

## PREDICTORS OF BURDEN IN CAREGIVERS OF STROKE PATIENTS IN PAKISTAN<sup>1</sup>

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### ABSTRACT

#### OBJECTIVE

To examine patient-caregiver characteristics and caregiver psychological distress as predictors of burden in caregivers of stroke patients in Pakistan.

#### STUDY DESIGN

Correlational study.

#### PLACE AND DURATION OF THE STUDY

The study was conducted in government teaching hospitals of Lahore, Pakistan from February to June 2014.

#### SUBJECTS AND METHODS

The sample comprised of 90 caregivers (14 men and 76 women) performing the activities of daily living of stroke patients for at least 2 months and aged between 20-45 years were included. Incapacity Status Scale, Depression Anxiety Stress Scale and Family Burden Interview Schedule were used.

#### RESULTS

Correlation and regression analyses were applied. The caregivers' factors related to caregivers' burden included family monthly income, anxiety, depression and stress. Caregivers' single marital status, family monthly income, anxiety and depression emerged as significant predictors of care giving burden.

#### CONCLUSION

Caregivers' marital status, family monthly income, anxiety and depression tend to make the caregivers' experience burdensome. Interventions planned to manage the symptoms of anxiety and depression may be conducive for lessening caregivers' burden.

#### KEY WORDS

Stroke caregivers, Caregivers' burden, Psychological distress.

### INTRODUCTION

The burden of cerebrovascular disease in developing countries is rising sharply. The prevalence of modifiable risk factors (e.g., hypertension, diabetes mellitus, obesity & tobacco) for stroke is substantially high in Pakistan<sup>1,2,3</sup>. A recent community-based survey suggested an estimated 21.8% prevalence of stroke and/or TIA in Karachi<sup>4</sup>.

Stroke is a very complex illness and produces adverse effects on survivors such as physical problems<sup>5</sup>, emotional problems<sup>6</sup> and cognitive problems<sup>7</sup>. In Pakistani culture the patient of stroke is usually under the caretaking of family members particularly women. They help the stroke survivors with their activities of daily living, such as toileting, dressing, coordinating transportations, medical care and appointments. The responsibilities on women increases as they are expected to carry out various tasks such as managing household and care giving tasks simultaneously which make them experience high levels of stress and burden<sup>8</sup>.

According to Platt (1985)<sup>9</sup> burden refers to the problems, difficulties and/or adverse events that affect negatively the patient's significant others' lives. Hoenig and Hamilton (1966)<sup>10</sup> classified burden into two types; subjective and objective. Objective burden is linked to the social disturbances due to patient him/herself such as household routine, family relations, social relations, children and siblings, leisure time activities, career and finances. Subjective burden refers to resulting distress experienced by family members such as health and subjective distress<sup>11</sup>.

Stress process model<sup>12,13,14</sup> provided a conceptual framework which categorized predictors of caregiver burden which are (i) factors related to caregiving and demographic characteristics of both care-recipients and caregivers, (ii) primary stressors associated with patient symptomatology or illness progression and (iii) secondary stressors such as family conflicts, difficulties at work, financial difficulties etc.

In Pakistan, the situation for caregivers is troublesome because no facilitation centers such as rehabilitation centers and population welfare departments are established for providing aid or education to caregivers of neurological patients. The increased responsibility on caregivers and lack of professional assistance make the caregiving even more burdensome. Conducting this research will help identify the factors which predict burden in caregivers of stroke patients. The objective of the present study was to explore the relationship between demographic characteristics, psychological distress and burden in caregivers of stroke patients. It also aimed to determine the factors predicting caregivers' burden in stroke patients of Lahore, Pakistan. The following hypotheses were formulated:

H1: There is likely to be a relationship between patients' and caregivers' demographic factors and caregivers' burden.

H2: There is likely to be a positive relationship between psychological distress and burden in caregivers of stroke patients.

H3: Patient and caregiver related factors, and caregivers' psychological distress are likely predictors of burden in caregivers of stroke patients.

## SUBJECTS AND METHODS

### Participants

The sample comprised of caregivers of stroke patients (N=90). The demographic characteristics showed that the mean age of stroke patients was 62 years (SD= 17.4). Majority were women, n=59 (65.6%), illiterate, n=65 (72.2%) and married, n=85 (94.4%). Mean duration of treatment is 17 months (SD= 27.1). The patients suffered from at least one episode of stroke, n=71 (78.9%).

