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Relationship of Caregivers' Perceived Stress and Burden among Stroke Survivors: A prospective Cross-Sectional Study

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ABSTRACT

Objective: To determine the relationship between perceived stress and burden among caregivers of stroke survivors residing in Lahore city of Pakistan.

Methods: This prospective cross-sectional study was conducted at three health care institutes of Lahore, Pakistan from October 2021 to March 2022. The inclusion was limited to caregivers providing more than 6 hours of care per day to stroke survivors for at least one month duration after the discharge from hospital. The Zarit Caregiver burden interview and perceived stress scale were used to measure caregiver burden and perceived stress respectively.

Results: Of 384 caregivers of stroke survivors, the mean age was 34.79 ± 5.80 years. Mild to moderate burden was observed in 364 (94.8%) and only 20 (5.2%) had moderate to severe burden. Similarly, moderate stress was observed in 353 (91.9%) and only 31 (8.1%) had severe stress. A significantly weak positive correlation was found between stress score and burden score (r=0.26, p-value <0.001). Furthermore, significantly weak positive correlation of burden and stress score was observed when stratified on the basis of age, gender, and relationship with the stroke survivor.

Conclusion: In the current study, a weak positive correlation was observed between perceived stress and burden among caregivers of stroke survivors.

Keywords: Burden, Caregiver, Perceived Stress, Stroke, Zarit Caregiver Burden Interview.

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INTRODUCTION

Stroke is a chronic disabling disease with high morbidity and mortality rate that actually threatens the human health. The stroke results in long-term residual impairment or physical disability due to neurological impairment. It affects 16 million patients worldwide.[1] In Pakistan which is a developing country, the incidence of stroke is 584,000 out of 650,000, in patients of 75 to 85 years.[2]

It is reported that stroke caregivers have a high percentage of mental stress than stroke patients.[3] Addressing the needs of beloved ones who have suffered from stroke has been difficult and the subject of considerable research. It was found that the mental illness of caregivers harms their social skills, body functioning, quality of life, and psychological health. It also affects the prognosis of stroke patients.[4,3] After being discharged from the hospital, many survivors of strokes get family care at home. The quality of life of stroke patients is significantly impacted by the involvement of the family members. Patients undergo regular, prolonged assistance from family careers. Most importantly, providing care to chronic patients is stressful. It is reported that after caring for stroke patients, family carers are more prone to stress and feeling depressed.[5]

The caregiver is the main person who supports the patient and provides care. As time goes on, larger numbers of individuals are becoming aware of the importance of carers in the long-term care of stroke patients.[6] Because these carers are crucial to ensuring rehabilitation outcomes and the long-term well-being of stroke survivors, the emphasis in stroke rehabilitation needs to shift from a patient-focused approach to an incorporated patient and caregiver-focused approach. The caregivers also suffer from certain mental, physical, social, and financial problems when

they are providing care to their patients. The health of the caregivers is equally important as the health of the stroke survivors. According to the research, caregivers of stroke patients suffer from intense emotional and psychological stress during the process of caregiving.[5,6] A study also reported that if the caregiver is a spouse, there are great emotional challenges for both patient and caregiver.[7] Zarit carer burden interview (ZCBI) is one of the validated tool which estimate the role of caregivers for their beloved ones and relatives.[8] Moreover, the psychological health of the caregivers affects as badly as those of the survivors because of the strain and thoughts of the care of their beloved ones. According to estimates, 25% to 54% of people would endure hardship in the first year following a stroke.[9] The gap in the study is that the previous relationship between perceived stress and caregiver burden has not been studied extensively in Pakistan. This study will help to determine their relationship of burden of stroke care givers and level of stress among them. In addition the study will help the families and care providers to develop strategies to reduce level of stress, so that they could be able to better cope up in such cases where caregivers have a key role in improving quality of life of stroke survivors.

METHODS

This was a prospective cross-sectional study that was undertaken among the caregivers of stroke. While the patients from Chaudhry Muhammad Akram Teaching and Research Hospital, Neurology department of General Hospital and stroke care clinics, Rasheed Hospital and Ehsan rehab were approached from October 2021 to March 2022. The study was started after Institutional Ethical Research Committee (IERC) approval from Azra Naheed Center for Research and Development (ANCRD). All the individuals provided their signed informed consent before completing a self-administered questionnaire that was used to collect data.

