

## Caregiver burden among caregivers of mentally ill individuals and their coping mechanisms – A facility based study

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### Abstract

**Problem:** Mental illnesses not only affect the individual concerned but also the caregivers. Caregiver burden is a complex phenomenon. Caregivers who perceive high level of burden are those who lack both family and social support. They require tireless endeavor, sympathy and energy. Mostly family members fail to recognize it and caregiver's own physical, mental and social health is often ignored. Care givers adopt various coping mechanism. A Mechanism, adopted in a positive way would lessen the amount of burden.<sup>6</sup> Mal adaptive strategy in turn would affect the well being.<sup>7</sup>The study was done to measure and analyze caregiver burden and factors associated with the burden respectively. The study was also intended to explore coping mechanisms adapted by the caregivers in response to burden perceived by them. **Approach:** A cross sectional analytical study was conducted among 60 caregivers of patients with mental illnesses attending psychiatric medicine outpatient department in a tertiary care hospital, at Karur(India) between July 2022 and Dec 2022. After obtaining Institutional Ethics clearance and informed consent, study tool was administered. It consisted of 4 parts. Part 1 dealt with socio-demographic details of the participants. Part 2 enquired about clinical information of care recipient. Part 3 included the Burden Assessment Schedule. Part 4 was the brief COPE assessment scale. Data entry was done in Microsoft Excel. Entered data were exported to SPSS software version 20 for analysis. Appropriate descriptive and inferential statistics were done. Independent T test, one way ANOVA, Pearson's correlation and Chi square tests were applied. **Findings:** Among caregivers other than spouses, male caregivers perceive higher burden (mean score +/- SE = 28.75 +/- 2.272) than the female caregivers (mean score +/- SE = 26.25 +/- 2.192). Perceived severity of disease was higher among Care givers residing in urban area (mean score +/- SE = 8.0385 +/- 0.36577) than those residing in rural area (mean score +/- SE = 6.9118 +/- 0.28438). Among caregivers other than spouses, caregivers who had completed higher secondary schooling or diploma holders perceive higher level of burden (mean – 28.75) than those who completed primary schooling (mean – 24.75). Impact of chronic mental illness of care recipients on well being of caregivers was higher among spousal caregivers than the others. A Positive correlation existed between burden perceived among spousal caregivers and problem focused, emotional focused and adaptive coping. All these associations were statistically significant at p value 0.05, 0.01 or 0.001. Distribution of moderate to severe burden among caregivers other than spouses (**52.3%**) is slightly higher than that of spousal caregivers (**50%**) and the difference is not statistically significant (**p = 0.876**). **Conclusion:** Among various factors, gender, education, residence and chronic nature of care recipient's mental illness were found to be significantly associated with either one or another component of burden or the whole. Mental health professionals should broaden their vision so that burden perceived by the caregivers would also be attended. Public health personnel should take measures to implement family as well as community level approach to attend caregivers along with their mentally ill care recipients.

**Keywords:** caregiver burden, Burden Assessment Schedule, brief COPE assessment scale, gender, education, residence, chronic nature of care recipient's mental illness, coping strategies

## Main Text

### Introduction

Mental illnesses account for around 13 to 15 percentage of global burden of diseases. These illnesses not only affect the individual concerned but also the family members. Among family members, primary caregivers are badly affected. Burden perceived by a care giver has to be interpreted by its influence on care giver's well being. Caregiver burden is a complex phenomenon. It includes personal care, emotional support, deep listening, consoling, counseling and altering the surrounding environment for the care recipient's mood. In developing countries, caregivers who perceive high level of burden are those who lack both family and social support. Caregivers, especially of chronically ill patients, require tireless endeavor, sympathy and energy but on lacking those requirements, it will affect their daily living. Mostly family members fail to recognize their valuable caring effort. Caregivers' own physical, mental and social health is often ignored. Lack of family, social and financial support will lead on to stress and depression on due course.<sup>1,2</sup>

