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ASSOCIATION OF CAREGIVERS BURDEN WITH FUNCTIONAL DISABILITY IN CHRONIC STROKE SURVIVOR IN PESHAWAR: CROSS SECTIONAL STUDY

Original Research

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ABSTRACT

Background: Stroke remains a major global health burden, ranked as the second leading cause of death and the third most common cause of death and disability combined, as per Global Burden of Disease 2019 estimates. Stroke survivors often rely heavily on caregivers for daily activities, and this dependency may impact caregivers' physical, emotional, and financial well-being. Understanding the relationship between the functional limitations of stroke survivors and the burden experienced by caregivers is essential to improving care strategies and support systems.

Objective: To determine the association between caregiver burden and functional disability in chronic stroke survivors in tertiary care hospitals of Peshawar.

Methods: An analytical cross-sectional study was conducted involving 210 stroke survivors and their primary caregivers. Functional disability was assessed using the Functional Independence Measure (FIM), while caregiver burden was evaluated using the Zarit Burden Interview (ZBI). Participants were recruited from Khyber Teaching Hospital, Hayatabad Medical Complex, and Lady Reading Hospital over a 3-month period. Non-probability convenience sampling was used. Ethical approval was obtained from the KMU Ethical Review Committee, and informed consent was secured from all participants.

Results: Among the 210 stroke survivors, 82 (39.0%) had total dependence, 59 (28.1%) had moderate dependence, 47 (22.4%) had partial dependence, and 22 (10.5%) had complete independence. Regarding caregiver burden, 48 (22.9%) caregivers experienced no to mild burden, 43 (20.5%) had mild to moderate burden, 60 (28.6%) reported moderate to severe burden, and 59 (28.1%) faced severe burden. Statistical analysis using the chi-square test revealed no significant association between caregiver burden and functional disability (p-value = 0.1898).

Conclusion: The findings indicate no statistically significant association between caregiver burden and functional disability in chronic stroke survivors, suggesting the need to explore additional factors influencing caregiver stress in future research.

Keywords: Caregivers, Chronic Disease, Cross-Sectional Studies, Functional Disability, Quality of Life, Stroke, Surveys and Questionnaires.

INTRODUCTION

Stroke is a leading cause of long-term disability and death worldwide, posing a significant public health challenge due to its clinical complexity and the substantial socioeconomic burden it imposes. Clinically, stroke is characterized as an acute, focal neurological deficit caused by a vascular injury to the central nervous system, either through hemorrhage or infarction (1). The World Health Organization defines it as the sudden onset of neurological symptoms due to a disturbance in cerebral function that lasts beyond 24 hours or leads to death, with no other apparent cause. Historically, the term "stroke" was first introduced in medical literature by William Cole in 1689, replacing the older term "apoplexy," which was used to describe non-traumatic brain injuries (2). Globally, stroke remains the second most frequent cause of mortality and the third leading contributor to combined death and disability, as reported in the Global Burden of Disease 2019 study. It is estimated that strokes cost the global economy over $891 billion annually, equating to approximately 1.12% of the global GDP. Between 1990 and 2019, there was a 70% increase in incident strokes, a 43% rise in stroke-related deaths, and a 102% growth in stroke prevalence, with the highest burden seen in lower-income and lower-middle-income countries (3). Ischemic strokes, accounting for approximately 87% of all cases, have seen significant increases in incidence globally, influenced by better survival rates and improved treatment interventions (4).

In high-income nations such as the United States and the United Kingdom, stroke incidence remains considerable. In the US, the age-adjusted stroke mortality rate was 36.5 per 100,000 in 2014, with projections showing a likely increase due to aging populations (5). The UK reports over 113,000 strokes annually, with nearly one million people currently living with the consequences of stroke, largely due to improved post-stroke care and increased longevity (5,6). Similarly, China has witnessed a dramatic rise in stroke cases over the past four decades, now bearing the largest national burden of stroke-related deaths and disability-adjusted life years (7). In Pakistan, limited epidemiological data suggest a growing concern. A nationwide survey of 22,500 individuals found a stroke frequency of 1.2%, with a striking 30% of cases occurring in individuals under the age of 45, indicating a high incidence of young strokes (8). Stroke primarily results from vascular pathologies including cerebral infarction, intracerebral hemorrhage, and subarachnoid hemorrhage (4,9). The underlying mechanisms include embolism, large and small vessel disease, arterial dissection, and cardiac disorders such as atrial fibrillation and cardiomyopathies (10). Modifiable risk factors such as hypertension, diabetes mellitus, and dyslipidemia play pivotal roles in stroke development. Of these, hypertension remains the most influential, significantly increasing the risk of both ischemic and hemorrhagic events (11,12).

