

ORIGINAL RESEARCH ARTICLE

BURDEN AND COPING STRATEGIES AMONG CAREGIVERS OF MENTALLY ILL PATIENTS ADMITTED IN TEACHING HOSPITAL

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Received: 15 Nov, 2022

Accepted: 25 Dec, 2022

Published: 31 Dec, 2022

**Key words:** Care burden; Caregivers; Coping mechanism; Mental illness.

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DOI: <https://doi.org/10.54530/jcmc.1211>

**Citation**

Subba R, Subba HK, Nepal S, Ghimire G. Burden and coping strategies among caregivers of mentally ill patients admitted in teaching hospital. Journal of Chitwan Medical College.2022;12(42):2-7.

**ABSTRACT**

**Background:** The family member is an important support system in the care of patient with chronic mental illness. The caregivers experience from a number of significant stresses and burden and need concern from the mental health professionals. The objective of the study was to assess the extent of burden and coping strategies among caregivers of mentally-ill patients.

**Methods:** Descriptive cross-sectional study design was used among 102 caregivers of mentally ill patients admitted in Psychiatric ward of Chitwan Medical College, Teaching Hospital. Non-probability consecutive sampling technique was used to select the sample. Ethical approval was taken from the Institutional Review Committee. Data were collected from 27 January 2020 to 29 May 2020 using a structured interview schedule and record review. Data was analyzed using Statistical Package for Social Sciences version 20 and analyzed by using descriptive statistics and inferential statistics.

**Results:** Among 102 caregivers, it was found that 47.1% caregivers perceived moderate to severe burden, 41.2% of the caregivers experienced mild to moderate and 11.8% experienced minimal burden. The highest median percentage of caregivers reported financial burden (50%) where 41.66% reported burden in the relationship. The most frequently used strategies were use of informational support (62.5%), venting (62.5%), positive reframing (62.5%), acceptance (62.5%), and religion (62.5%).

**Conclusions:** The highest percentage of caregivers experienced moderate to severe burden. So, mental health professionals should develop training programs that include counseling to support both patients and family caregivers to reduce the family burden and improving coping skills.



Peer Reviewed

**INTRODUCTION**

Mental illness is leading causes of ill-health and disability which is approximately 970million people currently suffers from mental illnesses globally.<sup>1</sup>Significant emotional, cognitive, behavioral problems are hallmarks of mental illnesses. Common mental illness includes schizophrenia, depression, bipolar, and anxiety disorders.<sup>2</sup>

In Nepal, one of the least important development topics is mental health. The vast majority of people still lack access to basic health care.<sup>3</sup>Mental illness is thought to be responsible for 18% of the burden of NCDs.<sup>4</sup>Although there are treatments available, about two thirds of people with mental disease never seek medical assistance.<sup>1</sup>

Globally, the prevalence and disease burden of mental disorders have remained high and considerable treatment gap for mental illness. Caregiving is thought to result in caregiver burden.The caregiver is often a family member who involved in all of the patient's daily activities, interactions, and medical care.<sup>5,6</sup>Caregivers face many challenges when caring for

patients with serious mental disorders.<sup>7</sup>

Several studies revealed that the caregivers of mentally ill individuals experiences burden from moderate to severe.<sup>8-10</sup>Caregivers experience moderate amount of burden and they used positive cognitive coping strategies more frequently followed by distraction and problem-solving.<sup>9</sup>The burden placed on the caregivers of mentally ill people is significant, accounting for 40.9% of all severe burden.<sup>9</sup> Findings demonstrate that caregivers use a variety of positive and negative coping strategies to manage the challenges and stresses they encounter.<sup>11</sup> So, this study was conducted to explore the extent of burden and coping strategies among caregivers of mentally-ill patients.

**METHODS**

A descriptive cross-sectional study design was used to assess the extent of burden and coping strategies among caregivers of mentally-ill patients. The research was conducted in in-patient department of Psychiatric of Chitwan Medical College, Bharatpur-10, Chitwan. The study population consisted of

all family caregivers of patients with mental illness admitted in psychiatric ward. Total 102 caregivers were taken as a sample by using non probability consecutive sampling technique. Those caregivers whose patients had diagnosed with depression, schizophrenia, bipolar disorder, obsessive compulsive disorder, panic disorder and posttraumatic stress disorder were included in the study. Others inclusion criteria were caregiver aged more than 18 years, caring patient during last 1 year prior to the data collection, the caregiver should not have any previously diagnosed psychiatric illness and who were willing to participate in the study.