Caregivers' role include ensuring that the recipients are compliant with the treatment and to inform doctors regarding the status of mental condition whether it is improving, static or worsening. Caring of chronic mentally ill patients will put on excess of burden on care givers and the consequences are depression, burn out and anxiety when compared with care givers of other chronic illnesses. As the severity of mental illness increases, caregiver burden also increases which in turn results in negative impact on patient's care. Various studies have highlighted that caregivers often make use of projection as their defense mechanism. Burden gets exposed in certain areas like family leisure, interactions and financial situations. Mental health professionals should be aware about care giver burden and should attend the care givers along with treating the patients. They should be concerned about the coping ability of care givers. They are obligated to measure the level of burden and plan for suitable interventions.<sup>3, 2</sup> Various factors like characteristics of both caregivers and patients, inter – personal relationship, time spent in care giving and varying degree of severity of illness will have impact on amount of burden perceived.<sup>4</sup> For the past few decades, decentralization of treatment especially rehabilitation services from hospital towards community and family settings, the responsibility of caregiver is exponentially increasing.<sup>5</sup>

Care givers adopt various coping strategies which may be adaptive or mal adaptive. A coping mechanism if adopted by the care giver in a positive way would be lessening the amount of burden.<sup>6</sup> Mal adaptive strategy in turn would affect in turn, the well being of caregiver.<sup>7</sup> The study was done to measure and analyze caregiver burden and factors associated with the burden respectively. The study was also intended to explore coping mechanisms adapted by the caregivers in response to burden perceived by them.

### Methodology

A cross sectional analytical study was conducted in a tertiary care hospital situated in Karur. Based on a study conducted in the state of Assam, India (Assam), with  $Z\alpha$  at 95% level, prevalence of 74.17 and relative precision of 15%, sample size of about 60 was calculated.<sup>8</sup> The study was conducted between July 2022 and Dec 2022.

After obtaining institutional ethics clearance, caregivers of patients with mental illnesses attending psychiatric medicine outpatient department were selected as study participants. Caregivers who were providing care for at least 1 year were included. Caregivers with diagnosed mental disorders were excluded. Probability sampling method was employed and study tool was administered after obtaining informed consent. Study tool consisted of 4 parts. Part 1 dealt with socio-demographic details of the participants. Part 2 enquired about clinical information of care recipient. Part 3 was Burden assessment schedule. Part 4 was the brief COPE assessment scale.

Schizophrenia Research Foundation in collaboration with the regional office for South – East Asia of WHO (SEARO) developed the Burden assessment schedule. BAS is a 3 point scale (“Not at all” - grade 3, “to some extent” – grade 2 and “very much” – grade 1). Finally modified version is a 20 item questionnaire. 20

questions were grouped under 5 factors. The factors are impact on well being, impact on marital relationship (only if the care giver is the spouse), appreciation for caring, impact on relationship with others and perceived severity of the disease respectively. The maximum overall score is 60 while minimum overall score is 20. In a similar way maximum score for each factor is 12 while minimum score is 4 for each factor. The Brief-COPE is a validated tool. It is a self administrable, 20 item scale. It is framed in such a way to assess adaptive and mal-adaptive ways of coping with stressful life events. The scale would help to determine how patients are reacting to certain stressful situations. The scale will determine someone's coping style as problem focused, emotional focused or avoidant Approach Coping. Subscales are Self-distraction, Active coping, Denial, Substance use, Use of emotional support, Use of instrumental support, Behavioral disengagement, Venting, Positive reframing, Planning, Humor, Acceptance, Religion, & Self-blame. It is a 4 point likert scale ranging from 1 – "I – have not been doing this at all", 2 – "I have been doing this sometimes", 3 – "I have been doing this for most of the time" and .4 – "I have been doing this for a lot". Each of the fourteen sub-scales is comprised of 2 items; Total score on each sub-scale ranges from minimum of 2 to maximum of 8. High level of score denotes the increased practice of that particular coping mechanism. Data entry was done in Microsoft Excel. Entered data were exported to SPSS software version 20 for analysis. Appropriate descriptive and inferential statistics were done, considering p value at less than 0.05, 0.01 and 0.001 as significant respectively.

## Results

About 60 caregivers participated in the study. Mean age of caregivers was 43.57 (in years) with standard error of 1.607 (in years). Their socio-demographic details are depicted in table 1.

