

## Caregiving Burden Among Family Members Of People With Mental Illness

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### Abstract

**Background:** Presence of a person with mental disorder in family is often associated with some objective and subjective burden on family members, especially those who have a caregiving role. The present study aimed to assess the levels of caregiving burden among family members of people with mental illness.

**Method:** This is a descriptive cross-sectional study in a sample of 56 family caregivers of people with mental illness. Sample was selected using purposive sampling method and their caregiving experience was assessed by using Burden Assessment Schedule.

**Result:** Among the 56 caregivers, 48.2 % had moderate level of burden and 32.1% had severe level of burden. Highly significant difference was observed in the distribution of burden according to level of burden but no significant gender difference was found in the distribution of burden in total and in different domains of BAS. Highly significant burden was found among married and spouse caregivers.

**Conclusion:** As moderate to severe level of caregiving burden was reported by the family caregivers, it is recommended that family intervention should focus on strengthening coping behaviors and social support system to manage caregiving stress.

**Keywords:** Family caregiving burden, Mental illness, Burden Assessment Schedule (BAS)

### INTRODUCTION

The presence of a person with mental illness in a family is often associated with objective and subjective burden on family members, especially those who have a caregiving role. The extent of burden depends on several factors like caregiver's age and gender, pre-morbid relationship with patient, patient's problems, coping strategies and perception of patient's illness, emotional and practical support available to the family, coping behavior and socio-cultural and ethnic variables<sup>1</sup>. It is estimated that one in four families has at least

one member currently suffering from mental or behavioural disorder<sup>2</sup>. These families are required not only to provide physical and emotional support, but also to bear negative impact of stigma and discrimination present in all parts of the world. While the burden of caring for a family member with a mental or behavioural disorder has not been adequately studied in different socio-cultural context, the available evidences suggest that it is indeed substantial<sup>3, 4, 5</sup>. The burden on families ranges from economic difficulties to emotional reactions to illness, stress of coping with

disturbed behaviour, disruption of household routine and restriction of social activities<sup>2</sup>. In 2004, mental disorders accounted for 13% of global burden of disease<sup>6</sup>. Families who perceived a higher level of caregiver burden are those who lived in a family with poorer functioning, worse health status and less satisfaction of social support<sup>7</sup>.

In the country like Nepal where formal and paid type of caregiving is rarely in practice and psychiatric services are minimal in the community, the major responsibility of caregiving to people with different psychiatric conditions is shouldered by close family members or relatives. Caregiving is a very challenging task where the quality of caregiving determines the well being of individual with disability or illness and also that of caregivers<sup>8,9</sup>. Different aspects of caregivers' life are affected by the task of caregiving and the hidden economic, social and health impacts of caregiving on caregivers ultimately affects treatment outcome and increases the chance of relapse in the case of mental illness. The present study aimed to assess level of caregiving burden among family members of patients with mental illness in the context of Nepal.

#### **MATERIAL AND METHOD**

This is a descriptive and cross sectional study conducted among family caregivers of people with mental illness admitted in Psychiatry Ward of Tribhuvan University Teaching Hospital (TUTH) in a sample (N= 56) fulfilling inclusion criteria using purposive sampling method during the period of 6 months (April 2013 to September 2013). In order to collect primary data, a standardized scale was used to explore the level of family burden of caregiving of the people with mental illness. The scale was in English Language and therefore, translation and back translation was done to develop scale in Nepali language.

Semi-structured pro-forma was used to record the socio-demographic characteristics of both caregivers and their patients. Burden Assessment Schedule (BAS)<sup>10</sup> was used to collect their caregiving experiences. BAS was developed & standardized by step wise ethnographic exploration method in India. The inter rater reliability and content validity are

high<sup>10</sup>. Criterion validity was established by comparing with Family Burden Interview Schedule<sup>11</sup> ranging between 0.71-0.82. There are 40 items rated on a three point scale (1-3): 1-mild burden, 2-moderate burden & 3-severe burden. In this study, the severity of burden was categorized into 4 groups<sup>12</sup>. A score up to 40 on BAS indicate no burden, 41-60 minimal burden, 61-80 moderate burden, 81-100 severe burden and 101-120 very severe burden. There are 9 domains. Increasing scores indicate increasing level of burden. The scale was selected as it can be administered to literate individuals and has similarity in socio-cultural aspects between India and Nepal. Ethical clearance was taken from Institutional Review Board (IRB), Institute of Medicine (IOM), Tribhuvan University. The study variables were analyzed using descriptive and inferential statistics using Statistical Package for Social Sciences (SPSS) version 17 for windows.