Ethical approval was taken from CMC Institutional Review Committee (CMC-IRC) (Reference no. CMC-IRC/076/077-137 dated January 26, 2020. Prior to data collection, written informed consent was taken from each respondent and the purpose of the study was explained. Data were collected by researcher themselves using structured interviews schedule and records reviews from 27 January 2020 to 29 May 2020.

The study instrument consisted of a questionnaire made up of the following parts: socio demographic characteristics, extent of care giving burden and coping strategies. The socio demographic of caregivers included age, sex, level of education, employment status, relationship with patient, perceived income adequacy, duration of care giving and losing the job because of caregiving responsibilities. Patients' clinical characteristics included age, sex, type of diagnosis and duration of illness.

To assess the level of burden, Zarit Burden Interview 22 (ZBI); Nepali Version<sup>13</sup> was used. It has 22- item Likert scale, which assesses five main domains of burden namely burden in the relationship, emotional well family being, social and life, finances and loss of control over one's life. Reliability measured by Cronbach coefficient has been reported as 0.77-0.94.<sup>14</sup> The ZBI describes the degree of burden being experienced from 0 = never to 4 = almost always. The final scores range from 0 to 88. It is further stratified into four categories, that is, a score of 0-20 indicates no or minimal burden, 21-40 mild to moderate burden, 41-60 moderate to severe burden and 61-88 indicates severe burden. In this study, Brief COPE Questionnaire<sup>15</sup> was used to assess coping strategies. This scale consists of 28 items that measure 14 factors of 2 items each, which corresponds to a 4 point Likert Scale ranged from 1= I haven't been doing this at all to 4=I have been doing this always.

All collected data were coded and organized before entry. Data were entered in Statistical Package for Social Sciences (SPSS) version 20 and analyzed by using descriptive statistics (frequency, percentage, median and inter quartile range) to describe the extent of caregiver burden and coping strategies. Inferential statistic (Chi-square test) was used to find out association between extent of caregiver burden with selected variables.

## RESULTS

Regarding caregiver's socio demographic information, the median age was 40 years where minimum age was 18 years

and maximum age was 65 years old, 51% were male, 94.1% were followed Hindu religion, 52.9% were from rural area and 81.4% were married. Regarding education 52% were illiterate, 50 % were unemployed, 26.5% caregivers left their job due to care giving, 34.3% were suffered from any one health problem. Similarly, duration of care giving of caregiver was less than 24 months (56.9%) and 54.9% caregivers were spouse (Table 1).

**Table 1: Socio demographic characteristics of the caregiver (n= 102)**

Variables	Number (%)
<b>Age</b>	
Less than 20	7 (6.9)
20-40	45 (44.1)
40-60	47 (46.1)
more than 60	3 (2.9)
<i>Median age: 40, Q1=30, Q2=40, Q3=51, min=18, max=65</i>	
<b>Sex</b>	
Male	52 (51.0)
Female	50 (49.0)
<b>Religion</b>	
Hindu	96 (94.1)
Christian	3 (2.9)
Muslim	3 (2.9)
<b>Residence</b>	
Urban	48 (47.1)
Rural	54 (52.9)
<b>Marital status</b>	
Married	83 (81.4)
Unmarried	17 (16.7)
Divorced	2 (2.0)
<b>Educational status</b>	
Illiterate	53 (52.0)
Literate	49 (48.0)
<b>Occupation</b>	
Unemployed	51 (50.0)
Self employed	38 (37.3)
Employed	13 (12.7)
<b>Health problems</b>	
Yes	35 (34.3)
No	67 (65.7)
<b>Duration of care giving</b>	
< 24 months	58 (56.9)
≥ 24 months	44 (43.1)
<b>Job loss due to care giving</b>	
Yes	27 (26.5)
No	75 (73.5)
<b>Relationship with patient</b>	
Children	13 (12.7)
Parents	18 (17.6)
Siblings	15 (14.7)
Spouse	56 (54.9)

Regarding patient's related information, 48% were belonged to young age group, 51% were male, 55.8% were literate, 73.5% were married, 18.6% had other co-morbid conditions, duration

of illness of patient was equal and more than 28 months (51%) and 52.9% were hospitalized equal and more than 3 times in past one year. Majority of patient (72.5%) had nuclear family, 31.4% had family history of mental illness, majority (73.5%) had belonged to middle family class and 59.8% had less than 25000 rupees per month income (Table 2).