### *Socio – demographic details of care givers*

*Table - 1*

S. no	Characteristics	Frequency	Percentage
1	Gender		
	Female	39	65%
	Male	21	35%
2	Residence		
	Rural	34	56.7%
	Urban	26	43.3%
3	Education		
	Primary schooling	11	18.3%
	Secondary schooling	19	31.7%
	Higher secondary/diploma	6	10%
	Graduate	24	40%
4	Relationship with care recipient		
	Wife		
	Husband	11	18.3%
	Mother	5	8.3%
	Father	9	15%
	Sister	15	25%
	Brother	11	18.3%
Daughter	1	1.7%	
		8	13.3%
5	Socio-economic classification		
	Upper		
	Upper middle	17	28.3%
	Lower middle	10	16.7%
	Upper lower	14	23.3%
	Lower	7	11.7%
		12	20%

*Distribution of various types of psychiatric illnesses among care recipients***Table - 2**

S.no	Type of psychiatric illness of care recipient	Frequency	Percentage
1	Schizophrenia	19	31.7%
2	Alcohol/drug addiction	18	30%
3	Bipolar disorder	8	13.4%
4	Depression	6	10%
5	Anxiety	2	3.3%
6	Delusional disorders	2	3.3%
7	Others	5	8.3%

*Correlation (Pearson's) between age and caregiver burden*

A very weak positive correlation ( $r = 0.155$ ) existed between age of caregivers other than spouses and burden. It was not statistically significant ( $p = 0.315$ ).

A weak negative correlation ( $r = -0.256$ ) existed between age of spousal caregivers and burden. It was not statistically significant ( $p = 0.338$ ).

*Association between gender of caregiver and caregiver burden (independent t test)***Table - 3**

S. no	Gender	Factors and overall burden	N	Mean	Standard Deviation	Standard Error	t value	p value
1	Female	Impact on well being	39	5.5385	2.58382	0.41374	0.443	0.659
	Male		21	5.2381	2.34318	0.51132	0.457	0.650
2	Female	Impact on marital relationships#	11	7.82	1.471	.444	1.574	.138
	Male		5	6.60	1.342	0.600	1.633	0.139
3	Female	Appreciation for caring	39	7.5128	1.84778	0.29588	-1.414	0.163
	Male		21	8.3333	2.61406	0.57044	-1.277	0.211
4	Female	Impact on relationship with others	39	7.8462	1.54815	0.24790	-0.757	0.452
	Male		21	8.1429	1.23635	0.26979	-0.810	0.422
5	Female	Perceived severity of the disease	39	7.2051	1.73478	0.27779	-1.130	0.263
	Male		21	7.7619	1.97243	0.43042	-1.087	0.284
6	Female	<b>Burden perceived among caregivers other than spouses</b>	<b>28</b>	<b>26.2500</b>	<b>3.79693</b>	<b>0.71755</b>	<b>-2.192</b>	<b>.034*</b>
	Male		<b>16</b>	<b>28.7500</b>	<b>3.33667</b>	<b>0.83417</b>	<b>-2.272</b>	
7	Male	Burden perceived among spousal caregivers	11	40.64	4.781	1.441	0.704	0.586
	Female		5	38.40	8.019	3.586	0.579	

#this factor can be elicited only if the caregiver is the spouse of the patient

\*Statistically significant ( $p < 0.05$ )

From the table – 3, it would be inferred that among caregivers other than spouses, male caregivers perceive higher burden (mean score  $\pm$  SE = 28.75  $\pm$  2.272) than the female caregivers (mean score  $\pm$  SE = 26.25  $\pm$  2.192) and the difference was found to be statistically significant ( $p = 0.34$ )