While stroke types are broadly classified into ischemic and hemorrhagic, the variability in etiological subtypes and risk profiles complicates both prevention and treatment strategies. Nonetheless, ischemic stroke remains the most prevalent form, with common subtypes including cardioembolic, atherosclerotic, and lacunar strokes (12). Beyond its acute impact, stroke often results in chronic disability, including motor deficits, cognitive decline, and emotional disturbances. Neurological disorders, primarily stroke-related, account for more disability-adjusted life years than many other major disease categories, a burden projected to rise without targeted interventions (13). Long-term stroke effects can impair independence, with approximately 30% of survivors unable to walk unaided and half experiencing hemiparesis (14,15). These outcomes necessitate ongoing support and rehabilitation. Consequently, the role of caregivers becomes essential. Caregivers, often family members, provide daily assistance and emotional support, yet face significant physical, psychological, and financial challenges. The burden is particularly high when survivors exhibit severe disability, cognitive impairment, or depression, further amplifying stress for caregivers (16–18). This strain adversely impacts not only the caregiver's health and well-being but also the quality of care provided, potentially affecting stroke recovery outcomes (19). Given these concerns, the current study aims to determine the association of caregiver burden with functional disability in chronic stroke survivors in Peshawar, addressing a critical gap in understanding the socio-clinical dynamics of post-stroke care in low-resource settings.

METHODS

This study employed an analytical cross-sectional design and was conducted across three public sector tertiary care hospitals in Peshawar, Pakistan: Khyber Teaching Hospital, Hayatabad Medical Complex, and Lady Reading Hospital. The study focused on the medical and neurology wards of these institutions. Although the research was initially planned for six months following approval by the

Research Committee of Khyber Medical University (KMU), the data collection phase was completed within three months due to the timely achievement of the required sample size. A total of 210 participants were included in the study, calculated using the RAOSOFT sample size calculator with a 95% confidence interval and an assumed population proportion (p) of 50%. Non-probability convenience sampling was used to recruit participants, which, while practical and commonly used in clinical settings, may limit the generalizability of findings due to potential selection bias. Participants included confirmed stroke survivors diagnosed via magnetic resonance imaging (MRI) or computed tomography (CT), encompassing both ischemic and hemorrhagic stroke types (3,4). Eligible stroke survivors were those undergoing rehabilitation at tertiary care hospitals in Peshawar, specifically at Khyber Teaching Hospital and Hayatabad Medical Complex. Only chronic stroke patients who were more than six months post-onset were considered. Both male and female stroke survivors and their respective caregivers were enrolled.

Exclusion criteria for stroke survivors included the presence of any coexisting condition that could independently impair activities of daily living, such as traumatic brain injury or progressive neurological disorders like multiple sclerosis or Parkinson's disease. Additionally, individuals unable to comprehend or follow verbal and visual commands were excluded. Caregivers were excluded if they were unable to provide informed consent, and in cases where multiple caregivers were present for a single patient, only one primary caregiver was included to avoid data duplication. All participants provided informed consent prior to inclusion in the study, and ethical approval was secured from the KMU Ethical Review Committee. The study adhered to the ethical principles outlined in the Declaration of Helsinki, ensuring respect, autonomy, and confidentiality of all participants.

RESULTS

A total of 210 participants were enrolled in the study. Among them, 106 (50.5%) were male and 104 (49.5%) were female. The mean age was 50.76 years with a standard deviation of ±10.50, ranging from 30 to 73 years. The median age was 50.00 years, with an overall age range of 43 years. Regarding the assessment of functional disability among stroke survivors, 82 participants (39.0%) were found to have total dependence, while 59 (28.1%) exhibited moderate dependence. A further 47 participants (22.4%) reported partial dependence, and only 22 individuals (10.5%) achieved complete independence in daily functioning. In the evaluation of caregiver burden, 48 caregivers (22.9%) experienced no to mild burden, whereas 43 (20.5%) reported mild to moderate burden. The majority of respondents fell into the moderate to severe burden category, accounting for 60 participants (28.6%), followed closely by 59 (28.1%) who reported severe burden. The association between caregiver burden and functional disability was analyzed using the Pearson Chi-Square test, which yielded a value of 189.863 with a p-value greater than 0.05, indicating no statistically significant association between the two variables. The number of valid cases assessed was 210. Correlation analysis further supported this finding. Both Pearson's and Spearman's correlation coefficients were calculated at -0.800, indicating a strong negative association; however, these findings were not statistically significant. Risk assessment analysis revealed a risk estimate of 0.156, suggesting a modest probability (15.6%) of the burden occurring within the exposed group compared to the non-exposed group. The 95% confidence interval ranged between 0.106 and 0.229.