Mean age of the caregivers was 35 years (SD= 8.3). Majority were women, n=76 (84.4%), illiterate, n=28 (31.1%), married, n=69 (76.6%) and unemployed, n=70 (78.9%). Most of the caregivers were children (n=67) of stroke patients. Mean family monthly income was Rupees twenty-two thousand (SD= 18306.4). Mean duration of caregiving is 11 months (SD= 11.4). Majority of the caregivers owned personal residence and lived in nuclear family system.

The sample was selected through non-probability purposive sampling strategy from indoor department of medical wards of Government teaching hospitals of Lahore, Pakistan i.e., Mayo Hospital, Jinnah Hospital, Services Hospital and Sir Ganga Raam Hospital. Inclusion criteria comprised of stroke patients with diagnosis of ischemic stroke or hemorrhagic stroke, with substantial severity of disability, and accompanied by primary caregivers. Stroke patients with a diagnosis of transient ischemic attack (TIA) and having any another terminal illness were excluded.

A caregiver was defined as a person who assisted the patient in carrying out his/her daily life activities such as providing food via nasogastric tube, rubbing and washing patient's body, changing clothes, emptying urine bag and satisfying other medical requirements such as meeting appointments for medical check-ups, MRI, and blood tests. The caregivers, taking care of the patient for at least last 2 months at home and currently providing care at hospital, and were falling within the age range of 20-45 years were included. Those caregivers with any serious and terminal medical condition (such as Hepatitis, cancer, cardiac problems, and renal failure) and with the prior history of mental illness were excluded.

### Measures

Demographic information sheet included age, gender, education, marital status and duration of illness of the patients of stroke and caregivers' information like age, gender, education, relationship with patients, marital and working status, family monthly income, caregiving duration, family system and residence.

### Incapacity Status Scale

Urdu translation of Incapacity Status Scale (ISS)<sup>15</sup> was administered to ascertain the physical disabilities and impairments in the abilities to perform activities of daily living. This scale has 20 items graded on a Likert scale of 4-points (0=normal to 4= loss of function). The Cronbach's alpha of this scale is .82 in the present study.

### Depression Anxiety Stress Scale

The caregivers' psychological distress (anxiety, depression and stress) was assessed using Urdu translation of Depression Anxiety Stress Scale (DASS 42)<sup>16</sup>. The psychological distress was taken on state

level and the responses were rated on a 4-point Likert scale (0=did not apply to 3= applied very much). The alpha reliability of total DASS is .97 in the present study.

### Family Burden and Interview Schedule

The caregivers' burden was assessed with Urdu translation of Family Burden and Interview Schedule (FBIS)<sup>17</sup>. This scale measures objective and subjective burden. It consists of six sub-categories of burden: financial burden, family routine, family leisure, family interaction, physical health and mental health. Each item is graded on a Likert scale of 3-points (0= no burden, 1= moderate burden and 2= severe burden). In the present study, the reliability co-efficient of overall scale is .71.

### Procedure

This study protocol was approved by Doctoral Program Coordination Committee (DPCC), Centre for Clinical Psychology, University of the Punjab, Lahore. Written permissions were taken from the authors of measures used and from hospital authorities. Caregivers were asked to sign an informed consent which stated the rationale and purpose of the study, right to withdraw from participation at any time, confidentiality of the identity and responses and use of responses for research purpose only. No financial and other inducements were offered for participation in this study. The caregivers were approached in hospitals and data were collected. The data was analyzed using SPSS 21.0.

## RESULTS

Inter-correlations were calculated by Pearson's Product Moment Correlation as a pre-requisite for multiple regression analysis. Correlations were computed to determine the relationship between patients' and caregivers' demographic characteristics, psychological distress and burden (see Table 1). A significant weak negative relationship was found between monthly income and burden on family finances ( $r = -.38$ ) and burden on family routine ( $r = -.37$ ) in caregivers of stroke patients. Anxiety ( $r = .39$ ), depression ( $r = .31$ ) and stress ( $r = .24$ ) had significant but weak positive relationship with burden on family interaction in family caregivers.

To understand the relative contribution of demographic characteristics of patients and caregivers and caregivers' psychological distress (i.e., anxiety, depression and stress), multiple regression analyses (Stepwise method) were carried out separately for each domain of caregivers' burden (i.e., family finance, family routine, family leisure activities, family interaction, physical health and mental health).

