

BURDEN ON FAMILY MEMBERS OF PSYCHIATRIC PATIENTS ATTENDING OUTPATIENT DEPARTMENT OF A TEACHING HOSPITAL

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ABSTRACT

Introduction: The modern trend of deinstitutionalization led social integration for the individual suffering from a mental illness, while at the same time creating greater pressures for caregivers. The family members, as a caregiver has role and responsibilities after discharge of the patient. Thus, present study aims to assess the level of burden on family members of psychiatric patients attending the Outpatient Department (OPD) of Patan Hospital. **Materials and Methods:** This was a descriptive cross-sectional study conducted among 72 psychiatric patients attending the psychiatric outpatient department of Patan Hospital. Purposive sampling technique was used to select the family members. Data was collected from 4th October 2020 to 17th October 2020 by face-to-face interview technique using a self-developed, structured questionnaire. Data was analyzed using PSPP. Descriptive statistics was used to analyze the data and interpret on the basis of statistical calculation such as frequency, percentage, mean and standard deviation. **Results and Discussion:** Forty-six percentages of family members of the psychiatric patient had a moderate level of burden, 33% had severe burden and 21% had a mild burden. Higher level of burden was found in the psychological domain with the mean score of 14.7 and standard deviation 7.4. **Conclusions:** Nearly half of the family members had moderate burden, more than one forth had severe burden and less than one forth had mild burden.

KEYWORDS: Caregiver's burden, Family members, Psychiatric patients.

INTRODUCTION

Globally, 450 millions of people suffer from mental disorders at any point of time.^[1] These include 264 million people with depression, 45 million with bipolar disorder, 20 million with schizophrenia and 50 million with dementia.^[2] About 10– 20% of children and adolescents are sufferer of mental disorders.^[3] Mental illness caused 7% of all global burden of disease and 19% of all Years Lived with Disability (YLDs).^[4] The burden of mental illness exaggerates significant problem on health and major social problems like homelessness, bullying, drug abuse; human rights and economic consequences in all countries across the world.^[2]

Mental illness is a distressing condition having significant disturbance in cognition, emotional balance, and behavioral functioning. The common mental illnesses are schizophrenia, depression, bipolar, and anxiety disorders.^[5] Mental disorders are considered as one of the public health problems for both; people with mental illness as well as their family members.^[6] As

there is constant fear of recurrence of illness, it abruptly causes sudden and unexpected disruption of the lives of family members.^[7]

Burden can be described as the negative effect caused by the occurrence of a psychiatric disorder in the family environment, involving economic, cultural and emotional elements that the family members face.^[8]

The World Health Organization (WHO) reported, that one in four families has at least one member with mental illness and get total support from family members.^[9] Also, it is estimated that 50-90 % of psychiatric patient live with their family members and often become their caregivers.^[10] Families often become overwhelmed by patient care, which encompasses areas like personal care, management of medication and everyday functioning.^[11] Continuous care of the patients with mental illness in absence of supportive resources could lead to frustration and burden in family caregivers and degrade their coping skills and quality of life.^[9]

In mid 1950s, the basic way of managing psychiatric patient was hospitalization. The phase of deinstitutionalization in the latter half of the century moved the management of these individuals from state hospitals to community care centers.^[6] The emerging trend in psychiatry emphasizes on reducing inpatient treatment and early hospital discharge, which may add on burden to the family members and increases caregiver's role and responsibilities after discharge of the patient.^[12] Burdened caregivers have chances of developing high levels of expressed emotion, which certainly arise a new psychotic symptom and may require hospitalizations.^[13]

MATERIAL AND METHODS

Research Design

A quantitative descriptive cross-sectional design was used to assess the level of burden on family members of psychiatric patients attending Psychiatric OPD of Patan Hospital.

Place of Study

This study was conducted in the Psychiatric OPD of Patan hospital which is a tertiary level teaching hospital in Lalitpur district. This hospital provides services to nearly 320 000 outpatients and 20 000 inpatients every year. A total of 450 beds is occupied by inpatients who come to seek healthcare services and treatment. Psychiatric OPD provides services five days a week except Wednesday and Saturday between 10 am to 4pm. Before COVID 19 pandemic, approximately 90 to 130 psychiatric patients visited Psychiatric OPD per day. During COVID 19 pandemic, approximately 25- 30 psychiatric patients visited the Psychiatric OPD per day.