Table 1: Distribution of Gender Frequency

Gender	Frequency	Percentage
Male	106	50.5
Female	104	49.5
Total	210	100

Table 2: Age Demographic Statistics

No. Of participants	210 Caregivers and stroke survivors
Mean	50.76
Median	50.00
Std. Deviation	10.501
Range	43
Minimum	30

Table 3: Functional Disability of Stroke Survivors

Level of dependence/Functional Disability	Frequency	Percent
Total dependence	82	39.0
Moderate dependence	59	28.1 67.1
Partial dependence	47	22.4 89.5
Independence	22	10.5 100.0
Total	210	100.0

Table 4: Caregiver Burden

Caregiver burden	Frequency	Percent
No to mild burden	48	22.9%
Mild to moderate burden	43	20.5%
Moderate to severe burden	60	28.6%
Severe burden	59	28.1%
Total	210	100%

Table 5: P-Value for Dependent and Independent Variables

Statistics	Value
Pearson Chi-Square	189.863a
Likelihood Ratio	218.214
N Of Valid Cases	210

Table 6: Correlation Between Caregiver Burden and Functional Disability

		Value
Interval by Interval	Pearson's	R -.800
Ordinal by Ordinal	Spearman Correlation	-.800
N of Valid Cases	210	210

Table 7: Risk Estimate of Caregiver Burden Relative to Functional Disability in Stroke Survivors

Risk Estimate			
			95% Confidence Interval
	value	lower	Upper
For cohort 2 = 1.00	1.56	.106	.229
N of Valid Cases	210		

