

PREVALENCE OF DEPRESSION IN CAREGIVERS OF STROKE PATIENTS IN KARACHI, PAKISTAN

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ABSTRACT

Background and Objective:

Caregivers of patients with chronic debilitating illnesses are at risk of developing mental health problems. The objective of this study is to determine the frequency of depression in caregivers of stroke patients at a tertiary care teaching hospital in Karachi, Pakistan.

Methods:

A cross-sectional study was conducted among caregivers of stroke, who were recruited from the Aga Khan University Hospital between January 2018 to October 2018. Data was collected through the Urdu Hamilton rating scale for depression (HAM-D-U) and it was analyzed using descriptive and inferential statistics.

Results:

A total of 136 caregivers participated in the study. Among them, 44.1 % were male and 55.9% were female. The mean age of caregivers was 45.38 ± 10.33 years. Using the HAM-D-U scale, depression was present in 64 (47.1%) of caregivers. Out of them (n=64), 46 (33.8%) had mild depression whereas 18 (13.2%) had moderate depression. Depression was found to have a significant relationship with the age of the patient ($p=0.002$), education level of caregiver ($p=0.012$), employment status of caregiver ($p=0.012$), being a sole caregiver ($p=0.039$), and monthly family income ($p=0.016$).

Conclusion:

Caring for patients with neurological disorders is highly challenging and demanding. The need for this role may arise unexpectedly in one's life leaving little space for adjustment and coping. Caregiver depression can be debilitating especially if moderate to severe in intensity. Depression in stroke caregivers can be missed as patients are the center of management. Hence, strategies should be designed and reinforced to screen caregivers for depression with a pathway for easy and timely referral.

Key Words: Caregivers, Hamilton rating scale, depression, stroke, Pakistan

INTRODUCTION

Stroke is ranked as the third most common cause of disability-adjusted life-years (DALYs) worldwide. It is also the second most common cause of death world-wide.¹ It is estimated that in 2019, there were 12.2 million new cases of stroke, 101 million cases of prevalent stroke, and 6.55 million deaths due to stroke globally.¹

Developing countries bear major stroke burden, where 75.2% of all mortalities are due to stroke and 81.0% DALYs due to stroke. According to WHO report, around 86% of stroke-related fatalities were seen in low- and

middle-income countries (LMIC).² In South Asia, the current stroke prevalence ranges from 45–471 per 100,000.³ A study from Pakistan conducted in 2011 reports stroke incidence approximately 250 per 100,000 population, or 350,000 new stroke patients annually.⁴

Stroke often impairs sensory (45%), motor (35%), memory (32%), language (31%), and vision (20%) functions.⁵ About one-third of stroke survivors experience neuropsychiatric symptoms such as depression, anxiety, apathy, irritability and PTSD. Other

less common symptoms include pseudobulbar affect, impulsivity, mania, and psychosis.⁶ The prevalence of depression in stroke caregivers world wide is estimated to be 40.2%.⁷ A study from Pakistan shows that 48% of stroke caregivers were depressed and 24% had a borderline score i.e. they were at risk of developing depression.⁸ In another study, stroke caregivers reported stress and mood symptoms, due to caregiver burden, reduction in social activities, added unanticipated financial burden,⁹ sleep disturbance, and workload with time constraints.¹⁰ Caregiver anxiety is also associated with the level of the patients' functional disability.¹¹

Lack of support makes them more vulnerable to burnout and negative psychological consequences.¹² Caregiver's concerns regarding survivor's care usually include managing medications, communicating with the patients, managing their emotional needs, and ensuring adequate meal intake.¹³ This reduces the patient's as well as caregiver's quality of life, who often report a feeling of confinement with little opportunity for relief.¹⁴ Since stroke patients need caregivers as part of their recovery process, caregiver depression can compromise the quality of patient care. It is therefore important to provide caregivers the required support and treatment to improve the long term recovery of stroke patients. This study aimed to identify the prevalence of depression in caregivers of stroke patients visiting a tertiary care teaching hospital in Karachi, Pakistan.

