

**BURDEN AND COPING AMONG CAREGIVERS OF CHRONIC MENTALLY ILL PATIENTS: A HOSPITAL BASED STUDY**

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Received date: 01 May 2020

Revised date: 21 May 2020

Accepted date: 11 June 2020

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**ABSTRACT**

**Background:** Family caregivers of people with mental illnesses are a key support system. The caregivers suffer substantial burden as a result of the care giving role and need help from the mental health professionals, since it is typically a chronic and long term challenge. Caregivers use different coping strategies to cope with their burden. The objective of the study was to assess the level of burden and coping among caregivers of chronic mentally ill patients attending Psychiatric Department BPKIHS.

**Methods:** A hospital based cross sectional study was adopted among 100 caregivers who had attended OPD and IPD of Psychiatric department with mentally ill patients. Purposive sampling technique was used. Caregivers who were staying with the patient for at least 6 months were interviewed face to face using the Zarit burden Interview scale and Brief Cope Inventory. **Results:** Majority of caregivers (66%) had severe burden, 28% had moderate to severe burden and six percent of them had mild to moderate burden. Mean score and SD of using Active coping as coping strategies was  $6.97 \pm 1.167$ , followed by Acceptance  $6.28 \pm 1.621$  and Religion  $6.28 \pm 1.471$  respectively. Problem focused coping strategies were adopted more than emotion focused coping strategies. There was significant association between patient's position in the family and patient's occupation with the burden. Positive correlation was found between caregiver's burden and coping strategies that are statistically significant. **Conclusions:** Majority of the caregivers experienced severe burden while caring their mentally ill relatives. Problem focused strategies were adopted by most of the respondents.

**KEYWORDS;** Caregivers, Chronic mentally ill patients, Burden, Coping, ZBI, COPE Inventory.

**INTRODUCTION**

Around 20% of the world's children and adolescents have mental disorders, which are among the leading causes of worldwide disability.<sup>[1]</sup> Approximately 30% of population of Nepal is suffering from psychiatric problems. The gap between treatment and the magnitude of the mental health problem is over 85%. Government spending is less than 1% of its total health care budget on mental health.<sup>[2]</sup>

The deinstitutionalization movement that began more than five decades ago resulted in many families having to care for a relative suffering from mental illness. Care giving in these situations is the increment of extraordinary care that goes beyond the bounds of normal or usual care. Family caregivers of persons with

mental illnesses are a key support system in our country as well as in most of the nonwestern world.<sup>[3]</sup>

The family caregivers suffer substantial burden as a result of the care giving role and need help from the mental health professionals. Caregiver burden is an all-encompassing term used to describe the physical, emotional and financial toll of providing care. Over 90 percent of the population who needs mental health services has no access to treatment. Mental health is highly overlooked and neglected in Nepal.<sup>[4]</sup>

Substantial body of research shows that family members who provide care to individuals with chronic or disabling conditions are themselves at risk. Emotional, mental, and physical health problems arise from complex care giving

situations Caregivers adopt different coping strategies which may be constructive or destructive.<sup>[5]</sup>

A caregiver's burden increases due to negative coping skills and lack of resources. Studying coping strategies could be a useful way of generating information that can guide management strategies. This research can be instrumental for providing preliminary data to work upon these issues. So, Researcher was interested to explore the burden and coping strategies of caregivers with chronic mental illness.

## MATERIALS AND METHODS

Descriptive Cross sectional research was conducted in Psychiatric outpatient and inpatient Department of B.P Koirala Institute of Health Sciences after obtaining ethical clearance from Institutional Review Committee (IRC 1058/017) of BPKIHS from December 2016 to August 2018 among the caregivers of chronic mentally ill patients, meeting inclusion criteria. Purposive sampling technique was used for selecting the sample of 100 participants which was calculated on the basis of previous study.<sup>[4]</sup> Caregivers aged 16 years and above who were accompanying the patient in Psychiatric OPD or staying with the patient in Psychiatric ward and Caregivers who were taking care of patients with chronic mental illness and residing with patients at least for past 6 months were included in the study. Those who were not willing to participate in the study, caregivers who were suffering from chronic illnesses and unable to communicate properly, caregivers who are paid and don't have any relation with patient were excluded.

