

The Study of Burden of Family Caregivers of Patients Living with Psychiatric Disorders in Remote Area of Nepal

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ABSTRACT

Background

Family caregivers of psychiatric disorders likely to face burden. There is a paucity of data regarding the caregiver burden in psychiatric disorders in context of Nepal.

Objective

To study the caregiver burden in families with psychiatric illness and to find association between socio-demographic variables and caregiver burden in families with psychiatric illness.

Method

This is an analytical cross-sectional study. The participants (n=96) were caregiver of patients visiting outpatient department of two government of Nepal primary health care centers namely, Panchkhal Primary Health Care Center (PHC) Kavre District and Barhabise Health Care Center Sindhupalchowk district. The sample size has been determined by using statistical formula. Family burden assessment schedule (FBIS) was used for the study.

Result

The majority of the caregivers were females 56.3%. Most of the caregivers were aged below 45 years 54.2%. The large number of participants were single or separated 74%. The mean score of family burden assessment schedule was 27 ± 9.8 (range 0 to 48) with positive rate of 59.4%. Among the objective burden domains disruption of family leisure 61.5% was the most frequently reported burden. The subjective burden was reported in 95%. There were significant differential demographic associations with different domains of caregivers' burden.

Conclusion

Caregivers of Psychiatric patients experience different kind of burden of care. Our findings highlight the support to the family members to reduce their burden.

KEY WORDS

Caregivers, Burden, Mental disorder, Nepal

INTRODUCTION

Family caregiver refers to any unpaid individuals such as family, friends, relatives, neighbors who render help to the individuals who need it.¹ The term "caregiver burden" implies to the effects on physical, emotional and financial aspects of caregivers life.² Shift from institution based to community based care for mental disorders has put a burden on the caregivers of mentally ill patients.³ The caregivers are not well prepared to look after mental ill patients at home. As a result, there is a higher prevalence of minor psychiatric disorders in the caregivers of a mentally ill person.⁴ Caregivers for chronically ill disease have reported a greater overload and tend to have taken poorer care of themselves.⁵ Living conditions and environments that support mental health play a key role in promotion of mental health.⁶ The caregiver burden in mental illness can be subjective and objective.^{7,8}

The caregiver burden is a global issue.⁹ Several factors are associated with caregiver burden such as having another member in family who needs care.¹⁰ A study done in Iran and Pakistan reported that the burden experienced by women was more than that experienced by men, caregivers had higher burden when the duration of illness of patients was longer and the burden was more in schizophrenia than in mood disorders.¹¹ A study done in Nepal, reported 50% prevalence of caregiver stress in family with mental.¹² Another study conducted in Nepal, showed that 48.2% of caregiver experienced moderate burden and 32.1% had severe burden.¹³ There are very few studies has been done in Nepal so we have planned to study the burden on family of caregivers of psychiatric patients.

METHODS

This is an analytical cross-sectional study. The participants are caregiver of patients visiting outpatient department of two government of Nepal primary health care centers namely, Panchkhal Primary Health Care Center (PHC) Kavre District and Barhabise Health Care Center Sindhupalchowk district.

The sample size has been determined by using statistical formula,

$$n = (Z_{\alpha/2})^2 \cdot p \cdot q / d^2$$

where,

$Z_{\alpha/2} = (1.96/0.05)$, considering 95% confidence interval.

$p =$ prevalence of caregiver burden(50% Prevalence)(12)

$q = 1-p$

$d = 10\%$

The minimum sample size has come to be 96. The study was initiated after receiving approval from the Institutional

Review Committee (IRC), Kathmandu University School of Medical Sciences (KUSMS). Informed consent was obtained and those who were willing to participate and who were providing care of patients diagnosed with psychiatric disorders were included in the study and those who were giving care for less than one month has been excluded.

We designed a questionnaire focusing on sociodemographic profile of caregiver. The questions concerned: age, marital status, working status, education, living with patient or not, relation of caregiver with patients, duration of care, type of mental illness in the family member and personal history of psychiatric illness.

In our study we used Pai and Kapoor's Family Burden Interview Schedule for the assessment of family burden. This scale consists of twenty four items arranged into six different categories: 1. Financial burden 2. Disruption of routine family activities. 3. Family leisure. 4. Family interactions. 5. Effect on physical health of others and 6. Effect on mental health of others.

Each item is scored as absent (score 0), moderate (Score 1) and Severe (Score 2).

The 25th question is the qualitative question assessing the subjective burden (1 item).

The total objective score of FBIS ranges from 0 to 48, the higherscores indicates higher burden.

A mean score of FBIS is obtained by dividing the total score of FBIS by the number of items, with a positive result defined as a mean score of ≥ 1 , indicating moderate and Severe burden.

Statistical analysis was done in SPSS 21.0 (SPSS Inc, Chicago, USA). variables were expressed in terms of mean and standard deviation (SD) Chi-square test was done for comparison of variables. P value of less than 0.05 was considered statistically significant.