**Table 2: Patient and family related information (n=102)**

Variables	Number (%)
<b>Age (in completed years)</b>	
Adolescence	4 (3.9)
Young adult	49 (48.0)
Middle adult	43 (42.2)
Older adult	6 (5.9)
<i>Median age: 40 yrs, Q1=30, Q2=40, Q3=52, min=14, max=64</i>	
<b>Sex</b>	
Male	52 (51.0)
Female	50 (49.0)
<b>Educational status</b>	
Illiterate	45 (44.1)
Can read and write	18 (17.6)
Primary	19 (18.6)
Secondary	9 (8.8)
Higher secondary	2 (2.0)
Bachelor and above	9 (8.8)
<b>Marital status</b>	
Married	75 (73.5)
Unmarried	26 (25.5)
Divorced	1 (1.0)
<b>Co-morbidity</b>	
Yes	19 (18.6)
No	83 (81.4)
<b>Duration of illness</b>	
< 28	50 (49.0)
≥ 28	52 (51.0)
<i>Median 28, min 1 max 260, Q1=12, Q2=28, Q3=63</i>	

**Table 4: Item-wise analysis of the pattern of burden under five domains (n=102)**

Domain	No of Items	Maximum Possible score	Obtained score range	Median	IQR (Q <sub>1</sub> , Q <sub>3</sub> )	Median Percentage
Relationship	6	24	2-20	10	8.75, 14	41.66
Emotional wellbeing	7	28	1-24	12	8, 15	42.85
Social and family life	4	16	1-14	7	4, 9	43.75
Finance	1	4	0-4	2	1, 3	50.00
Loss of control over one's life	4	16	1-15	7	5, 9.25	43.75
Total	22	88	11-72	36	27, 51	40.90

Out of 14 coping styles, the most frequently used strategies were use of informational support (62.5%), venting (62.5%), positive reframing (62.5%), acceptance (62.5%), religion (62.5%). Whereas each 50% caregivers were used other 9 coping styles i. e. self- distraction, active coping, denial, substance use, emotional support, behavioral disengagement, planning, humor and self blame respectively (Table 5).

When the extent of care burden was compared with the socio-

<b>Number of hospitalization</b>	
< 3 times	48 (47.1)
≥ 3 times	54 (52.9)
<b>Family history of mental illness</b>	
Yes	32 (31.4)
No	70 (68.6)
<b>Type of family</b>	
Nuclear	74 (72.5)
Joint	28 (27.5)
<b>Family status</b>	
High	2 (2.0)
Middle	75 (73.5)
Low	25 (24.5)
<b>Income per month</b>	
≤ 25000 rupees	61 (59.8)
> 25000 rupees	41 (40.2)

Table 3 shows the extent of burden perceived by the caregivers of mentally-ill patients. It was found that 47.1% caregivers perceived moderate to severe burden, 41.2% of the caregivers experienced mild to moderate and 11.8% experienced minimal burden (Table-3).

**Table 3: Extent of burden experienced by caregivers of mentally-ill patients**

Level of care burden	Number (%)
Minimal burden (0-20)	12 (11.8)
Mild to moderate (21-40)	42 (41.2)
Moderate to severe (41-88)	48 (47.1)
<b>Total</b>	<b>102 (100.0)</b>

The pattern of burden experienced by the caregivers under five domains i.e. burden in the relationship, emotional wellbeing, social and family life, finance and loss of control over one's life. Highest median percentage of caregivers reported financial burden (50%) where 41.66% reported burden in the relationship (Table 4).

demographic characteristics of the caregivers, the age, sex, marital status, occupation and job loss of the caregivers was found to be significantly associated with the amount of burden perceived by caregivers. However, education, type of family, monthly income, duration of care giving, health problems of care giver and family history of mental illness did not show any significant association with the amount of burden perceived by the caregivers of mentally-ill patients (Table 6).