#### **RESULT**

##### **Socio-demographic variables**

Among 56 caregivers, the mean age was 39.45 ±11.974 (Male: 40.61 ± 13.295 and female: 38.29 ± 10.607). Similarly, among caregivers' respective patients, the mean age was 30.62 ±13.612 (male: 31.47 ± 13.990 and female: 29.32 ± 13.22). The t test showed no significant difference in the distribution of age of caregivers ( $t = .722, p >.05$ ) and of patients ( $t = .654, p >.05$ ) by sex.

Similarly, among 56 caregivers, 50 % were male, 42.9 % belonged to 31-45 years' age group, 75% were married, 23.2 % had education up to intermediate level, 44.6 % were unemployed, 57.1 % were from urban areas and joint families, 53.6 % were from lower middle socioeconomic status family, and 51.8 % had family history of mental illness. Among 56 patients of these caregivers, 60.7 % were male, 50 % were in the age group of 16-30 years, 46.4 % were unmarried, 32.1 % had secondary level education, 71.4 % were unemployed, 42.9 % were cared by parents, 46.4 % had schizophrenia or psychotic disorders, 51.8 % had total duration of illness more than five years, and 41.1 % had first hospitalization.

**Table 1: Socio-demographic Variables of Caregivers and Burden (N=56)**

Socio-demographic Variable	N	Mean	SD	F-ratio	df	p value
<b>Age of Caregiver</b>						
18-30	15	72.20	14.785	-1.054	3	.132 (NS)
31-45	24	71.33	13.927			
46-60	15	80.73	10.229			
60-65	2	82.00	4.243			
<b>Total</b>	<b>56</b>	<b>74.46</b>	<b>13.497</b>			
<b>Marital Status of Caregiver</b>						
Unmarried	11	64.09	9.148	5.150	2	.009**
Married	42	76.50	13.549			
Widowed	3	84.00	3.606			
<b>Total</b>	<b>56</b>	<b>74.46</b>	<b>13.497</b>			
<b>Education of Caregiver</b>						
Literate	17	76.41	8.761	2.135	5	.076 (NS)
Primary	3	64.00	2.000			
Secondary	10	72.70	10.740			
Intermediate	13	68.15	15.066			
Bachelor	8	80.00	16.784			
Master	5	85.20	17.936			
<b>Total</b>	<b>56</b>	<b>74.46</b>	<b>13.497</b>			
<b>Occupation of Caregiver</b>						
Unemployed	25	72.72	13.126	2.982	2	.059 (NS)
Employed	18	80.39	13.236			
Self Employment	13	69.62	12.560			
<b>Total</b>	<b>56</b>	<b>74.46</b>	<b>13.497</b>			
<b>Socioeconomic Status</b>						
Upper	1	71.00	-	.227	4	.922 (NS)
Upper Middle	5	77.60	20.452			
Lower Middle	16	73.25	14.327			
Upper Lower	30	75.27	11.962			
Lower	4	70.25	17.727			
<b>Total</b>	<b>56</b>	<b>74.46</b>	<b>13.497</b>			
<b>Religion of Caregiver</b>						
Hinduism	45	75.29	13.48	.731	2	.486 (NS)
Buddhism	8	69.12	14.60			
Christianity	3	76.33	11.59			
<b>Total</b>	<b>56</b>	<b>74.46</b>	<b>13.497</b>			
Socio-demographic Variable	N	Mean	SD	t-test	df	p value
<b>Type of Family</b>						
Nuclear	24	75.75	12.432	.614	54	.542 (NS)
Joint	32	73.50	14.364			
<b>Total</b>	<b>56</b>	<b>74.46</b>	<b>13.497</b>			
<b>Permanent Residence</b>						
Rural	24	73.42	13.141	-.500	54	.619 (NS)
Urban	32	75.25	13.914			
<b>Total</b>	<b>56</b>	<b>74.46</b>	<b>13.497</b>			
<b>Family History of Mental Illness</b>						
Yes	29	73.14	12.944	-.759	54	.451 (NS)
No	27	75.89	14.173			
<b>Total</b>	<b>56</b>	<b>74.46</b>	<b>13.497</b>			