As shown in table 2, the overall regression model of caregivers' burden on finances was statistically significant,  $R^2 = .17$ ,  $F = 8.57$ ,  $p < .001$ . Two out of eleven predictors came out to be significant and reached in two steps with no variables removed. In model 1, family monthly income of caregivers came out to be significant negative predictor and accounted for 11% of the variances in regression model. The addition of caregivers' marital status came out to be second significant predictor. Unmarried caregivers explained additional 6% of the variance in the overall model. For caregivers' burden on family routine, model was significant,  $R^2 = .18$ ,  $F = 18.33$ ,

**Table 1**  
Correlation between Demographic Characteristic, Stroke Severity, Psychological Distress and Burden (N=90)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1 Patient Age	-																
2 Patient Gender	.07	-															
3 Treatment Dur	.18	.08	-														
4 Carer Age	.42*	.12	.02	-													
5 Carer Gender	-.08	.46**	.07	-.12	-												
6 Monthly Income	.09	.06	-.00	-.07	-.06	-											
7 Caregiving Dur	.18	.16	.39*	.12	.00	.15	-										
8 Stroke Severity	.31**	-.05	-.06	.16	.03	-.15		-									
9 Anxiety	-.04	-.02	-.07	.09	-.03	-.22*	.14	-.05	-								
10 Depression	.15	-.07	-.01	.13	-.09	-.29**	.10	.04	.62**	-							
11 Stress	.09	.10	.06	.05	-.09	-.29**	.15	.03	.63**	.52	-						
12 Finance	-.17	.09	-.03	-.05	-.03	-.38**	-.09	.09	.10	.05	.19	-					
13 Routine	-.07	-.18	.04	.01	-.02	-.37**	-.04	.02	-.04	.10	.21*	.33**	-				
14 Leisure	-.06	-.06	.03	.04	.08	-.26*	-.01	.04	-.12	.01	.13	.28**	.78**	-			
15 Interaction	-.04	.03	.03	.11	.11	.04	.01	.05	.39**	.31**	.24*	.07	-.01	-.09	-		
16 Physical	-.00	-.04	-.10	.07	-.09	.07	-.15	-.12	.01	.15	-.11	.03	.03	.04	.29**	-	
17 Mental	-.08	-.04	.11	.01	.11	-.01	.02	-.01	.00	.14	-.09	-.13	-.07	-.09	.22*	.17	-
<i>M</i>	61.6	-	16.5	34.9	-	21833.3	10.8	74.0	18.2	16.1	20.4	5.4	6.6	6.6	2.8	.2	2.9
<i>SD</i>	17.4	-	27.1	8.3	-	18306.4	11.4	8.5	6.5	5.1	5.9	1.5	.5	.2	1.6	.9	.8

Note. Dur= Duration, \**p*<.05, \*\**p*<.01

*p*<.001 and contained one predictor. In model 1, family monthly income of caregivers came out to be significant negative predictor and accounted for 18% of the variance in caregivers' burden on routine life.

As shown in table 3, for the sub-domain of burden on leisure time activities only one significant model emerged, *R*<sup>2</sup> = .09, *F* = 8.26, *p*<.01 and reached in one step with no variables removed. In model 1, caregivers' family monthly income was a significant negative predictor and accounted for 9% of the variance being explained. Afterwards, another sub-category of burden on family interaction was entered as an outcome variable. For this sub-category, one significant model emerged, *R*<sup>2</sup> = .16, *F* = 16.69, *p*<.001 and reached in one step with no variables removed. In model 1, anxiety was a significant positive predictor and accounted for 16% of the variance in caregivers' burden on family interaction. In the end, the last sub-domain of burden on mental health was entered as outcome variable. The model contained one predictor (*R*<sup>2</sup> = .06, *F* = 5.76, *p*<.05) and reached in one step with no variables removed. In model 1, depression came out to be significant predictor and explained 6% of the variance in the model. For caregivers' burden on physical health, no predictors were significant. Results revealed that caregivers' factors such as monthly income and psychological distress i.e., anxiety, depression and stress were related to caregivers' burden. Caregivers' factors such as family monthly income, being unmarried, anxiety and depression predicted burden in caregivers of stroke patients.

**Table 2**  
Multiple Regression (Stepwise) for predicting Caregivers' Burden on Family Finances and Family Routine (N=90)

Variable	Burden on Family Finances			Burden on Family Routine	
	Model 1B	B	95% CI	Model 1B	95% CI
Constant	6.02***	5.91***	[5.44, 6.38]		
Patient Gender					
Patient Age					
Caregivers Gender					
Caregiving Duration					
Caregiver-Patient Relationship					
Family Monthly Income	.00**	-.00***	[.00, .00]	-.00***	[.00, .00]
Caregivers' Marital Status		.86*	[.15, 1.56]		
Stroke Severity					
Anxiety					
Depression					
Stress					
<i>R</i> <sup>2</sup>	.11	.17		.18	
<i>F</i>	10.71*	8.57***		18.33***	
$\Delta R^2$		.06			
$\Delta F$		5.83			

Note. Coding for patient and caregiver gender (women = 0 and men = 1), caregiver-patient relationship children vs. any other (children/siblings= 0 and any other= 1), caregiver-patient relationship children vs. siblings (children/any other=0 and siblings= 1), caregivers' marital status married vs. unmarried (married/widowed=0 and unmarried= 1), caregivers' marital status married vs. widowed (married/ unmarried= 0 and widowed= 1) \**p*<.05, \*\**p*<.01, \*\*\**p*<.001.