**Table 5: Coping style scores (Brief Cope-28) among the caregivers (n=102)**

Domain	No of Items	Maximum Possible score	Obtained score range	Median	IQR (Q <sub>1</sub> , Q <sub>3</sub> )	Median Percentage
Self-distraction	2	8	2 -8	4	3, 5	50.0
Active coping	2	8	2 -8	4	3, 5	50.0
Denial	2	8	2 -6	4	3, 5	50.0
Substance use	2	8	2 -8	4	3, 5	50.0
Emotional support	2	8	2 -8	4	3, 5	50.0
Use of informational support	2	8	2 -8	5	4, 6	62.5
Behavioral disengagement	2	8	2 -8	4	3, 5	50.0
Venting	2	8	2 -8	5	3, 5	62.5
Positive reframing	2	8	2 -8	5	4, 6	62.5
Planning	2	8	2 -8	4	3, 6	50.0
Humor	2	8	2 -6	4	3, 5	50.0
Acceptance	2	8	2 -8	5	3.75, 6	62.5
Self-blame	2	8	2 -8	4	3, 5	50.0
Religion	2	8	2 -8	5	4, 5	62.5
<b>Total</b>	<b>28</b>	<b>112</b>	<b>11-72</b>	<b>36</b>	<b>27-51</b>	<b>32.14</b>

**Table 6: Association between extent of burden among caregivers and selected variables (n=102)**

Variables	Extent of Care burden			p value
	Minimal No. (%)	Mild to Moderate No. (%)	Moderate to Severe No. (%)	
<b>Age (in years)</b>				
≤ 40	7 (13.5)	15 (28.8)	30 (57.7)	0.040
> 40	5 (10.0)	27 (54.0)	18 (36.0)	
<b>Sex</b>				
Male	10 (19.2)	18 (34.6)	24 (46.2)	0.046
Female	2 (4.0)	24 (48.0)	24 (48.0)	
<b>Type of family</b>				
Nuclear	7 (9.5)	30 (40.5)	37 (50.0)	0.422
Joint	5 (17.9)	12 (42.9)	11 (39.3)	
<b>Marital status</b>				
Married	12 (14.5)	39 (47.0)	32 (38.6)	0.002 <sup>f</sup>
Unmarried	0 (0.0)	3 (15.8)	16 (84.2)	
<b>Educational status</b>				
Illiterate	3 (5.7)	22 (41.5)	28 (52.8)	0.119
Literate	9 (18.4)	20 (40.8)	20 (40.8)	
<b>Occupation</b>				
Unemployed	4 (7.8)	21 (41.2)	26 (51.0)	0.034 <sup>f</sup>
Self employed	8 (21.1)	18 (47.4)	12 (31.6)	
Employed	0 (0.0)	3 (23.1)	10 (76.9)	
<b>Monthly income</b>				
≤ 25000 rupees	8 (13.1)	23 (37.7)	30 (49.2)	0.686
> 25000 rupees	4 (9.8)	19 (46.3)	18 (43.9)	
<b>Duration of care giving</b>				
≤ 24	8 (13.8)	23 (39.7)	27 (46.6)	0.815 <sup>f</sup>
> 24	4 (9.1)	19 (43.2)	21 (47.7)	
<b>Health problem</b>				
Yes	4 (11.4)	11 (31.4)	20 (57.1)	0.283 <sup>f</sup>
No	8 (11.9)	31 (46.3)	28 (41.8)	
<b>Job loss</b>				
Yes	1 (3.7)	7 (25.9)	19 (70.4)	0.016 <sup>f</sup>
No	11 (14.7)	35 (46.7)	29 (38.7)	
<b>Family history of mental illness</b>				
Yes	5 (15.6)	12 (37.5)	15 (46.9)	0.690
No	7 (10.0)	30 (42.9)	33 (47.1)	