Note: NS = Not significant, \*\*  $p < 0.01$

Table 1 showed burden of caregiving according to socio-demographic variables. The mean score on caregiving burden was found to be high among caregivers belonging to age group 60-65 years ( $82.00 \pm 10.229$ ), widow ( $84.00 \pm 3.606$ ), with education up to master level ( $85.20 \pm 17.936$ ), having employment ( $80.39 \pm 13.236$ ) and from upper middle socio-economic status ( $77.60 \pm 20.452$ ). Likewise, the mean score on caregiving burden was high among the caregivers following Christianity ( $76.33 \pm 11.59$ ), from urban areas ( $75.25 \pm 13.914$ ), from nuclear family ( $75.75 \pm 12.432$ ), with family history of mental illness ( $73.14 \pm 12.944$ ). One way ANOVA showed no significant difference in the distribution of burden by age, educational level, occupation, socioeconomic status and religion. Highly significant difference was found in the distribution of burden by marital status ( $F=5.15$ ,  $df = 2$ ,  $p<0.01$ ). The t-test showed no significant difference in the distribution of burden by

family type, permanent residence and family history of mental illness.

Table 2 illustrated the distribution of experience of burden of caregiving to people with mental illness according to different illness variables. Mean score burden was found to be high among caregivers of patients with more than five years of illness ( $75.45 \pm 14.007$ ), with mood disorders ( $79.12 \pm 10.176$ ), with first hospitalization ( $75.96 \pm 12.833$ ) and cared by spouse ( $82.67 \pm 9.642$ ). One way ANOVA showed no significant difference in the distribution of burden by total duration of illness, type of illness and number of hospitalization where as highly significant difference was found in the distribution of burden according to caregiver's relation with the patient ( $F=7.493$ ,  $df= 3$ ,  $p <0.01$ ).

**Table 2: Illness Variables and Caregiving Burden (N=56)**

Illness Variables	N	Mean	SD	F-ratio	df	p value
<b>Total Duration of Illness</b>						
Less than one year	10	70.90	13.609	.425	2	.656 (NS)
1-5 year	17	74.88	12.995			
More than 5 years	29	75.45	14.007			
<b>Total</b>	<b>56</b>	<b>74.46</b>	<b>13.497</b>			
<b>Type of Illness</b>						
Schizophrenia and Psychotic Disorders	26	77.00	13.711	1.227	4	.311 (NS)
Mood Disorders	8	79.12	10.176			
Neurotic and Stress Related Disorders	11	71.00	10.936			
Childhood Disorders	2	71.50	30.406			
Substance Related Disorders	9	67.89	14.120			
<b>Total</b>	<b>56</b>	<b>74.46</b>	<b>13.497</b>			
<b>No of Hospitalization</b>						
First	23	75.96	12.833	.244	2	.789 (NS)
Second	14	73.00	15.044			
Third or More	19	73.74	13.670			
<b>Total</b>	<b>56</b>	<b>74.46</b>	<b>13.497</b>			
<b>Caregiver's Relation with Patient</b>						
Parents (Father/Mother)	24	78.38	12.60	7.493	3	.000**
Spouse	12	82.67	9.642			
Children (Son/Daughter)	9	65.11	11.252			
Sibling	11	64.64	11.439			
<b>Total</b>	<b>56</b>	<b>74.46</b>	<b>13.497</b>			

Note: NS = Not significant, \*\*  $p < 0.01$

**Table 3: Level of Burden on Burden Assessment Schedule (BAS) (N = 56)**

Level of Caregiving Burden	BAS Range	N (%)	Mean (SD)	p value
Minimal	40-60	10 (17.9)	54.50 (4.503)	F=81.57 df= 3, p=.000**
Moderate	61-80	27 (48.2)	71.78 (6.559)	
Severe	81-100	18(32.1)	88.06 (5.173)	
Very Severe	101-120	1(1.8)	102.00	
<b>Total (N)</b>	<b>40-120</b>	<b>56 (100)</b>	<b>74.46 (13.497)</b>	

Note: \*\* p<0.01

Table 3 shows the levels of caregiving burden. 48.2 % of caregivers had moderate level of caregiving burden (Mean±SD:71.78 ± 6.56) and 32.1% had severe level of burden (Mean±SD:88.06 ± 5.173). Highly significant difference was observed in the distribution of burden according to severity (F=81.57, df=3, p<0.01).