Population of Study

The study population was family members of psychiatric patients above 18 years accompanying patient to the psychiatric OPD of Patan Hospital.

Sampling Technique

A purposive sampling technique was used. The researcher chose the sample size based on the inclusion and exclusion criteria.

Sample Size

The sample size of this study was 72 family members of psychiatric patients. Data was collected for five days per week, except Wednesday and Saturday as OPD remains closed on these two days. On average 6-7 family member were interviewed per day for two weeks.

Inclusion and Exclusion Criteria

Inclusion Criteria

- Family members who were 18 years and above
- Those willing to participate
- Those who can understand and talk Nepali language

Exclusion Criteria

- Family members whose patient is violent during the hospital visit.
- Family members whose patients were on medication for less than six months.

Data Collection Instruments

A self-developed, structured questionnaire was used for data collection. It consists of three parts:

Part I: Questions related to demographic information of the family members of psychiatric patients that has nine questions related to age, sex, marital status, types of family, occupation, family income, education, relationship with the patient and time spent with the patient at home.

Part II: Questions related clinical Variables that has two questions; duration involved in patient care and diagnosis of the patient.

Part III: Questionnaire related to burden on family members of psychiatric patients consisted of 24 questions.

Scoring Criteria^[14,15]

The response to the statement of questionnaire related to burden of family members was rated as (0= Not at all, 1= To some extent, 2= Very much) based on three Likert scale.

There were 24 questions in part III so; the maximum scores were $2 \times 24 = 48$ Interpretation of scores for level of burden;

1. 0-10 score= No burden
2. 11-20 score= Mild burden
3. 21- 30 score= Moderate burden
4. 31-48 score= Severe burden

Validity and Pretesting of Instruments

The face validity and content validity of the instrument was done by consulting with the research guide.

Ethical Consideration

The study was conducted after obtaining approval from the Research Committee of School of Nursing and Midwifery (Lalitpur Nursing Campus). Prior to data collection, permission was taken from the Nursing Director and OPD in charge of Patan Hospital. Informed verbal consent was taken from each family member before the interview. During the data collection, confidentiality was assured by using code number on the interview sheet instead of writing their names. The collected data was used for study purposes only and the collected information was not disclosed to anyone other than the research guide. Family members were not forced to participate in the study. Family members were given freedom to withdraw from the study at any time they wish to.

Data Collection Procedure

Data collection was done after approval from Research Committee of Lalitpur Nursing Campus. Informed verbal consent was taken from each family member. A face-to-face interview was conducted separately with family members in the OPD, using social distancing and mask due to the COVID-19 pandemic. Data was collected for two weeks from 18th Ashoj 2077 to 1st Kartik 2077 (4th October 2020 to 17th October 2020) between 10am to 3pm each day. On average 6-7 family members were interviewed per day. Interview time did not exceed 20 minutes for each family member.

Data Analysis

All data were checked, reviewed and organized daily for accuracy and completeness. Collected data were edited, classified, coded and stored in the PSPP for data analysis. Descriptive statistics was used to analyze the data and interpret on the basis of statistical calculation such as frequency, percentage, mean and standard deviation. Data presentation was done using tables and figures.

RESULTS

Part I: Questions related to demographic information of the Family Members of Psychiatric Patients.

Table 1: Demographic Information of Family Members

S. n	Characteristics	Frequency	Percentage (%)
1.	Age (in completed years)		
	19-29	20	27.8
	30-39	29	40.3
	40-49	15	20.8
	50-59	8	11.1
	Mean age \pm S. D= 35.9 \pm 10		
	Min- Max=19-59		
2.	Gender		
	Female	43	59.7
	Male	29	40.3
3.	Educational status		
	No education	16	22.2
	Primary level (1-5)	15	20.8
	Secondary level (6-9)	5	6.9
	SLC/SEE	9	12.5
	Above SLC/SEE	27	37.5
4.	Marital status		
	Married	52	72.2
	Unmarried	20	27.8
5.	Occupation		
	Agriculture	18	25.0
	Professional (Health, IT, Banker, Engineer)	12	16.7
	Business	15	20.8
	Laborer	2	2.8
	Homemaker	19	26.4
	Student	5	6.9
	Others - Security personnel	1	1.4
6.	Type of family		
	Nuclear family	49	68.1
	Joint family	23	31.9
7.	Family income per month (In NRs.)		
	Up to 10000	2	2.8
	>10000 - \leq 30000	42	58.3
	>30000 - \leq 50000	26	36.1
	Above 50000	2	2.8
8.	Relationship to the patient		
	Parents (father/mother)	24	33.3
	Spouse (husband/wife)	14	19.4
	Siblings (brother/sister)	13	18.1
	Son/daughter	21	29.2
9.	Time spent in hour per day with the patient		
	Up to 6 hours	50	69.4