*Association between residence and burden (independent t test) Table - 4*

S. no	Residence	Factors and overall burden	N	Mean	Std. Deviation	Std. Error	t value	p value
1	Rural	Impact on well being	34	5.2647	1.79745	0.30826	-0.557	0.581
	Urban		26	5.6538	3.19928	0.62743		
2	Rural	Impact on marital relationships#	8	7.25	1.669	0.590	-0.486	0.635
	Urban		8	7.63	1.408	0.498		
3	Rural	Appreciation for caring	34	7.7647	2.06058	0.35339	-0.143	0.886
	Urban		26	7.8462	2.32710	0.45638		
4	Rural	Impact on relationship with others	34	8.0294	1.31392	0.22534	0.484	0.63
	Urban		26	7.8462	1.61722	0.31716		
5	<b>Rural</b>	<b>Perceived severity of the disease</b>	<b>34</b>	<b>6.9118</b>	<b>1.65818</b>	<b>0.28438</b>	<b>-2.471</b>	<b>0.016*</b>
	<b>Urban</b>		<b>26</b>	<b>8.0385</b>	<b>1.86506</b>	<b>0.36577</b>		
6	Rural	Burden perceived among caregivers other than spouses	26	27.2692	3.86324	0.75764	0.229	0.820
	Urban		18	27.0000	3.80402	0.89662		
7	Rural	Burden perceived among spousal caregivers	8	37.63	4.173	1.475	-1.694	0.112
	Urban		8	42.25	6.497	2.297		

#this factor can be elicited only if the caregiver is the spouse of the patient

\*Statistically significant ( $p < 0.05$ )

Perceived severity of disease was higher among Care givers residing in urban area (mean score +/- SE = 8.0385 +/- 0.36577) than those residing in rural area (mean score +/- SE = 6.9118 +/- 0.28438) and the difference was found to be statistically significant ( $p = 0.016$ )

*Association between education and burden (One way ANOVA) Table - 5*

s.no	Education	Burden-Mean score	N	Mean difference	Standard error	p value
1.	Caregivers other than spouses					
	<b>Higher secondary</b>	<b>28.7500</b>	<b>4</b>			
	<b>Primary</b>	<b>24.7500</b>	<b>8</b>	<b>4.0000</b>	<b>0.61962</b>	<b>0.018*</b>
	secondary	27.3571	14	1.39286	1.21622	0.766
	Graduate	27.7222	18	1.02778	0.92109	0.822
2	Spousal caregivers					
	Higher secondary	45	2			
	Primary	42	3	4.000	3.055	0.679
	secondary	31.80	5	9.200	3.639	0.289
	Graduate	41.17	6	3.833	3.540	0.798

\*Statistically significant ( $p < 0.05$ )

Among caregivers other than spouses, caregivers who had completed higher secondary schooling or diploma holders perceive higher level of burden (mean – 28.75) than those who completed primary schooling (mean – 24.75). The mean difference (04.00) was found to be statistically significant ( $p = 0.018$ )

No statistically significant mean differences existed among spousal caregivers in related to educational status (mean burden score for primary schooling, secondary schooling, higher secondary/ diploma and graduate are 41, 35.8, 45 and 41.17 respectively)

***Association between relationship with care recipient and burden (One way ANOVA)***

**Table - 6**

S. no	Relationship	Factors and overall burden	N	Mean	Mean difference	t value	Standard Error	p value
1	Spouse	Impact on well being	16	8.6875				
	Parents		24	4.2083	4.47917*		0.60022	.000*
	Others		20	4.3000	4.38750*		0.62086	.000*
2		<sup>§</sup> Impact on marital relationships#						
	Wife		11	7.82		1.574	0.444	0.138
	Husband		5	6.60			0.600	
3	Spouse	Appreciation for caring	16	7.8750	0.58333		0.75323	0.722
	Parents		24	8.4583				
	Others		20	6.9500	0.92500		0.79866	0.488
4	Spouse	Impact on relationship with others	16	8.4375				
	Parents		24	7.8750	0.56250		0.34389	0.245
	Others		20	7.6500	0.78750		0.50727	0.282
5	Spouse	Perceived severity of the disease	16	7.5000	0.16667		0.65155	0.965
	Parents		24	7.6667				
	Others		20	7.0000	0.66667		0.50908	0.398
6		<sup>§</sup> Burden perceived among caregivers other than spouses						
	Parents		24	28.2083		2.011	0.59582	0.053
	Others		20	25.9000			0.98114	
7		<sup>§</sup> Burden perceived among spousal caregivers						
	Wife		11	40.64		0.579	1.441	0.586
	Husband		5	38.40			3.586	

*§ - independent t test*

*#this factor can be elicited only if the caregiver is the spouse of the patient*