METHODS

Study Design: An analytical cross-sectional design was used in this study. This design identifies the association between the factors studied and outcome at one point in time.¹⁵

Place and Duration of Study: The study population were caregivers of patient with stroke. The study participants were recruited from the Neurology outpatient clinic of the Ag Khan University Hospital from January 2018 to October 2018/

Inclusion and Exclusion Criteria: The inclusion criteria for the study included caregivers of stroke patients either male or female with the age 18-65 years, duration of stroke diagnosis greater than or equal to 6 months, able to speak and understand Urdu, having one caregiver per patient, willing to participate

and give informed consent. We excluded the caregivers, who were suffering from any psychiatric illness, unable to understand the Urdu language, or refused to participate.

Sample Size: Taken prevalence of caregiver depression as 71%¹⁷ and precision of 8% with 95% confidence interval and based on least sample size proportion of outcome variable, the estimated sample size was 124 patients. An additional 10% of patients were included to cater for non-responders. Therefore, the total sample size is 136 patients.

Sampling Technique: Non-probability consecutive sampling.

Study measures:

Demographic questionnaire

A demographic questionnaire was used to elicit patients' and their caregiver's information including age, gender, occupation, marital status, family structure, and so on.

Hamilton rating scale for depression – Urdu (HAM-D-U)

Depression was measured using the Hamilton Rating Scale for Depression.¹⁶ The scale has a score range of 0-66. A score of 0-7 = Normal, 8-13 = Mild Depression, 14-18 = Moderate Depression 19-22 = Severe Depression and ≥ 23 = Very Severe Depression Urdu HAM-D is a validated and reliable scale for depression, administered by clinician. It showed good internal consistency (Cronbach alpha 0.71) when used in the Pakistani population.¹⁶

Data Collection: Data collection was carried out after the College of Physicians and Surgeons Pakistan (CPSP) approval of synopsis and the study approval from Ethics Review Committee of AKUH (5244-Psy-ERC-18). The permission was also obtained from the head of the study setting (Neurology outpatient clinic). Caregivers were selected based on the inclusion criteria. The study participants were provided information about the purpose, risks, benefits of the study, and their rights as participants. Caregivers who consented to the study signed a written informed consent and were interviewed face to face at a discrete place in the Neurology clinic. For participants' convenience, the consent form and the study proforma were also made available in Urdu language. Patient demographics were collected using patient medi

records. Any missing details of patient demographics in the medical records were obtained from caregivers. Caregivers were interviewed using a demographic questionnaire, Modified Rankin Scale (MRS)¹⁸ and HAM-D-U.¹⁶ All interviews were conducted by the Primary Investigator and duration of each interview was 10 minutes. Participants' confidentiality and anonymity was maintained. Participants ID numbers were used instead of their names and data was kept in lock and key, and electronic files were password protected. The study data was accessible only to the research staff.

Data Analysis: Data was analyzed in the Statistical Package for social sciences 19.0. Mean and SD (Standard Deviation) were computed for continuous variables including the age (of patient and caregiver), duration of the stroke, and estimated medical

expenditure. Frequency and percentage of categorical variables such as gender (of patient and caregiver), marital status, occupation, education, employment status of patient and caregiver, the family set up, functional impairment, the relationship of caregiver to the patient, and depression as present or absent and if present then either low, moderate or high were also calculated. Effect modifiers were controlled through stratification of age and gender of patient and caregiver, marital status, occupation, duration of the stroke, educational level of caregiver, employment of patient and caregiver, relationship to the patient, duration of taking care of the patient, to see their effect on the outcomes. Post-stratification Chi-square test was used to see the effect on outcome variables. A p-value of <0.05 was taken as significant.

RESULTS

The descriptive statistics of the sample population are given in Table 1.

Table 1: Descriptive Statistics

Variables	n	Minimum	Maximum	Mean	Std. Deviation
Duration of stroke in months	136	6	60	11.71	8.777
Age of caregiver	136	23	65	45.38	10.333
Monthly family income in PKR	113	20000	400000	78584.07	47895.296
Patients estimated medical expenditure in PKR in last 6 months	118	2000	150000	15885.59	17677.961

A total of 136 caregivers were included in the study. Among them, 44.1 % were males and 55.9% were females. The mean age of caregivers was 45.38 ± 10.33 years, ranging from 25 to 65 years. The mean duration of the patient's stroke and caregiving was

11.71 ± 8.77 months (refer table 1). Majority of the caregivers (77%) were married. In terms of education level, 44% were graduate and 35% were intermediate, as presented in Table 2.