Zarit Burden Assessment Scale (ZBI) with 22 questionnaire item with the total score of 88 (Cronobach's alpha 0.93 and reliability 0.89) was used to measure burden level<sup>[6]</sup> and Brief COPE Inventory which consists of 14 subscale and 28 questionnaire items where the score range from 28-112 [Cronobach's alpha for the original subscales ranged from 0.50 (venting) to 0.90 (substance use)] was used to find out the coping strategies.<sup>[7]</sup>

Informed written consent was obtained from each participant. Face to face interview was conducted by maintaining privacy and confidentiality of each participant throughout the study. Psycho education was provided to Caregivers according to burden and coping level. Caregivers were referred to Psychiatric Outpatient department for consultation.

## STATISTICAL METHODS

The collected data were checked for completeness, organized, coded and entered in Microsoft EXCEL and converted into SPSS 16 version. Descriptive and inferential statistics taking 95% confidence, 5% permissible error and p value=0.05 were used to analyze the data. Descriptive statistics (frequency, percentage,

mean and standard deviation) were calculated to find the status of demographic variables. Inferential statistics i.e. Independent T -test and one way ANOVA were applied to find the association between demographic variables and caregiver's burden and coping. Pearson Correlation coefficient test was applied to find out the relationship between caregiver's burden and coping. Analyzed data and results were presented through tables and figures.

## RESULTS

**Table 1: Socio demographic characteristics of the respondent.**

N=100

Characteristics	Category	Frequency	Percentage
Age(in years)	<20 years	1	1.0
	21-40 years	49	49.0
	41-60 years	45	45.0
	>61 Years	5	1.0
	<b>Mean age: 42.40 SD:12.43</b>		
Marital Status	Married	83	83.0
	Single	11	11.0
	Widow/Widower	4	4.0
	Divorced	2	2.0
Religion	Hindu	93	93.0
	Buddhist	3	3.0
	Christian	1	3.0
	Kirat	2	2.0
	Muslim	1	1.0
Ethnicity	Brahmin/Chhetri	45	45.0
	Dalit (Hill/Terai)	11	11.0
	Janajati (Hill/Terai)	34	34.0
	Madhesi	10	10.0
Educational Status	Basic	31	31.0
	Secondary	42	42.0
	Higher education	9	9.0
	No school education	18	18.0
Occupation	Agriculture	21	21.0
	Homemaker	33	33.0
	Service/jobs	31	31.0
	Unemployed	8	8.0
	Others	7	7.0
Duration of Care giving	<5 years	13	93.0
	6-10 years	65	65.0
	11-15 years	15	15.0
	16-30 years	7	7.0
Perceived health problems	Headache	10	10.00
	Stress	41	41.0
	Decreased sleep	9	9.0
	Not any problem	40	40

Table 1 depicts that nearly half of the respondents were of the age group more 21- 40 years. Mean age was 42.7. Majority of the respondents (83%) were married. Ninety three percent of the respondents were Hindu. Nearly half of the respondents were Brahmin/Chhetri. Among the 82% literate respondents most of them (42%)

had secondary education. Most of the respondents (65%) had cared the patients for 6-10 years. More than 50% of respondents had perceived health problems i.e, Stress (40%) followed by headache (10%) and decreased sleep (9%).

**Table 2: Burden experienced by caregivers.**

N=100

Category	Frequency	Percent
Mild to moderate burden	6	6.0
Moderate to severe burden	28	28.0
Severe burden	66	66.0
Total mean $\pm$ standard deviation of ZBI-63.03 $\pm$ 11.791		

Table 2 depicts maximum of the respondents (66%) had severe burden and six percent respondents had mild to

moderate burden while caring their relatives with chronic mental illness.

