of patient's families and could possibly reduce family member's burden. The nurse should provide care not only to the patients but also to their family. The present study suggests that the family-centred approach is an important aspect of providing comprehensive care to patients and families.

REFERENCES

1. Rafiyah I, Kp S. Burden on Family Caregivers Caring for Patients with schizophrenic psychosis and its connected factors. Nurse Media Journal of Nursing 2011;11: 29 – 41. Available from: <https://www.ncbi.nlm.nih.gov/pubmed>
2. Biegel D, Schultz R. Caregiving and caregiver interventions in aging and psychopathy. Family Relations 1999; 48: 345-55. available from <http://www.lin.springer.com>
3. Townsend M.C. Schizophrenia spectrum and other psychotic disorders. Textbook of Psychiatric Mental Health Nursing, 8th ed. JP Brothers Medical Publishers: 2013.p.420.
4. Reine G, Lancon C, Simeoni MC, Duplans, & Anquier P. Caregiver burden in relatives of persons with schizophrenia: an overview of measure instruments. Encephale. 2003 Mar-Apr;29(2):137-47.
5. Natalie C, Ian MD, Steve H, Paul H. Measuring chronic patients' feelings of being a burden to their caregivers: Development and preliminary validation of a scale. Official Journal of Medical Care Section, American Public Health Association 2003;41:110-18. available from <http://dx.doi.org/10.14257/ijbsbt>
6. Esra YAZICI, Ümit KARABULUT, Mustafa YILDIZ et. al. Burden on Caregivers of Patients with Schizophrenia and Related Factors. *Noro Psikiyatry Ars.* 2016 Jun; 53(2): 96–101.
7. Batra BS, Ghildiyal R, Mathews M. Coping Strategies Among Caregivers of Patients with Schizophrenia. *IOSR-JDMS* 2015; 14: 20-29.
8. Vyas JN & Ahuja N. Textbook of postgraduate psychiatry. New Delhi: Jaypee Brothers Medical Publishers (p) Ltd; 1999.174, 153-154.
9. Lalitha K. Mental health and psychiatric nursing. 1st ed. Bangalore: VMG book house, 2007: P 20-8.
10. Thara R, Padmavati R, Kumar S, Srinivasan L. Burden Assessment Schedule. *Indian journal of psychiatry* 1998;40:20-29. available from www.indianjpsychiatry.org
11. Carver, C. S. You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine* 1997, 4, 92-100
12. Yusoff N, Low WY, Yip CH. Reliability and Validity of the transient COPE Scale (English Version) Among ladies with carcinoma Undergoing Treatment of Adjuvant therapy. *Med J Malaysia* March 2010; 65(1)
13. Singh PM and Prajapati A. Burden of schizophrenia on caregivers in Nepal. *Nepal Med Coll J* 2012; 15(2): 140-143.
14. Pun KK, Heb G, Wang XH. The extent of Burden and header among Family Caregivers Living with Schizophrenic Patients in an Asian country. *International Journal of Sciences: Basic and Applied Research (IJSBAR)* 2014;14:428-43.
15. Gerson R, Wong C, Davidson L, Malaspina D, Glashan TM, and Corcoran C. Self-reported coping strategies in families of patients in the early stages of psychotic disorder: an exploratory study. *Early Intervention Psychiatry* 2011;5(1):76-80.
16. Geriani D, Savithry S K, Shivakumar S, Kanchan T. Burden of Care on Caregivers of schizophrenic psychosis Patients: A Correlation to temperament and header. *J Clin Diagn Res* 2015;9:1–4.
17. Hassan WN, Mohamed II, Elnaser AE, and Sayed NE. Burden and header methods in caregivers of schizophrenic patients. *Journal of American Science* 2011;7(5).

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