Up to 12 hours	21	29.2
Up to 18 hours	-	-
Up to 24 hours	1	1.4

Table 1 shows 29(40.3%) family members were between the ages of 30-39 years, 43(59.7%) were females. Nearly half 27(37.5%) of the family members had educational status above SLC/SEE and few of them 5(6.9%) had obtained secondary level education. Most of 52(72.2%) family members were married. More than half 49(68.1%) family members belong to nuclear family. Regarding

relationship to the patient 24(33.3%) of them were parents (father/mother), 50(69.4%) spent time with the patient up to 6 hours per day.

Part III: Questionnaire related to burden on Family Members of Psychiatric Patients.

Table 2: Family Members Physical Burden of Psychiatric Patients. N=72.

S.N.	Items	Not at alln (%)	To some extentn (%)	Very muchn (%)
1.	Do you feel physically tired caring for your patient?	11(15.3%)	42(58.3%)	19(26.4%)
2.	Do you feel your health has suffered because of your involvement in taking care of your patient?	15(20.8%)	46(63.9%)	11(5.3%)
3.	Do you feel like you are neglecting your own health because you are devoting most of your time in taking care of your patient?	18(25.0%)	38(52.8%)	16(22.2%)
4.	Do you feel your sleep has disturbed because of caring for your patient?	25(34.7%)	30(41.7%)	17(23.6%)
5.	Do you feel that you are physically strong enough to take care of your patient?	17(23.6%)	45(62.5%)	10(13.9%)
6.	Do you think you have a poor appetite due to involvement in taking care of your patient?	17(23.6%)	39(54.2%)	16(22.2%)

Table 2 shows 84.7% of family members felt physically tired caring for the patient. More than half (69.2%) felt their health is suffered due to involvement in patient care, and because of devoting most of the time in patient

care. One third of family members (75.0%) felt they are neglecting their health. Majority of family members felt (64.1%) sleep disturbance and (74.4%) poor appetite respectively.

Table 3: Family members Financial Burden of Psychiatric Patients N=72.

S.N.	Items	Not at alln (%)	To some extentn (%)	Very muchn (%)
1.	Do you feel burdened by the cost related to patient treatment?	14(19.4%)	37(51.4%)	21(29.2%)
2.	Does your family member support you financially to look after the patient?	19(26.4%)	26(36.1%)	27(37.5%)
3.	Have you ever borrowed money or took loan for the treatment and looking after your patient?	16(22.2%)	27(37.5%)	29(40.3%)
4.	Do you feel troubled that only you are responsible for fulfilling the financial requirements of the patient?	31(43.1%)	20(27.8%)	21(29.2%)
5.	Have you ever felt that, in addition to the rest of your expenses, you don't have enough money to care for your patient?	6(8.3%)	49(68.1%)	17(23.6%)
6.	Has the financial condition of your family declined after the illness of the patient?	18(25.0%)	39(54.2%)	15(20.8%)

Table 3 shows that majority of (80.6%) family member's felt burdened by the cost related to patient treatment. Family members also expressed that 76.6% were provided financial support and 77.8% needs to borrow money or take loan for treatment. Overall, having the financial burden also, 43.1% of family member didn't felt troubled for fulfilling the financial requirements of

the patient.

Table 4: Family Members Psychological Burden of Psychiatric Patients N=72.