Significance level at 0. 05, f-Fisher Exact Test

## DISCUSSION

The present study was conducted to assess the extent of burden and coping strategies among caregivers of mentally-ill patients at Chitwan Medical College Teaching Hospital. The data was collected from 102 family members of patients from inpatient department of Psychiatric ward by using an interview schedule. The study results showed that 47.1% care givers experienced moderate to severe amount of burden, 41.2% experienced mild to moderate burden and 11.8% experienced minimal burden. The findings of the study were found to be consistent with the findings of Kumar & Saini<sup>8</sup> which reported 43.8% caregivers perceived moderate burden, 31.3% of the caregivers experienced severe and 25% experienced low burden. In Nepal, similar finding by Adhikari et al<sup>16</sup> reported that maximum of the caregivers (66%) had severe burden, less than half (28%) had moderate to severe burden and least six percent had mild to moderate burden while caring their relatives with chronic mental illness. Though another findings were reported in Nepal who reported that 46.9% were perceived moderate burden, 36.7% mild burden, 11.6% little burden and 4.8% were experienced severe burden during caring their patient.<sup>17</sup>

Similarly, care giving leading to severe burden was reported by 40.9% and moderate burden by 59.1% in Karnataka state.<sup>11</sup> However, a study finding by Chakrabarti et al<sup>18</sup> reported that 80% of the caregivers with moderate amount of burden with only 19% falling experiencing severe burden to patient's illness.

In this study, the financial burden was found to be more contributing to the overall burden experienced by the caregivers followed by disruption in social and family life and loss of control over one's life which was found consistent with the Kumar & Saini<sup>8</sup> study of extent of burden and coping strategies among caregivers of mentally-ill patients which reported more burden experienced on financial burden followed by disruption in routine family activities and interaction with other family members. This financial burden is highest due to majority of the caregivers belonged to middle class family. This can be the result of the caregivers' 24-hour care of sick family members as well as the impulsive tendency of patients with mental illnesses. Caregivers had lost their job after taking care their patients. Additionally, the government has not provided a sufficient budget for mental health care. There isn't a consumer organization that focuses on mental health services in the nation.<sup>19</sup>

This study reported that more often, caregivers adopt use of informational support coping strategy followed by venting, positive reframing, acceptance and religion to overcome burden due to patient's illness. Similarly a study by Suriyamoorthi et al<sup>20</sup> reported that care giving for a mentally ill relative is an enduring stressor and emotion focused coping strategies, such as acceptance and religion were more likely to be adopted,

as seen in the present study. Another study in India<sup>10</sup> found that family members use more acceptance as coping strategies followed by religion, planning respectively. It is seen that mean score was higher with acceptance coping strategy and rare use of denial, behavioral disengagement and substance use

There was significant association between extent of caregiver's burden and care giver's age, sex, marital status, occupation and job loss. Findings are consistent with the study conducted in Turkey on Caregivers burden and Anger in primary caregivers of individual with Chronic mental illness showed the significant relationship between gender and educational status of caregivers and the burden level.<sup>21</sup> But another study showed no significant difference in the distribution of burden by age, educational level, occupation, socio economic status, family type and religion but highly significant differences were found in distribution of burden by marital status.<sup>22</sup>

This study has certain limitations. Firstly, the study design was cross-sectional that does not show causal relationship between coping strategies with burden and related factors, risk of biased responses such as social desirability bias by which caregivers either exaggerate or minimize their burden for some reason and using non-probability consecutive sampling method also might be considered as a limitation. Second, this study is limited sample size and single setting thus generalization of this study is limited. Therefore, it could be suggested that conducting further studies using a larger sample with a diverse setting would get a better understanding of strategies used by caregivers to deal with the mentally ill family member.

## CONCLUSION

The findings of the study concluded that caregivers of mentally ill patients do undergo any kind of burden, which accounted that highest percentage of caregivers experienced moderate to severe burden. Financial burden was the top area of burden seen among caregivers. There was a significant association between the extent of burden perceived by caregivers with age, sex, marital status, occupation and job loss of the caregivers. Caregivers frequently used coping strategies were use of informational support, venting, positive reframing, acceptance and religion to get relief from burden.

Thus education, counseling and motivation are essential for care givers when they have experienced any level of burden. Mental health professionals should develop training programs that include counseling to support both patients and family caregivers to reduce the family burden and improving coping skills.

**CONFLICT OF INTEREST:** None

**FINANCIAL DISCLOSURE:** None

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