By using Open EPI sample size calculator taking 54% proportion of the condition,[10] level of confidence 95%, 5% margin of error. The estimated sample size was 380. However, we enrolled 384 caregivers. The data were collected using non-probability convenient sampling technique. The inclusion was limited to those caregivers who were assisting in most of the daily routine work of at least 45 years aged stroke patients. Moreover, caregivers providing more than 6 hours of care to stroke survivors for at least one month duration after the discharge from hospital while the caregivers suffering from severe cognitive, sensory or intellectual disability and unavailability of caregiver were excluded.

The perceived stress and burden of caregivers were assessed through the perceived stress scale (PSS) and ZCBI respectively. A PSS 10 items is a reliable tool that is used for estimation of stress level.[10-12] While Zarit scale is based on score from 0-5 and respondents were asked to rate their burden experienced.[13,14] The minimum score on the ZCBI scale was 0 and maximum score was 88. The score of "0 to 20" was labeled as no to mild ,21-40 as mild to moderate, 41 -60 as moderate to severe and more than 60 as severe burden.[15,16] The Stress was categorized based on scores from 0-13 as low, 14-26 as moderate and 27-40 as high perceived stress.[17]Data entry and analysis were done using a Statistical Package for Social Sciences (SPSS) version 20.0. Mean ± SD were computed for quantitative variables like, age of the caregivers while frequency and percentages were computed for categorical variables like, gender of the caregivers and relation to patients. Inferential statistics were explored using Chi-square/Fisher exact test to compare caregivers' perceived burden and stress with baseline characteristics of the caregivers. Moreover, Pearson's correlation test was applied to see the relationship between caregivers' perceived burden and stress. The p-value of ≤0.05 was considered statistically significant.

RESULTS

Of 384 caregivers of stroke survivors, the mean age was 34.79 ± 5.80 years. There were 177 (46.1%) females and 207 (53.9%) males. Most of the caregivers were spouse of the patients i.e., 167 (43.5%) followed by children 121 (31.5%), son-in-law/daughter-in-law 52 (13.5%), grandchildren 32 (8.3%), and siblings 12 (3.2%).

None of the participant reported no to mild and severe burden. However, mild to moderate burden was observed in 364 (94.8%) and only 20 (5.2%) had moderate to severe burden. Among them mild to moderate burden was insignificantly higher in 40-55 years of age 48 (96.0%) as compared to 20-40 years of age 316 (94.6%) (p-value 0.758). Similarly, mild to moderate burden was found insignificantly higher in male caregivers 200 (96.6%) as compared to female caregivers 164 (92.7%) (p-value 0.106) (Table 1).

Low stress was not observed in any caregiver. Majority of the caregivers had moderate stress 353 (91.9%) and only 31 (8.1%) had severe stress. Moderate stress was observed significantly higher in spouses 165 (98.8%) as compared to siblings 11 (91.7%), son-in-law/daughter-in

law 46 (88.5%), grandchildren 28 (87.5%), and children 103 (85.1) (p-value 0.002) (Table 2).

A significantly weak positive correlation was found between stress score and burden score (r=0.26, p-value <0.001). Similarly, when stratified on the basis of demographic characteristics of caregivers, a significantly weak positive correlation of stress and burden score was found with 20-40 years of age (r=0.24, p-value <0.001), 40-55 years of age (r=0.46, p-value <0.001), male caregivers (r=0.19, p-value 0.005), female caregivers (r=0.33, p-value <0.001), children of the patient (r=0.21, p-value 0.018), son in law/daughter in law of the patient (r=0.29, p-value 0.034), and spouse of the patient (r=0.30, p-value <0.001). While, a significantly moderate positive correlation of stress and burden score was found with 40-55 years of age (r=0.46, p-value <0.001) and female caregivers (r=0.33, p-value <0.001). (Table 3)

Table 1: Comparison of caregivers' perceived burden with baseline characteristics of the caregivers (n=384)