Table 2: Demographic information of the caregivers (n=136)

<i>Gender</i>		
Male	60	44.1
Female	76	55.9
<i>Age (years)</i>		
25-35	28	20.6
36-50	75	55.1
51-65	33	24.3
<i>Marital status</i>		
Divorced	6	4.4
Married	105	77.2
Separated	2	1.5
Unmarried	22	16.2
Widowed	1	0.7
<i>Education</i>		
Not formally educated	4	2.9
Primary	3	2.2
Secondary	17	12.5
Intermediate	47	34.6
Graduate	60	44.1
Postgraduate	5	3.7
<i>Occupation</i>		
Businessmen	8	5.9
Professional	16	21.1
Home maker	58	42.6
Labor	9	6.6
Student	3	2.2
Others	5	3.7
<i>Relationship with patient</i>		
Children	51	37.5
Sibling	19	14
Spouse	41	30.5
Others	25	18.4
<i>Sole Caregiver</i>		
Yes	106	77.9
No	30	22.1
<i>Family Structure</i>		
Nuclear	71	52.2
Extended	65	47.8
<i>Any medical/surgical illness</i>		
Yes	33	24.3
No	103	75.7

With regard to stroke patients' demographics (n=136), 70.6% patients were males and 29.4% were females. The mean age of the patients was 62.07 ± 13.902 years, ranging from 26 to 91 years. Only

26.5% of the patients were employed and 73.5% were unemployed. 77.2% of patients had a stroke during the last 6-12 months. Functional impairment among stroke patients according to MRS presented in Table 3.

Table 3: Functional impairment among stroke patients as per MRS scale (n=136)

	Frequency	Percentages
No symptoms at all	14	10.3%
No significant disability despite symptoms; able to carry out all usual duties and activities	40	29.4%
Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance	33	27.9%
Moderate disability; requiring some help, but able to walk without assistance	27	19.98%
Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance	17	12.5%
Total	136	100.0%

Around 24.3% (n=33) of caregivers were diagnosed with some medical/ surgical illness including diabetes mellitus, hypertension, ischemic heart disease, anemia, and hypothyroidism. The mean family income reported by 113 participants was 78584 ± 4789 Pakistani rupees (PKR) and the estimated medical expenditure of the patient in the last 6 months was PKR 15885.59 ± 17677.961 . Out of a total of 136 caregivers, 72 (52.9%) caregivers had no depression while 64 (47.1%) caregivers had depression, shown in Figure 1. Among these 64 caregivers with depression, 46 (33.8%) had mild depression and 18 (13.2%) had moderate depression, as presented in Figure 2. There were no patients with severe depression.

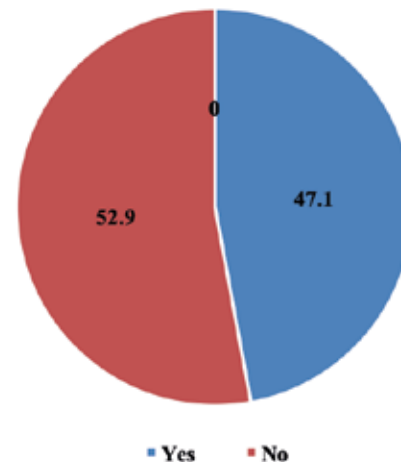


Figure 1: Prevalence of Depression among caregivers of stroke patients (n=136)