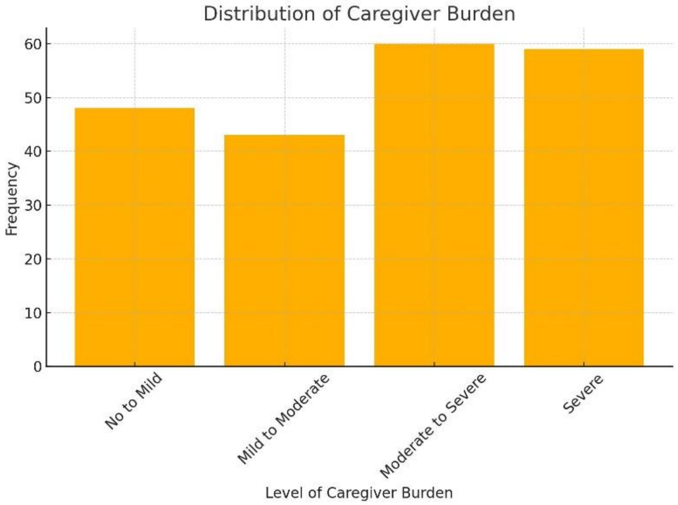

Figure 1 Distribution of Caregiver Burden

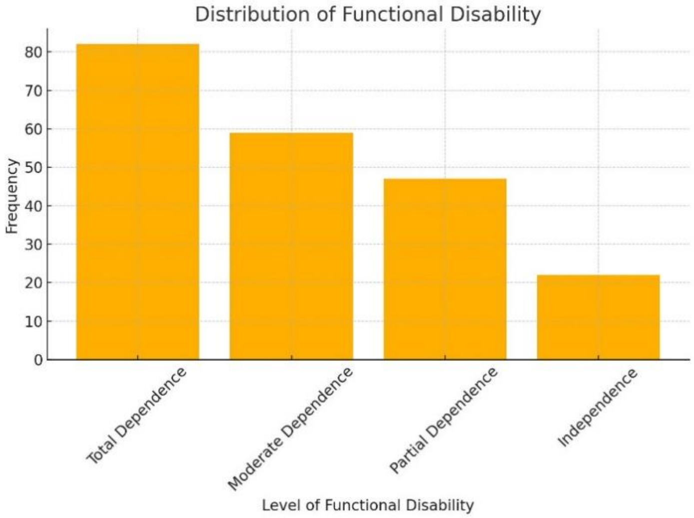

Figure 2 Distribution of Functional Disability

DISCUSSION

The present study examined the association between functional disability in chronic stroke survivors and caregiver burden, yielding findings that contrasted with much of the existing literature. Although the majority of stroke patients in the sample demonstrated moderate to total functional dependence, no statistically significant association was identified between the level of disability and the burden experienced by caregivers. These findings diverge from those of previous investigations that reported a clear positive correlation between increasing physical or functional disability and caregiver burden (20). A potential explanation for this discrepancy may lie in the variation in how disability was conceptualized. While prior studies predominantly focused on physical disability alone, this study employed a broader lens, assessing overall functional disability, which includes a combination of cognitive, physical, and psychosocial impairments. This divergence in definitions may account for the differing results. Moreover, past researches have highlighted that caregiver burden is frequently influenced more strongly by caregivers' personal factors—such as emotional health, social support, and unmet psychosocial needs—than by the severity of the patient's disability alone (21,22). These findings emphasize the multifactorial nature of caregiver burden, suggesting that assessments limited to patient functionality may not fully capture the complexity of the caregiving experience.

Further studies also demonstrated that functional deficits in stroke survivors are significantly associated with the psychological distress of caregivers, including elevated anxiety and depression, and reduced quality of life (23). The current findings did not align with this evidence, possibly due to methodological differences such as the exclusion of psychological assessments or a limited duration of caregiving experience among participants. Additionally, some studies focused on early post-stroke phases, whereas this investigation targeted chronic cases beyond six months post-onset, potentially influencing caregiver adaptation levels and the burden perceived. Interestingly, the lack of association in this study is partially supported by findings from longitudinal cohort studies, which observed no consistent relationship between caregiver burden and stroke-related disability when measured at multiple time points. These studies emphasized that caregiver strain may fluctuate based on social support systems, health literacy, and changes in caregivers' personal circumstances (24,25). It is therefore plausible that caregivers in this study, having adapted over time or receiving adequate institutional or familial support, reported relatively stable burden levels regardless of patient dependency.

One of the strengths of this study is its use of validated tools—the Zarit Burden Interview and a standardized functional disability scale—ensuring reliable data collection and analysis. Furthermore, the multicenter nature of the study, incorporating three tertiary care hospitals, adds to the generalizability of the results within the region. However, notable limitations must be acknowledged. The use of non-probability convenience sampling may have introduced selection bias, and the cross-sectional design limits causal inference. Psychological parameters of caregivers, such as stress, anxiety, or social support, were not evaluated, which are known to critically influence perceived burden. Moreover, the analysis did not stratify participants based on stroke type, duration since stroke, caregiver demographics, or caregiving duration—all of which may have moderated the relationship under investigation. This study underscores the need for a broader understanding of caregiver burden beyond patient disability. Future research should consider longitudinal follow-up designs with psychological profiling of caregivers to identify temporal variations and predictors of sustained burden. There is a need to investigate the impact of targeted caregiver support interventions and to examine how sociocultural factors may buffer or exacerbate caregiver strain in resource-constrained settings. Expanding this research to the provincial or national level with a larger sample size would strengthen the external validity and provide more granular insights into caregiving dynamics. Clinical trials evaluating therapeutic, psychosocial, and community-based interventions for caregivers are crucial. Such evidence could inform health policies aimed at integrating caregiver support into stroke rehabilitation programs, ultimately improving the quality of life for both stroke survivors and their families.

CONCLUSION

This study concluded that while varying levels of functional disability were observed among chronic stroke survivors, and caregivers experienced a wide spectrum of burden, no statistically significant association was found between the degree of functional limitation and the burden reported by caregivers. These findings suggest that caregiver strain may be influenced by factors beyond the patient's physical dependency alone, highlighting the complexity of caregiving dynamics in stroke rehabilitation. The results emphasize the need for a more comprehensive approach to caregiver support that considers emotional, social, and contextual factors, rather than focusing solely on the functional status of the stroke survivor.

AUTHOR CONTRIBUTION

Author	**Contribution**
Muhammad Rehman	Substantial Contribution to study design, analysis, acquisition of Data Manuscript Writing Has given Final Approval of the version to be published
Hafiz Yaseen Khan*	Substantial Contribution to study design, acquisition and interpretation of Data Critical Review and Manuscript Writing Has given Final Approval of the version to be published
Nafeesa Ishfaq	Substantial Contribution to acquisition and interpretation of Data Has given Final Approval of the version to be published
Dania Junaid	Contributed to Data Collection and Analysis Has given Final Approval of the version to be published
Ayesha	Contributed to Data Collection and Analysis Has given Final Approval of the version to be published
Shumaila Khan	Substantial Contribution to study design and Data Analysis Has given Final Approval of the version to be published

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