Baseline Characteristics of Caregivers	Total	Caregivers' Perceived Burden		p-value
		Mild to Moderate Burden (n=364)	Moderate to Severe Burden (n=20)	
Age, years				
20-40	334	316 (94.6)	18 (5.4)	0.758˜
40-55	50	48 (96.0)	2 (4.0)	
Gender				
Male	207	200 (96.6)	7 (3.4)	0.106^
Female	177	164 (92.7)	13 (7.3)	
Relation to Patient				
Siblings	12	11 (91.7)	1 (8.3)	0.067˜
Children	121	119 (98.3)	2 (1.7)	
Son-in-Law/Daughter-in-Law	52	47 (90.4)	5 (9.6)	
Grandchildren	32	28 (87.5)	4 (12.5)	
Spouse	167	159 (95.2)	48 (4.8)	

-None of the participant reported no to mild and severe burden
^Chi-Square/˜Fisher Exact test applied

Table 2: Comparison of caregivers' perceived stress with baseline characteristics of the caregivers (n=384)

Baseline Characteristics of Caregivers	Total	Caregivers' Perceived Stress		p-value
		Moderate Stress (n=353)	Severe Stress (n=31)	
Age, years				
20-40	334	305 (91.3)	29 (8.7)	0.291˜
40-55	50	48 (96.0)	2 (4.0)	
Gender				
Male	207	193 (93.2)	14 (6.8)	0.350^
Female	177	160 (90.4)	17 (9.6)	
Relation to Patient				
Siblings	12	11 (91.7)	1 (8.3)	0.002˜*
Children	121	103 (85.1)	18 (14.9)	
Son-in-Law/Daughter-in-Law	52	46 (88.5)	6 (11.5)	
Grandchildren	32	28 (87.5)	4 (12.5)	
Spouse	167	165 (98.8)	2 (1.2)	

-None of the participant reported low stress
^Chi-Square/˜Fisher Exact test applied, *p-value ≤ 0.05

Table 3: Correlation between caregivers' perceived stress and burden stratified on the basis of demographic characteristics of caregivers (n=384)

Baseline Characteristics of Caregivers	Caregivers' Stress Score vs. Caregivers' Burden Score	
	r (95% C.I)	p-value
Total (n=384)	0.26 (0.16 to 0.36)	<0.001*
Age, years		
20-40	0.24 (0.11 to 0.35)	<0.001*
40-55	0.46 (0.28 to 0.61)*	<0.001*
Gender		
Male	0.19 (0.04 to 0.33)	0.005*
Female	0.33 (0.21 to 45)	<0.001*
Relation to Patient		
Siblings	0.17 (-0.68 to 0.69)	0.583
Children	0.21 (0.01 to 0.40)*	0.018*
Son-in-Law/Daughter-in-Law	0.29 (-0.04 to 0.53)	0.034*
Grandchildren	0.30 (-0.06 to 0.59)	0.095
Spouse	0.30 (0.17 to 0.41)	<0.001*

-C.I: Confidence Interval, vs: versus
Pearson's correlation test applied, *p-value ≤ 0.05

DISCUSSION

This study was aimed to determine the association between perceived stress and caregiver burden among caregivers of stroke survivors, this study was carried out in Lahore on a sample of 384 stroke caregivers. In current findings, majority of the caregivers had mild to moderate level of stress due to care of patients of stroke that is considerable to be addressed and can affect the care givers, that was more among male compared to females and in age middle adulthood. Male and female stroke survivors who care for them experience the same load, according to a study done in 2021.[18] Pont *et al.* stated that challenges of being a caregiver are greater for women than for men.[19] Lopez-Espuela *et a*l stated that caregiver burden in stroke caregivers is consistent over time.[20] The role family caregiver is an important factor that affect the quality of life and behavioral modification in stroke survivors *Dharma et al* concluded that caregivers were especially affected by stress in the spousal relationship due to caregiving.[21] The evidence states that depression and burden of diseased patients are linked to stress among the caregivers of stroke. [22]

In our findings significant positive correlation was found between caregivers level of stress and burden score While the studies states that care givers had perceived stress fatigue and depressive symptoms and relationship was reciprocal at 3rd and 6th month of care with that of physical health.[23] The long term rehabilitation and disability requires more care that can last up to 12 months in majority of the cases of stroke rehabilitation. This can be a source of stress that used to limit the self-care and restricted activities of caregivers that can lead to depressive symptoms.[24] The currents findings reported a positive correlation between stress and caregivers gender, with males beings effected more than the females. All those involved in the care, including offsprings spousses and in-lawas reported stress. This is contradictory to another study that reported that female were more burdened and psychologically effected by being caregivers of the stroke survivors[25]. Further caregivers's burden predictors were anxiety, stress scores and being the daughter-in-law of stroke survivor[26].but both were having stress and burden and all others involved in care including son/daughter and husband/wife or daughter in law. But in a study females were thought to be more effected being burdened and psychologically effected due to handling of patients with stoke.[25] Further caregiver burden predictor was anxiety among factors that used to induce anxiety among caregivers and it was stress score and being daughter in law of stroke survivors.[26]