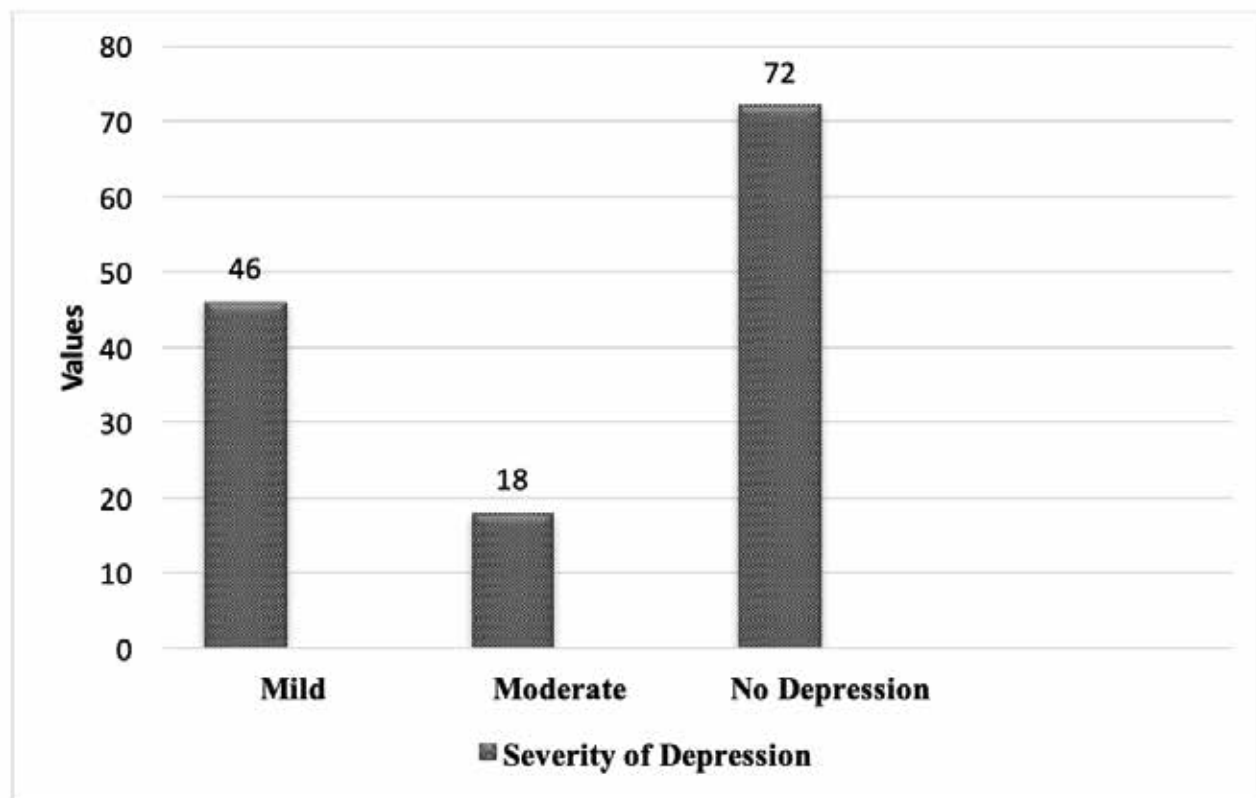


Figure2: Severity of Depression among caregivers of stroke patients (n=136)

Depression was found to have a positive correlation with age of the patient ($p=0.002$), education level of caregiver ($p=0.012$), employment status of caregiver ($p=0.012$), being a sole caregiver ($p=0.039$) and family monthly income ($p=0.016$) (refer Table 4). A negative correlation was seen between depression

and age of caregiver ($p=0.442$), gender of caregiver ($p=0.280$), gender of patient ($p=0.112$), marital status ($p=0.977$), occupation ($p=0.229$), duration of stroke and caregiving ($p=0.862$), employment status of patient ($p=0.532$), functional impairment of patient ($p=0.059$) and relationship with patient ($p=0.063$).