*\*Statistically significant (p < 0.05)*

Impact of chronic mental illness of care recipients on well being of caregivers was higher among spousal caregivers than the parents and others. Mean differences between spouses, parents (4.479) and others (4.387) were found to be statistically significant ( $p < 0.01$ )

***Association between socio – economic class and burden (One way ANOVA)***

No statistically significant mean differences existed among caregivers other than spouses in related to socioeconomic class (mean burden score for upper middle and above, lower middle and upper lower and below are 27.29, 27.2 and 26.92 respectively)

No statistically significant mean differences existed among spousal caregivers in related to socioeconomic class (mean burden score for upper middle and above, lower middle and upper lower and below are 36.83, 42.25 and 41.50 respectively)

***Correlation between caregiver burden and coping mechanism among caregivers other than spouses***

**Table 7**

s.no	Caregiver Burden	Coping	Pearson correlation	's	p value
1.	Burden perceived among caregivers other than spouses	Problem focused coping	-0.153		0.323
		Emotional focused coping	-0.254		0.116
		Adaptive coping	-0.158		0.306
2	Burden perceived among spousal caregivers	Problem focused coping	0.692		0.003**
		Emotional focused coping	0.560		0.024*
		Adaptive coping	0.578		0.019*

\* Correlation is statistically significant at the 0.05 level (2-tailed).

\*\* Correlation is statistically significant at the 0.01 level (2-tailed).

A strong Positive correlation existed between burden perceived among spousal caregivers and problem focused coping and it was statistically significant ( $p = 0.003$ ).

Moderate positive correlations existed between burden perceived among spousal caregivers and emotional focused and adaptive coping respectively. Correlations were statistically significant ( $p = 0.024$  and  $0.019$  respectively).

***Comparison of burden distribution between caregivers other than spouses and spousal caregivers***

***(Chi square test) Table – 8***

s. no	Caregivers	Burden score Mean +/- S.E	Moderate to severe burden		Mild burden		$\chi^2$	p value
			Frequency	Proportion (%) With 95% CI	Frequency	Proportion (%) With 95% CI		
1	Caregivers other than spouses	27.16+/- 0.57	23	<b>52.3</b> (36.7 – 67.5)	21	47.7 (32.5 – 63.3)	0.0243	0.876
2	Spousal caregivers	39.94+/- 1.45	8	<b>50</b> (24.7 – 75.3)	8	50 (24.7 – 75.3)		

Distribution of moderate to severe burden among caregivers other than spouses (**52.3%**) is slightly higher than that of spousal caregivers (**50%**) and the difference is not statistically significant ( $p = 0.876$ ).

## Discussion

The study was conducted among caregivers of mentally ill patients to assess the level of burden perceived by them and their coping mechanisms. Mean age of caregivers was 43.57 (in years) with standard error of 1.607 (in years). The result is similar to the studies conducted in Nigeria (43.65 years), Kerala (31 -50 years) and Ethiopia (38.45 years).<sup>2, 3, 9</sup>

In Ethiopian study age of the caregiver is significantly associated with burden. While in the current study, there was no significant correlation with burden ( $p = 0.315$  and  $0.338$  respectively). Social arrangement in the country which is strongly supported with bonding between family members might be the reason for breaching age factor and it was revealed in the study.<sup>9</sup>

In the study conducted in Katmandu, though female caregivers experience high level of burden it was not statistically significant. In the study conducted in Kerala, male caregivers experience high level of burden but it was not statistically significant. In the present study, male caregivers among caregivers other than spouses perceive more burden and it was statistically significant ( $p = 0.034$ ). Similarly husbands of care recipients perceive high burden than their counterparts even though it was not statistically significant. In Indian families, caring of dependent members is considered as the sole responsibility of female members. If the responsibility falls upon male members due to unavoidable reasons, they develop high level of burden as a result of complexity of care giving and its interspersion with various factors like finance, compliance with chronic treatment and household activities.<sup>1, 3</sup>

In the current study there was no statistically significant difference in burden based on residential status of care givers ( $p=0.820$  and  $0.112$  respectively) and the finding is similar to Kerala study in which caregivers from urban background experience little higher burden than the rural and semi – urban caregivers and the association was not statistically significant. Since the study was conducted at one of the highly urbanized states in the country and so the residential background had no association with burden.<sup>3</sup>