The stroke rehabilitation is a long term and time taking processes till the recovery of the patient. The findings

of the study can help stroke rehabilitation teams to overcome the level of stress and burden faced by their care givers. The current study's sample size was small and caregiver burden in different phases was not considered in the study. While different associated factors and data were collected from one city, this can limit external validity. It is recommended to carry out additional research with a larger sample size and from multiple settings to ensure the study's generalizability.

CONCLUSION

The stress and burden was highly prevalent among caregivers of stroke survivors. Old age people and females were at risk of moderate stress and burden.

ETHICAL APPROVAL: The study was approved by the Research Ethical Committee, Azra Naheed Center for Research and Development (Reference Number: SU/ANCRD/IERC/45).

AUTHORS' CONTRIBUTIONS: MZ: Substantial contributions to the conception or design of the work. WM: Analysis and interpretation of data. IW: Collection and assembly of data, Literature search. TM: Drafted the work or revised it critically for important intellectual content. RN: Literature search and approved the version to be published. All authors gave final approval to submit the manuscript.

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REFERENCES

1. Mahmood W, Ahmed Burq HS, Ehsan S, Sagheer B, Mahmood T. Effect of core stabilization exercises in addition to conventional therapy in improving trunk mobility, function, ambulation and quality of life in stroke patients: a randomized controlled trial. BMC Sports Sci Med Rehabil 2022; 4:62. doi:10.1186/s13102-022-00452-y
2. Khan MI, Khan JI, Ahmed SI, Ali S. Retracted: The epidemiology of stroke In a developing country (Pakistan). Pak J Neurol Sci 2019; 13:30-44.
3. Hu P, Yang Q, Kong L, Hu L, Zeng L. Relationship between the anxiety/depression and care burden of the major caregiver of stroke patients. Medicine (Baltimore) 2018; 97:e12638. doi:10.1097/MD.0000000000012638
4. Hekmatpou D, Mohammad Baghban E, Mardanian Dehkordi L. The effect of patient care education on burden of care and the quality of life of caregivers of stroke patients. J Multidiscip Healthc 2019; 12:211-7. doi:10.2147/JMDH.S196903
5. Han Y, Liu Y, Zhang X, Tam W, Mao J, Lopez V. Chinese family caregivers of stroke survivors: Determinants of caregiving burden within the first six months. J Clin Nurs 2017; 26:4558-66.
6. Pan Y, Jones PS, Pothier P. The Relationship Between Mutuality and Health-Related Quality of Life in Adult Child Caregivers in China. J Fam Nurs 2017; 23:366-91. doi:10.1177/1074840717718540
7. Ramazanu S, Lim Chiang VC, Valimaki M. The Experiences and Evaluation of a Complex Intervention for Couples Coping With Stroke. J Neurosci Nurs 2021; 53:18-23. doi:10.1097/JNN.0000000000000564
8. Liu Z, Heffernan C, Tan J. Caregiver burden: A concept analysis. Int J Nurs Sci 2020; 7:438-45. doi:10.1016/j.ijnss.2020.07.012
9. Elmstahl S, Dahlrup B, Ekström H, Nordell E. The association between medical diagnosis and caregiver burden: a cross-sectional study of recipients of informal support and caregivers from the general population study 'Good Aging in Skane', Sweden. Aging Clin Exp Res 2018; 30:1023-32. doi:10.1007/s40520-017-0870-0
10. Isaac V, Stewart R, Krishnamoorthy ES. Caregiver burden and quality of life of older persons with stroke: A community hospital study in South India. J Appl Gerontol 2011; 30:643-54. doi:10.1177/0733464810369340
11. Gbiri CA, Olawale OA, Isaac SO. Stroke management: Informal caregivers' burdens and strians of caring for stroke survivors. Ann Phys Rehabil Med 2015; 58:98-103. doi:10.1016/j.rehab.2014.09.017
12. Mondo M, Sechi C, Cabras C. Psychometric evaluation of three versions of the Italian Perceived Stress Scale. Curr Psychol 2021; 40:1884-92 doi:org/10.1007/s12144-019-0132-8
13. Wang G, Cheng Q, Wang Y, Deng YL, Ren RJ, Xu W, et al. The metric properties of Zarit caregiver burden scale: validation study of a Chinese version. Alzheimer Dis Assoc Disord 2008; 22:321-6. doi:10.1097/WAD.0b013e3181902334
14. Yu Y, Liu ZW, Li TX, Zhou W, Xi SJ, Xiao SY, et al. A comparison of psychometric properties of two common measures of caregiving burden: the family burden interview schedule (FBIS-24) and the Zarit caregiver burden interview (ZBI-22). Health Qual Life Outcomes 2020; 18:94. doi:10.1186/s12955-020-01335-x
15. Baik SH, Fox RS, Mills SD, Roesch SC, Sadler GR, Klonoff EA, et al. Reliability and validity of the Perceived Stress