RESULTS

The socio demographic details of patients were shown in table 1. The total sample size was 96, majority of the caregivers were females (n=54). Most of the caregivers were aged below 45 years (n=52). The large number of participants were single or separated (n=71). Majority of caregivers (n=71) were close relatives (spouse, children, parents) and majority (n=92) used to live with the patients.

Table 2 presents the level and domains of family burden. The mean score of family burden assessment schedule (FBIS) was 27 ± 9.8 (range 0 to 48) with positive rate of 59.4%. Among the objective burden domains disruption of family leisure 61.5% was the most frequently reported burden. When it comes to the subjective burden 35% reported moderateburden and 60% reported severe burden (table 3).

Table 1. Sociodemographic Details of Caregivers and Total Objective Burden (n=96)

Variables (caregivers)	Frequency (%)	Total Objective burden score Mean (SD)
Age(years)		
Up to 45	52(54.2)	24.6(9.8)
45 and above	44(45.8)	27.4(10.4)
Sex		
Male	42(43.8)	26.2(11.8)
Female	54(56.3)	25.7(8.8)
Marital status		
Married and Co-habiting	25(26)	23.7(10.3)
Single and Separated	71(74)	26.7(10.1)
Educational level		
No formal education	32(33.3)	23.2(11.9)
Formal education	64(66.7)	27.2(9.0)
Main work status		
Paid work	28(29.2)	25.5(10.6)
Unpaid work(student, house wife, retired)	68(70.8)	26.0(10.0)
Family income (monthly)		
Up to 10000	41(42.7)	25.8(11.0)
10000 and above	55(57.3)	25.9(9.6)
Duration of care		
Up to 5years	52(54.2)	24.5(10.2)
5 years and above	44(45.8)	27.5(10.0)
Relationship of caregiver with patients		
Close	71(74)	26.3(9.9)
Not close	25(26)	24.6(11.0)
Living with patients		
Yes	92(95.8)	26.0(10.3)
No	4(4.8)	24.2(7.5)

Demographic and socio psychological factors and its association with family burden domains were presented in table 4. Age, sex, marital status, educational status working status, monthly income, duration of care relationship with the patients of the caregivers all are associated (p value < 0.05) with different domains of family burdens.

DISCUSSION

The positive rate of burden in this study was 59.4% which was less than the other studies done in Nepal. Sharma et al. showed 85% burden and Bhandari et al. showed 80.3% burden among caregivers.^{13,14}

Our study showed total objective burden score FBIS 27 ± 9.8 which was comparable with Koujali et al. study from India.¹⁵ The mean burden score in our study was higher than that reported in Lasebikan et al. study of a Nigeria sample (22.69 ± 6.21), Thomas et al. study of another Indian sample (21.74 ± 7.50) and Chan et al. study in a Hongkong

Table 2. Level and Domains of Objective Family Burden (n=96)

Burden domains	Mean score (SD)	Positive burden %
Objective Burden	27.0(9.8)	59.4
Financial burden	7.7(2.5)	36.5
Disruption of routine family activities	5.5(2.4)	38.5
Disruption of family leisure	4.3(2.0)	61.5
Disruption of family interactions	4.1(2.6)	43.8
Effect on physical health of others	2.0(1.7)	34.4
Effect on mental health of others	1.8(2.1)	31.3

Table 3. Frequency Subjective Family Burden (n=96)

Burdens	N(%)
No burden	4(4.2)
Moderate burden	34(35.4)
Severe burden	58(60.4)

sample ($15.75 \pm 9.27 / 12.54 \pm 8.43$).¹⁶⁻¹⁸ however our score from our study was very less as compared to Fallahi et al. study from Iran.¹⁹

The different findings could be due to different assessment tools used by different authors. In our study the mean burden score in the financial domain 7.7 ± 2.5 and disruption of routine family activities 5.5 ± 2.4 , were comparable with financial burden score of 6.86 ± 2.44 and disruption of family routine activities score of 4.88 ± 1.64 findings of Hidru et al.²⁰

Other domains findings from our study Disruption of family leisure 4.3 ± 2.03 , disruption of family interactions 4.1 ± 2.6 , effect on physical health of others 2.0 ± 1.7 , effect on mental health of others 1.8 ± 2.1 were also consistent with findings from the study done by Lasebikan et al. which shows Disruption of family leisure 4.74 ± 2.03 , disruption of family interactions 4.42 ± 1.83 , effect on physical health of others 1.32 ± 0.72 , effect on mental health of others 0.99 ± 0.39 .¹⁶

Our study reported 95.8% caregiver's subjective burden which was also supported by the study conducted by Hailemariam et al.^{21,22}

Our study reported older age group experienced highly significant burden in the area of physical health of others (p 0.001) and family leisure (p 0.01). This finding might be, the medical conditions are more prevalent in older population.²³

Other significant factors that were associated with caregivers' burden were: sex in the domain of financial burden p value 0.01, single and separated in the domain of financial burden p value 0.03, education in the domain of family leisure p value 0.03, working status in the domain of family interaction p value 0.03, relationship with patients, duration of care and monthly income in domain of financial burden p value 0.04, 0.003 and 0.03