In Kathmandu study, caregivers who were illiterate perceived high level of burden and the association was found to be statistically significant. In Kerala and Nigerian studies there were no statistically significant differences among caregivers based on educational background. In contrast Ethiopian study revealed that caregivers who had no formal education were negatively associated with burden and it was statistically significant. The above finding was similar to our study in which, among caregivers other than spouses, those who had completed higher secondary schooling or diploma perceived higher level of burden (mean – 28.75) than those who completed primary schooling (mean – 24.75) and mean difference (04.00) was found to be statistically significant ( $p = 0.018$ ). Caregivers with higher education might be having less experience in strenuous activities and would have perceived high level of burden. No statistically significant mean differences existed among spousal caregivers in related to educational status.<sup>1, 2, 3, 9</sup>

In Nigerian study, there was no statistically significant association between relationship of caregiver with the patient and perceived burden. In case of Ethiopian study, spouse, sibling, child and other relatives were positively and significantly associated with burden. The present study findings were similar to Nigerian study. Social responsibilities and obligation of duties among Indian families might be the reason for no association between relationship and burden ( $p= 0.053$  and  $0.586$  respectively). In the study conducted in Kerala and in the current study, no statistically significant mean differences existed among caregivers in related to socioeconomic class. It might be due to focus on inclusive growth in both the states across social strata which would have reflected in socio – economic classes.<sup>2, 3, 9</sup>

In Lalithpur study, Caregivers used both problem focused and emotion focused coping strategies however it was found that Problem focused coping strategies were adopted more than emotion focused coping strategies and both of them were correlated statistically with burden. Similarly in the current study, strong to moderate statistically significant positive correlations existed between burden and problem focused, emotion focused and adaptive coping strategies among spousal caregivers ( $p = 0.003, 0.024$  and  $0.019$  respectively).



No significant correlations existed between burden and various coping strategies among caregivers other than spouses. Spouses are emotionally bound to their mentally ill partners. It was understandable that spousal caregivers developing emotion focused coping. On due course, sensing the lifetime realities and added responsibilities, most of them would adapt problem focused and adaptive coping strategies.<sup>8</sup>

In the present study, caregivers from urban background perceive more the severity of disease of their care recipients which rendered them unable to carry out their routine activities and job than the caregivers from rural background. The difference was statistically significant (**p=0.016**). Urban characteristics with added commitments might have made urban caregivers to perceive relatively more severe the magnitude of illness.

In the study, spouses' well being was highly affected due to the impact of chronic mental illness of care recipient than other relatives. The difference was statistically significant (**p<0.01**). Due to prevailing social and cultural arrangements, spouses had to hold more responsibilities than any other relatives. In marital relationship, spouses would gradually get bound to their partners emotionally. In this background partner's mental illness might influence the spouses about unexpectedly emerging commitments and it may create uncertainty to some extent in future. Cumulatively physical and mental wellbeing of the spouses would have been disturbed.

Distribution of moderate to severe burden among caregivers other than spouses (**52.3%**) is higher than that of spousal caregivers (**50%**) and the difference is not statistically significant (**p = 0.876**). Caregivers other than spouses experience high level of burden than the spouses though the difference was statistically not significant. As discussed earlier the bonding between spouses would always have a positive impact on burden by reducing its severity. Such a level of bonding was found to be lacking in relatives other than spouses and the same got revealed in the current study.

## Conclusion

As already discussed, caregiver burden is a complex phenomenon. It is comprised of various inter-related components. The study was intended to identify various factors associated with the burden. Among those factors, gender, education, residence and chronic nature of care recipient's mental illness were found to be significantly associated with either one or another component of burden or the whole. Though the study was a facility based study it would guide mental health professionals to broaden their vision so that burden perceived by the caregivers would also be attended. Regardless of family or social support if professional support was alone available, it would definitely have a great positive impact on well being of caregivers. In addition to facility based approach, public health personnel should take measures to implement family as well as community level approach to attend caregivers along with their mentally ill care recipients.

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