Scale-10 in Hispanic Americans with English or Spanish language preference. J Health Psychol 2019; 24:628-39. doi:10.1177/1359105316684938

16. Achilike S, Beauchamp JE, Cron SG, Okpala M, Payen S S, Baldridge L. Caregiver burden and associated factors among informal caregivers of stroke survivors. J Neurosci Nurs 2020; 52:277-83. doi: 10.1097/JNN.0000000000000552
17. Sharma R, Bansal P, Chhabra M, Bansal C, Arora M. Severe acute respiratory syndrome coronavirus-2-associated perceived stress and anxiety among indian medical students: A cross-sectional study. Asian J Soc Health Behav 2021; 4:98. doi: 10.4103/shb.shb_9_21
18. Badaru UM, Ogwumike OO, Adeniyi AF, Nelson EE. Determinants of caregiving burden and quality of life of informal caregivers of African stroke survivors: literature review. Int J Disabil Hum Dev 2017; 16: 249-58. doi:10.1515/ijdhd-2016-0041
19. Pont W, Groeneveld I, Arwert H, Meesters J, Mishre RR, Vliet Vlieland T, et al. SCORE-study group. Caregiver burden after stroke: changes over time? Disabil Rehabil 2020; 42:360-7. doi:10.1080/09638288.2018.1499047
20. Lopez-Espuela F, Gonzalez-Gil T, Amarilla - Donoso J, Cordovilla-Guardia S, Portilla-Cuenca JC, Casado-Naranjo I. Critical points in the experience of spouse caregivers of patients who have suffered a stroke. A phenomenological interpretive study. PLoS One 2018; 13:e0195190. doi:10.1371/journal.pone.0195190
21. Dharma KK, Damhudi D, Yardes N, Haeriyanto S. Increase in the functional capacity and quality of life among stroke patients by family caregiver empowerment program based on adaptation model. Int J Nurs Sci 2018; 5:357-64. doi:10.1016/j.ijnss.2018.09.002
22. Davis LL, Gilliss CL, Deshefy-Longhi T, Chestnutt DH, Molloy M. The nature and scope of stressful spousal caregiving relationships. J Fam Nurs 2011; 17:224-40. doi:10.1177/1074840711405666
23. Teel CS, Duncan P, Lai SM. Caregiving experiences after stroke. Nurs Res 2001; 50:53-60. doi:10.1097/00006199-200101000-00008
24. She R, Yan Z, Hao Y, Zhang Z, Du Y, Liang Y, et al. Comorbidity in patients with first-ever ischemic stroke: Disease patterns and their associations with cognitive and physical function. Front Aging Neurosci 2022; 14:887032. doi:10.3389/fnagi.2022.887032
25. Menon B, Salini P, Habeeba K, Conjeevaram J, Munisusmitha K. Female Caregivers and Stroke Severity Determines Caregiver Stress in Stroke Patients. Ann Indian Acad Neurol 2017; 20:418-24. doi:10.4103/aian.AIAN_203_17
26. Choi-Kwon S, Kim HS, Kwon SU, Kim JS. Factors affecting the burden on caregivers of stroke survivors in South Korea. Arch Phys Med Rehabil 2005; 86:1043-8. doi:10.1016/j.apmr.2004.09.013