**Table 3: Coping strategies adopted by Caregivers.**

N=100

Category	Mean	Standard deviation
Problem focused	47.24	5.013
Emotion focused	26.10	4.343
Total	73.34	7.189

Table 3 illustrates that respondents adopt more problem focused strategies than emotion focused strategies. The total burden score mean and SD was 73.34±7.189.

**Table 4: The mean score of each domain of Brief Copc.**

N=100

Coping Strategies	Mean	Standard Deviation
<b>Problem focused strategies</b>		
Using instrumental support	6.12	1.183
Using emotional support	5.13	1.169
Acceptance	<b>6.28</b>	1.621
Religion	<b>6.28</b>	1.471
Positive reframing	5.89	1.163
Active coping	<b>6.97</b>	1.167
Planning	6.00	1.181
Humor	4.57	1.085
<b>Emotion focused coping strategies</b>		
Self distraction	<b>6.29</b>	0.967
Venting	5.69	1.228
Behavioral disengagement	3.14	1.770
Denial	3.96	1.687
Self blame	3.28	1.457
Substance use	3.74	1.846

Table 4 reveals that, mean and SD of using Active coping as coping strategies was 6.97±1.167, followed by Acceptance 6.28±1.621 and 6.28±1.471 respectively.

**Table 5: Correlation between burden and coping Strategies.**

(N=100)

Correlation between	Coping Strategies	
	r value	p value
Caregiver's burden	<b>0.311 (positive correlation)</b>	<b>0.002</b>

*Pearson Correlation Coefficient, Correlation is significant at the 0.01 level (2 tailed)*

Table 6 depicts that there is positive correlation between caregiver's burden and coping and were also statistically significant.

**DISCUSSION**

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. This study finding is comparable with the study conducted in Nigeria entitled Caregiver burden among relatives of patients with schizophrenia in Katsina, Overall, 75.2% respondents indicated experiencing severe burden as a result of caring for their relatives.<sup>[8]</sup> Another study

conducted in Jordan in Caregivers of patient with serious mental illness found moderate to severe burden level.<sup>[9]</sup> Another cross sectional study conducted in Nigeria had reported 63% caregivers had more burden.<sup>[10]</sup>

Descriptive study conducted in India showed 50% caregivers had mild to moderate burden whereas only five percent caregivers experienced severe burden.<sup>[11]</sup>

May be in Nepal Financial constraints exist and the majority of the people in the country are poor and therefore, cannot afford treatment. There are some mental hospital in the country, which are not enough to address the huge need for inpatient care. Mental health services are not easily available in the rural areas and in remote places. There is a stigma around mental illness. The infrastructure of mental health services is poor and

the human resources are not sufficient. There is no mental health legislation as yet. There are no human rights issues addressed for mental health patients. The government has not allocated an adequate budget for mental health services. No consumer association exists in the country, which focuses on mental health services.<sup>[12]</sup>

This study reveals that there is considerable amount of burden present in caregiver's day to day life. This may be because caregivers have to spend day and night looking after their ill relatives and because of impulsive nature of mentally ill patients.

#### **Coping strategies used by caregivers**

Among the mean score of each sub scale of coping strategies, it was found that, mean and SD of using Active coping as coping strategies was  $6.97 \pm 1.167$ , followed by Acceptance  $6.28 \pm 1.621$  and religion  $6.28 \pm 1.471$  respectively. Caregivers used both problem focused and emotion focused coping strategies however it was found that Problem focused coping strategies were adopted more ( $47.24 \pm 5.013$ ) than emotion focused coping strategies ( $26.10 \pm 4.343$ ).

Every person uses a mixture of problem focused and emotion-focused coping strategies and skills, which tend to change over time. It is said that use of any type of coping, that is, problem focused or emotion-focused can be useful, but some researchers suggest that use of problem focused coping is associated with better adjustment in life as these allow a person to perceive higher control over the problem, compared with that of emotion-focused coping.<sup>[13]</sup> The findings in this study can be interpreted as the good coping in majority of caregivers.