Table 4. Association between different variables and family burden domains (n=96)

variables	Financial	Routine activities	Family leisure	Family interaction	Effect on Physical health	Effect on Mental health	Total objective burden
	Yes N (%)	Yes N (%)	Yes N (%)	Yes N (%)	Yes N (%)	Yes N (%)	Yes N (%)
Age							
Up to 45	16(45.7)	16(43.2)	26(42.4)	18(42.9)	10(30.3)	12(40)	49(53.3)
45 and above	19(54.3)	21(56.8)	33(55.9)	24(57.1)	23(69.7)	18(60)	43(46.7)
χ^2	1.6	2.9	6.2	3.84	11.5	3.5	0.73
df	1	1	1	1	1	1	1
p	0.20	0.08	0.01	0.05	0.001	0.06	0.39
Sex							
Male	21(60)	18(48.6)	25(42.4)	17(40.5)	15(45.5)	14(46.7)	39(42.4)
Female	14(40)	19(51.4)	34(57.6)	25(59.5)	18(54.5)	16(53.3)	53(57.6)
χ^2	5.9	0.58	0.11	0.32	0.05	0.15	1.65
df	1	1	1	1	1	1	1
p	0.01	0.44	0.73	0.57	0.80	0.69	0.19
Marital status							
Married and cohabitating	12(34.4)	10(27.0)	12(20.3)	8(19)	6(18.2)	7(23.3)	22(23.9)
Single/separated	23(65.7)	27(73.0)	47(79.7)	34(81)	27(81.8)	23(76.7)	70(76.1)
χ^2	2.0	0.03	2.5	1.9	1.6	0.16	5.19
df	1	1	1	1	1	1	1
p	0.16	0.86	0.10	0.16	0.20	0.63	0.02
Education status							
No formal	10(28.6)	11(29.7)	15(25.4)	12(28.6)	9(27.3)	8(26.7)	30(32.6)
Formal	25(71.4)	26(70.3)	44(74.6)	30(71.4)	24(72.7)	22(73.7)	62(67.4)
χ^2	0.56	0.35	4.3	0.76	0.83	0.87	0.52
df	1	1	1	1	1	1	1
p	0.45	0.55	0.03	0.38	0.36	0.90	0.47
Work status							
Earning	10(28.6)	13(35.1)	15(25.4)	17(40.5)	9(27.3)	9(30)	25(27.2)
Not earning	25(71.4)	24(64.9)	44(74.6)	25(59.5)	24(72.7)	21(70)	67(72.8)
χ^2	0.009	1.0	1.0	4.6	0.08	0.01	0.52
df	1	1	1	1	1	1	1
p	0.92	0.86	0.30	0.03	0.76	0.90	0.47
Relationship with patients							
Close	30(85.7)	27(73.0)	44(74.6)	28(66.7)	23(69.7)	23(76.7)	67(72.8)
Not close	5(14.3)	10(27.0)	15(25.4)	14(33.3)	10(30.3)	7(23.3)	25(27.2)
χ^2	4.0	1.0	0.03	2.06	0.47	0.16	1.47
df	1	1	1	1	1	1	1
p	0.04	0.30	0.86	0.15	0.49	0.68	0.22
Duration of care							
Up to 5 years	12(34.3)	18(48.6)	32(54.2)	21(50)	20(60.6)	18(60)	50(54.3)
5 and more years	23(65.7)	19(51.4)	27(45.8)	21(50)	13(39.4)	12(40)	42(45.7)
χ^2	8.7	0.73	0.00	0.52	0.84	0.59	0.02
df	1	1	1	1	1	1	1
p	0.003	0.39	0.98	0.47	0.35	0.43	0.86
Monthly income							
Up to 10000	20(57.1)	17(45.9)	20(33.9)	15(35.7)	8(24.2)	10(33.3)	39(42.4)
10000 and more	15(42.9)	20(54.1)	39(66.1)	27(64.3)	25(75.8)	20(66.7)	53(57.6)
χ^2	4.7	0.25	4.8	1.50	7.0	1.56	0.09
df	1	1	1	1	1	1	1
p	0.03	0.61	0.02	0.22	0.008	0.21	0.76

respectively. These findings are comparable with different study worldwide.^{16,20,24,25}

The study has some limitations. The participants were from specific geographical region so generalization of the result to other areas is difficult. Another limitation of the study was that the study participants included in the study were those who presented in the out patient department of government health care center so generalization of the result to the community cannot be done.

CONCLUSION

Caregivers of psychiatric patients experience different kind of burden of care. Among the objective burden domains disruption of family leisure was the most frequently reported burden disruption of mental health of others was the least frequent reported burden. Our study also revealed age, sex, marital status, educational status working status, monthly income, duration of care relationship with the patients of the caregivers all are associated with

different domains of family burdens. We recommend the strengthening of psychological and social support to reduce caregiving burden of the caregivers.

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