S.N.	Items	Not at all n (%)	To some extent n (%)	Very much n (%)
1.	Do you feel stressed out between caring for patient and trying to meet other responsibilities for your family and work?	10(13.9%)	36(50.0%)	26(36.1%)
2.	Do you feel that taking care of your patient has affected your relationship with other family members and friends?	22(30.6%)	30(41.7%)	20(27.8%)
3.	Do you think that your concern for the patient has influenced your social life?	8(11.1%)	40(55.6%)	24(33.3%)
4.	Do you feel uncomfortable inviting your friends because of your patient problems?	20(27.8%)	37(51.4%)	15(20.8%)
5.	Do you feel embarrassed by the specific behavior of your patient?	26(36.1%)	33(45.8%)	13(18.1%)
6.	Do you feel angry when you are around your patient?	31(43.1%)	34(47.2%)	7(9.7%)
7.	Are you worried what the future may hold for your patient?	3(4.2%)	12(16.7%)	57(79.2%)
8.	Are you worried about how long your patient's illness will last?	1(1.4%)	3(4.2%)	68(94.4%)
9.	Do you feel you should be giving more care to your patient than you do now?	3(4.2%)	43(59.7%)	26(36.1%)
10.	Do you wish someone else could take care of your patient?	8(11.1%)	35(48.6%)	29(40.3%)
11.	Do you feel that you have lost your personal interest in taking care of your patient?	8(11.1%)	38(52.8%)	26(36.1%)
12.	Overall, how burdened do you feel in taking caring for your patient?	5(6.9%)	39(54.2%)	28(38.9%)

Table 5 shows that 86.1% of family members felt stressed out between caring for patient and trying to meet other responsibilities for family and work, also 89.0% expressed their social life has been influenced. Furthermore, 69.5% felt that their relationship with friends and family has been affected, 72.2% felt uncomfortable inviting their friends, 63.9% felt embarrassed by specific

behavior of the patient. Although, having high psychological burden, almost all 96.0% were worried for the future of the patient as well as 98.6% family members were worried for how long the illness last. Majority 90.0% family members felt they have lost their personal interest in taking care of their patient and as well as 90.0% wishes someone could take care of the patient.

Table 5: Overall Level of Burden of Family Members of Psychiatric Patients N=72.

Level of Burden	Frequency	Percentage (%)
Mild burden (11-20)	15	20.8
Moderate burden (21-30)	33	45.8
Severe burden (more than 30)	24	33.3

Table 5 summarizes that the family members of the psychiatric patients had moderate to severe level of burden i.e. 45.8% had moderate burden, 33.3% had severe burden. Less percentage, (20.8%) family member

had mild burden. Therefore, the study concluded that the family members had some burden caring the psychiatric patient.

Table 6: Total mean value and standard deviation of Physical, Financial and Psychological Domains of Burden. N=72.

Domains	Mean	Standard deviation
Physical burden	5.08	3.9
Financial burden	6.36	4.3
Psychological burden	14.69	7.4

Table 6 states that the psychological burden was the highest of all three domains with the (mean score 14.6

and standard deviation 7.4).

Part II: Questions related Clinical Variables of Psychiatric Patients. N =72.

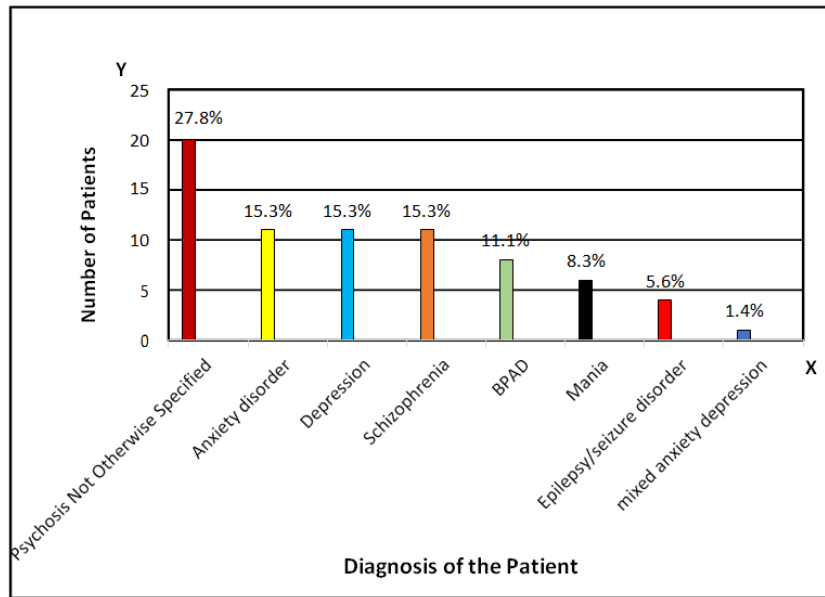


Fig. 1: Diagnosis of the Patient.