This result is comparable with the study conducted in Nepal in extent of burden and coping among Caregivers of Schizophrenic patients where it was found that mean and standard deviation of using instrumental support as a coping strategy was  $4.63 \pm 1.20$ , followed by using emotional support was  $4.61 \pm 1.04$  and acceptance was  $4.58 \pm 0.95$  respectively, where mean and SD of Active coping was  $4.12 \pm 1.01$ , Acceptance  $4.58 \pm 0.95$  and religion  $4.51 \pm 1.69$  respectively.<sup>[4]</sup> This finding is not supported by another study which found emotion focused strategies to be more employed by the relatives than others.<sup>[14]</sup> Similarly this finding is related with another study, reported that problem focused coping strategies were more common in caregivers of bipolar disorder and emotion focused strategies were more common in caregivers of schizophrenic patients.<sup>[15]</sup>

#### **Association between caregiver's burden and socio-demographic variables**

The association between Caregiver's burden and demographic variables showed no significant association. Findings are consistent with the study conducted in India on Burden of caregivers of Schizophrenia patients found that the caregiver's age,

sex), marital status and type of family did not have any significant influence on the level of burden suffered by them.<sup>[16]</sup> Another study conducted in Turkey in 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>[3]</sup> Another similar 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>[17]</sup> The cross sectional study conducted in India also don't agree with the present study where burden was significantly associated with gender, educational status and economic status.<sup>[18]</sup>

#### **Association between caregiver's coping and socio demographic variables**

The association between caregivers Coping strategies and selected demographic variables shows that there is no statistical significant between Caregiver's coping strategies and selected demographic variables. Similar study conducted in India revealed Caregiver's gender, patient-dysfunction and caregiver-neuroticism had a significant influence on coping patterns, but explained only a small proportion of the variance in use of different coping strategies. Studies from India suggest that caregiver's gender has a significant influence on coping patterns.<sup>[15]</sup>

Another descriptive study conducted in Mumbai had found that there was no association between the selected demographic variable and the caregivers' coping strategies.<sup>[5]</sup>

#### **Association between patient's socio demographic variables and burden**

The association between patient's socio demographic variables and burden showed the significant association between patient's positions in the family as well patient's occupation with the burden. The another study showed contrast that the level of burden experienced was significantly associated with place of residence and family size which was conducted in Nigeria.<sup>[8]</sup>

#### **Correlation between burden and coping**

The current study showed that there is positive correlation between caregiver's burden and coping strategies and were also statistically significant. The result did not support previous findings done in burden, coping, physical symptoms and psychological morbidity in caregivers of functionally dependent family members in Portugal which showed the negative correlation between burden and coping strategies.<sup>[19]</sup>

The result is similar with the study conducted in India in burden and coping of caregivers physical and mental illness found that there is a positive correlation between burden and coping.<sup>[2]</sup> The study conducted in CMC

Vellore presented that there is a tendency for inverse relationship between the care giver burden and the care giver coping, (as the burden increases the coping decreases).<sup>[20]</sup> The study conducted in Nigeria showed negative correlation between the caregiver burden and coping style which do not agreed this study.<sup>[21]</sup>

## CONCLUSION

This study finding revealed that the caregiver's demographic variables were not significantly associated with the burden and coping strategies. Most of the caregivers experienced severe burden while caring their mentally ill relatives. Problem focused strategies were adopted more than the emotion focused strategies. There was positive correlation between caregiver's burden and coping strategies and were also statistically significant. Among fourteen sub scale of coping strategies, self-distraction, active coping, positive reframing, humor, religion and self-blame were found to be significant relationship with burden of caregivers. Nursing education should prepare nurses with the potential for imparting information effectively and assisting the patient and family members to overcome from the burden. Caring for carer is important so family interventions including psycho educational program on reducing the family burden and improving coping and quality of life can be assessed.

**Conflict of interest:** None.

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