**Table 4: Distribution of Level of Caregiving Burden on BAS according to Caregivers' Sex (N=56)**

Level of Caregiving Burden	Male n (%)	Female n (%)	Total N (%)	p value
Minimal	5 (8.9)	5 (8.9)	10 (17.9)	χ <sup>2</sup> = 1.26, df= 3, p=.739 (NS)
Moderate	13 (23.2)	14 (25.0)	27 (48.2)	
Severe	10 (17.9)	8 (14.3)	18 (32.1)	
Very Severe	-	1 (1.8)	1 (1.8)	
<b>Total (N)</b>	<b>28 (50)</b>	<b>28 (50)</b>	<b>56 (100)</b>	

Note: NS = Not Significant

Table 4 showed that 8.9 % of both male and female caregivers reported minimal level of burden; 23.2 % of male and 25.0 % female caregivers reported moderate level of burden; 17.9 % of male and 14.3 % of female caregivers

reported severe level of burden; and only 1.8 % of female caregiver reported very severe level of burden. No significant difference was observed in the distribution of burden level among caregivers according to sex (χ<sup>2</sup>=1.26, df = 3, p >.05).

**DISCUSSION:**

Majority of family caregivers in the present study reported moderate to severe level of caregiving burden. Though no significant difference was observed in the distribution of caregiving burden in total and in different domains of BAS on the basis of sex, as the task of caregiving has been shouldered by female in different context throughout the world, most caregivers in studies reviewed in literature showed female to be the main caretakers in different physical and mental illnesses. The sex wise distribution of burden in different dimensions of Burden Assessment Schedule showed that female caregivers reported more spouse related burden than that of male. As female caretakers were mostly spouses of patients with alcohol related disorders and that might have increased the extent of burden. In a review of recent studies on alcohol<sup>13</sup> found that the alcoholic's family distinguishes itself from other families in that there may be a negative, critical, hostile, and rejectionist environment which is eventually passed on to their own children. A person with long term alcohol use show poor adjustment in their relationships with his wife and children, and there is expression of dissatisfaction and disinterest in dyadic relationship which increases their vulnerabilities to some other co-morbid psychiatric conditions like anxiety, depression etc.

Though no significant difference was observed in the distribution of burden by total duration of illness, type of illness and number of hospitalization, other studies have found significant difference in these variables (REF). In the present study, significant difference was found in the distribution of burden according to caregiver's relation with the patient (F=7.493, df= 3, p= .000<0.05). Caregivers experience burden in different dimensions and its extent depends on various characteristics of both

caregivers and patients. Employed caregivers reported higher level of burden of caregiving than unemployed and self employment caregivers. Higher level of burden was found among upper middle socio-economic status caregivers. Burden was found high among the married. As being married changes the role and increases responsibilities, the differential experience of burden is apparently understood. Majority of the patients in the present study were admitted for the first time (41.1%) followed by 33.9% for the third or more hospitalization and with total duration of illness more than 5 years (51.8 %). These two factors have found to be significant in increasing the experiences of burden among the caregivers, especially in first episode psychotic and mood disorders. The psychotic symptoms occurring for the first time are more frightening for the spouse of the person affected as the illnesses occur unexpectedly. In this situation, feelings of powerlessness, fear, and despair are often overwhelming<sup>13</sup>. The reported moderate to severe level of burden among the study caregivers supports the earlier findings. Parents of schizophrenia patients having problems and worries regarding the parent-child relation are of importance, such as the question of possibly being responsible for the illness because of poor parenting, and the dilemma of a permanent, possibly lifelong dependency of the patient<sup>15</sup>. Family intimacy and conflict have been found to reflect the degree of burden or reward experienced and it is suggested that the family system, as the context within which the patient exists, is seen as the mediating environment for caregiving burden and reward<sup>16</sup>.

Stigma attached to mental illness complicates care-giving for the family as it may lead to the increased social isolation of the affected family or the individual care-giver, financial difficulties, restrictions on the educational or occupational advancement of family members or the care-giver in particular, increased anxiety and feelings of helplessness, reduction in leisure time activities and breakdowns in social relationships<sup>17</sup>. Along with stigma experience itself, the amount of care-giver strain experienced and the degree to which the patient is dependent on the care-giver all represent

major problems for the resilience of care-givers<sup>18, 19</sup>.

#### CONCLUSION:

The study concluded that family caregivers of people with mental illness experience significant levels of caregiving burden and is associated with different socio-demographic characteristics of both patients and caregivers. In the country like Nepal where there are very few mental health professionals and stigma associated with mental illness are widely prevalent which maintains the people's hesitation to seek mental health treatment in the community, caregivers' self-help organization can be established to make integrated actions to reduce caregiving burden, learn better coping strategies and strengthen social support system. These initiatives can be helpful to plan and implement preventive measures and to ensure better treatment and rehabilitation facilities.

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