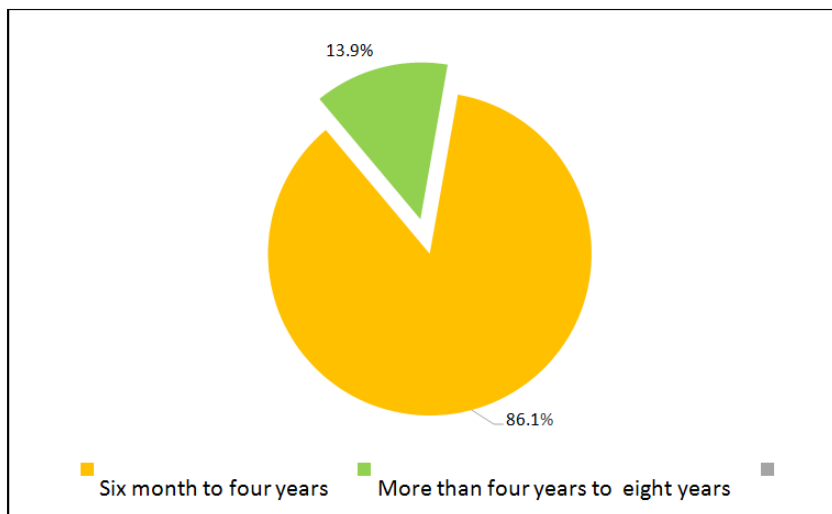


Fig. 2: Patient’s Duration of Illness.

DISCUSSION

The studies revealed that among 72 family members, most of the family members 29(40.3%) were between the age group of 30-39 years. The mean age of family members was 35.9. Minimum age of family members was 19 years and maximum 59 years. More than half of the family members 43(59.7%) were females. The current study showed that most of the family members 52(72.2%) were married. The family members with education above SLC/SEE were 27(37.5%) and a very few of them 5(6.9%) had obtained secondary level education. Majority of family members 49(68.1%) belonged to nuclear family. Regarding the occupation, 19(26.4%) were homemakers, 18(25.0%) of family members had agriculture, 15(20.0%) had a business, and 12(17%) were professional workers.

Regarding level of burden on family members of psychiatric patients

This study revealed that 33(46.0 %) family members had moderate level of burden and 24(33.3 %) had severe burden and 15(20.7%) had mild burden. Similarly, a study done in TUTH, Nepal among 56 family members showed that 27(48.2%) moderate burden, 18(32.1%) had severe burden, 10(17.9%) minimal burden and 1(1.8%) had severe burden.^[16]

In this study, family members burden was classified into three domains; physical, psychological and financial burden. Majority of the family members felt higher burden in psychological domain with the mean score 14.69 and standard deviation 7.4. Similar findings were found in KMC, Nepal among 100 family members

72(72%) had psychological stress.^[13]

Further, financial burden in this study had the mean score 6.3 with standard deviation 4.3 which showed that family members had moderate level of burden, in comparison to psychological burden and physical burden. This finding is contradictory to the finding of study done in Pokhara, Manipal which showed that financial burden was higher among the family members.^[17]

Likewise, least burdensome domain in this study was the physical domain which reflected the mean score with 5.8 and standard deviation was 3.9. Majority 61(84.7%) of the family members claimed that they felt tired for caring the patient, but also 76.4% of them felt physically strong to care of their patient. Similarly, a study done in India among the 96 family members of alcohol dependence showed the similar findings with least burden in physical domain.^[18]

CONCLUSION

Based on the findings of the study, it can be concluded that family members had overall moderate to severe level of burden. Nearly half of the family members had moderate burden. More than the quarter of family member had severe burden. Family members had highest burden felt in the psychological domain.

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