**Table 3**  
Multiple Regression (Stepwise) for predicting Caregivers' Burden on Family Leisure Time Activities, Family Interaction and Mental Health (N=90)

Variable	Burden on Leisure Time Activities		Burden on Family Interaction		Burden on Mental Health	
	Model 1 B	95% CI	Model 1 B	95% CI	Model 1 B	95% CI
Constant	6.71***	[6.64,6.78]	1.04*	[.10, 1.98]	2.29***	[1.76,2.84]
Patient Gender						
Patient Age						
Caregiver Gender						
Caregiving Duration						
Caregiver-Patient Relationship						
Family Monthly Income	.00**	[.00, .00]				
Caregivers' Marital Status						
Stroke Severity						
Anxiety			.10***	[.05, 1.5]		
Depression					.04*	[.01, .07]
Stress						
R <sup>2</sup>	.09		.16		.06	
F	8.26**		16.69***		5.76*	

Note. Coding for Patient and Caregiver gender (women = 0 and men = 1), Caregiver-patient relationship children vs. any other (children/siblings= 0 and any other= 1), Caregiver-patient relationship children vs. siblings (children/any other=0 and siblings= 1), Caregivers' marital status married vs. unmarried (married/widowed=0 and unmarried= 1), Caregivers' marital status married vs. widowed (married/ unmarried= 0 and widowed= 1)  
\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ .

## DISCUSSION

The present study was carried out to determine the factors predicting burden in caregivers. The results showed many interesting findings. One of the findings was that the caregiver's characteristics were the strongest predictor of caregiver's burden. The theorist of Stress process model<sup>15</sup> also believed that socio-demographic factors of caregivers predicted burden.

The present study provided evidence that caregivers' family monthly income was the factor predicting burden (family finance, family routine and family leisure) in caregivers of stroke patients. The results were consistent with the previous studies which reported that caregivers who suffered from low financial resources, low social support and more hours of caregiving experienced greater caregiving burden<sup>18</sup>. In another study, the findings showed that the monetary budget of family caregiving played an important role in caregiving burden for caregivers<sup>19</sup>. A study reported that more than one-third of the caregivers had used their savings and cut back on their own personal important things (such as home maintenance, spending for their own health or dental care)<sup>20</sup>. In the present study, the mean family monthly income of caregivers was Rs. 22,000 which

can easily put burden on caregivers' financial resources because this amount was too low to facilitate or meet the requirements of patients' treatment. Some caregivers abandon their jobs for the sake of caregiving while some hired other personnel such as maids and nurses for carrying out the activities of patients. However, caregivers in the present study were providing care to the patient by themselves without formal help due to decreased finances. These factors may become the factor behind increased burden on family routine of caregivers.

In the present study, it was also evident that caregivers' financial burden was predicted by caregivers' being unmarried. This finding was supported by other studies which claimed that married caregivers of cancer patients had lower economic caregiver burden than unmarried caregivers<sup>21</sup>. In another study it was reported that unmarried caregivers have increased vulnerability to a higher level of burden<sup>22</sup>.

The findings supported the hypothesis of the current study that the burden on family interaction and mental health of caregivers was predicted by caregivers' anxiety and depression respectively. In another study, it was reported that caregivers of stroke patients were having a high level of depression at acute and chronic phase of stroke<sup>23</sup>. The caregivers' psychological distress as predictor of caregivers' burden was supported by the various studies claiming that caregiver anxiety and depression were the factors influencing caregiver burden<sup>24,25</sup>.

The study has several limitations. The sample was taken from hospital settings. It would be more desirable if the data were collected from community and hospitals both for making comparisons. The sample belonged to lower socio-economic class, so the findings are less generalizable to middle and upper socio-economic class.

## CONCLUSION

It is concluded that that caregivers' factors predictive of burden included family monthly income, marital status, anxiety and depression. Interventions designed at reducing caregivers' level of burden may be beneficial.

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