Table 4: Association of demographic characteristics of caregiver with Depression (n=136)

Variables	Depression			P value
	No depression	Mild	Moderate	
Age				0.442
26-35 years	11	11	6	
36-50 years	43	23	9	
51-65 years	18	12	3	
Gender				0.280
Male	35	20	5	
Female	37	26	13	
Education				0.012*
Illiterate/ Primary	1	5	1	
Secondary	10	6	1	
Intermediate	18	18	11	
Graduate & Postgraduate	43	17	5	
Employment status				0.012*
Employed	38	17	4	
Unemployed after patients stroke	6	11	7	
Unemployed before patients stroke	28	18	7	
Others	2	2	0	
Marital Status				0.977
Unmarried	12	7	3	
Ever married (divorced, separated, widowed)	60	39	15	
Sole Caregiver				0.039*
No	60	36	10	
Yes	12	10	8	
Monthly family income				0.016*
<5000 Rs.	12	9	10	
5001-100000 Rs.	36	29	7	
100001 & above Rs.	8	3	0	
Relationship with patient				0.063
Children	18	4	29	
Sibling	4	1	14	
Spouse	18	6	17	
Others	6	7	12	

*Significant p values<0.05

DISCUSSION

In our study 52.9% caregivers had no depression while 47.1% (n=64) caregivers had depression. Among these 64 caregivers with depression, 46 (33.8%) had mild depression and 18 (13.2%) had moderate depression. This finding is in lieu with studies conducted worldwide as well as in Pakistan; where a vast range of 24-71% prevalence was seen.^{7,8,17}

Worldwide caregiving is traditionally considered to be a female's role and a systemic review shows that 71% of the caregivers of stroke patients are females.¹⁹ Our study showed similar results; a majority of 55.9% of the caregivers included were females. It can be ascertained to our cultural setup as well that majority of caregivers were not only females but also of the immediate family and paid caregivers were seen in less than 25% of the cases. However, the relationship of the caregiver didn't correlate with the depression score.

Our study showed that the education level of the caregiver was a protective factor from depression; similar to that suggested by evidence.²⁰ Employment outside the home also showed a protective effect; possibly by helping the caregiver financially, relieving them time windows off caregiving responsibilities, and probable peer support.

Taking care of the patient single-handedly may cause more emotional, physical, and mental strain; a greater part of the day may hence be spent in caregiving with little opportunity for personal time and leisure activities. As seen in our study if caregiving is shared lesser depression is seen. Despite a nuclear family setup in a majority of the caregivers; those being a part of shared caregiving were seen to have lesser depression.

In our study, we didn't find a significant association with patient age, duration of the stroke, and hence caregiving along with monthly medical expenditure which may be due to a small sample size along with data collected from one set up only.

The severity of patients' functional impairment can increase the risk of caregiver burden.²¹ Our study showed a similar association between functional

impairment of stroke patients and severity of depression in caregivers. Increased functional impairment of a stroke survivor can increase time spent in caregiving along with emotional and physical energy invested in caregiving which can explain a proportionate rise in caregiver burden and depression.

This study may help clinicians be more equipped and mindful to explore depressive symptoms in patients and caregivers and seek appropriate and timely psychiatry referral in those indicated. The study may also help design policies and organize support groups for caregivers involved in prolonged caregiving.

Strengths and Limitations

This study has addressed an issue that is clinically under-recognized and under-studied. A major limitation of this study is a small subset of the population studied, only in urban setting, at one point in time only i.e. single interview only. The study results cannot be generalized to the whole population due to its limited sample size. Study findings can also be due to other confounding factors which were not accounted for in the study. Depression amongst caregivers is an understudied and clinically unacknowledged area. Our study adds to data from a tertiary care hospital from a major city in Pakistan, which wasn't done previously in the city (Karachi) This study, to some extent, has established grounds for further research and has highlighted the importance to explore depressive symptoms not only from the patient but also the caregivers

CONCLUSION

This study reports a high prevalence of depression of 47.1% among the caregivers of stroke patients caregiving support from other family members, a higher education level, and employment appear to play a protective role. strategies should be designed and reinforced in the clinical settings to screen both the patients and the caregivers for depression along with a pathway for an easy and timely referral to reduce morbidity and mortality and improve quality of life of patients and caregivers..

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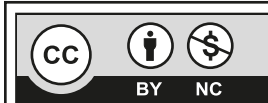
Author's contribution:

Marium Mansoor; concept, data collection, data analysis, manuscript writing, manuscript review

Shahina Pirani; manuscript writing, manuscript review

Rabeeka Aftab; concept, manuscript review

Tania Nadeem; concept, manuscript review



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