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THE BURDEN OF CAREGIVING AND ITS IMPACT ON THE QUALITY OF LIFE OF INFORMAL CAREGIVERS OF STROKE SURVIVORS

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ABSTRACT

BACKGROUND

Stroke is a leading cause of long-term disability, with survivors often relying on informal caregivers for both physical and emotional support. However, caregiving can impose significant strain on caregivers, potentially affecting their quality of life. It is crucial to examine the burden on informal caregivers and its impact on their well-being.

OBJECTIVE

The aim of this study was to evaluate the burden experienced by informal caregivers of stroke survivors and examine the relationship between caregiving burden and the caregivers' quality of life.

MATERIALS AND METHODS

A convenience sampling method was used to select informal caregivers who worked over 7 hours per day and cared for stroke survivors for 3-12 months. The Modified Caregiver Strain Index (MCSI) was used to measure caregiver burden, while the WHOQOL-BREF assessed the caregivers' quality of life.

RESULTS

The sample comprised 57.69% females and 42.31% males, with 75% of participants aged between 30 and 45 years. Key findings included 42.02% of caregivers consistently experiencing challenges such as sleep disturbances, physical strain, and emotional changes. Meanwhile, 51.92% encounter these issues occasionally, while 6.05% do not face such difficulties. A Pearson correlation test between MCSI and WHOQOL-BREF showed a very weak positive correlation ($r = 0.121$), which was not statistically significant ($p = 0.392$).

CONCLUSION

Caregivers experienced significant strain across physical, emotional, and financial domains. However, the connection between caregiver burden and quality of life was weak and not statistically significant, indicating no substantial relationship.

Keywords: Stroke survivor, Informal caregivers, Burden, and Quality of life

INTRODUCTION

Stroke continues to be one of the leading chronic conditions globally, posing a significant challenge for healthcare organizations that will need to address its implications for the foreseeable future **[1]**. Unlike other chronic disabilities, stroke occurs suddenly, often leaving both the individual and their family unprepared to manage its consequences.**[2]** Stroke rehabilitation has increasingly focused on patient-centred interventions, which have led to a reduction in disability levels and a greater number of stroke survivors receiving care at home from informal caregivers **[3]**.

Informal caregivers, such as spouses, children, in-laws, or close friends of the stroke survivor, play a crucial role in providing essential care and support **[4]**. However, the demands placed on these caregivers may lead to adverse effects that could undermine the recovery and well-being of stroke survivors.[3] Caregivers of stroke survivors often endure high levels of stress, reflecting the financial, emotional, physical, and mental burdens they face, as well as the effects of family relationships and cultural norms on their experience **[5-7]**. This strain may not only jeopardize the sustainability of home care but also hinder the recovery process of stroke patients. Consequently, it is crucial for healthcare professionals to adopt a comprehensive approach that optimizes the well-being of both stroke survivors and their caregivers **[8]**.

A caregiver is an individual who resides with the patient and assumes primary responsibility for their care. Caregivers play a crucial role in assisting stroke survivors in managing a range of challenges, including physical impairments, daily living tasks, as well as communication and emotional or psychological adjustments **[9]**. In addition to providing direct support, caregivers must often modify their personal schedules to accommodate the needs of the patient. When the caregiver is also the primary wage earner within the household, they may face the necessity of reducing or foregoing employment to ensure adequate care, which in turn imposes a substantial economic burden on the family. This financial strain can contribute to heightened levels of anxiety and uncertainty for both the caregiver and the stroke survivor **[10]**.

Research indicates that caregiving for stroke survivors, particularly those with severe disabilities, places substantial strain on informal caregivers, potentially affects their quality of life (QoL) **[3, 11]**. Therefore, the primary aim of this study was to assess the burden faced by informal caregivers of stroke survivors, while the secondary aim was to explore the relationship between this caregiving burden and the caregivers' quality of life.

MATERIALS AND METHODS

The research was conducted as a cross-sectional study, with participants selected from Surat, Gujarat, through a convenient sampling technique. A total of 52 participants were included in the study. The eligibility criteria for inclusion were as follows: participants must be informal caregivers of stroke survivors, provide caregiving for more than 7 hours per day, and have been caring for a stroke survivor for a minimum of three months. Additionally, informal caregivers must be between the ages of 18 and 45 years. The stroke survivor's FAC score must fall between 1 and 3. Exclusion criteria included informal caregivers with any addiction to alcohol or drugs and those with neurological and other incapacitating conditions.

OUTCOME MEASURES

Modified Caregiver Strain Index (MCSI)

To evaluate the burden experienced by informal caregivers of stroke patients, the Modified Caregiver Strain Index was utilized. This index consists of 13 items that assess four key dimensions of caregiver strain: physical, emotional, social, and financial. Each item is followed by a Likert-scale response, where participants can choose from three options: 2 for "Yes, On a Regular Basis," 1 for "Yes, Sometimes," and 0 for "No." The scores for each item are then summed to generate an overall caregiver stress score. A higher total score indicates greater perceived stress among caregivers. The Modified Caregiver Strain Index demonstrates strong internal reliability, with a coefficient of 0.90 in samples of long-term caregivers. Additionally, the test-retest reliability coefficient is 0.88, providing substantial evidence for the stability and dependability of the MCSI as a measure of caregiver strain **[12]**.

WHOQOL-BREF

WHOQOL-BREF consists of 26 items that evaluate four key quality of life domains: physical health (7 items), psychological health (6 items), social relationships (3 items), and environment (8 items). Additionally, two items gauge overall quality of life and general health. Participants respond to each item on a 5-point Likert scale, where scores range from 1 (indicating the lowest level of agreement) to 5 (indicating the highest level). The raw scores for each domain are then transformed into a scale from 0 to 100, with higher scores representing better quality of life in each respective domain. The test-retest reliability coefficients for the domains are as follows: 0.66 for physical health, 0.72 for psychological health, 0.76 for social relationships, and 0.87 for the environment. Cronbach's alpha values for the four domains range from 0.66 to 0.84, demonstrating adequate internal consistency **[13]**.

PROCEDURE

Informal caregivers will be recruited from various study settings, in accordance with the eligibility criteria. Participants will be informed about the study's purpose, and those who agree to participate will be asked to provide written consent. Demographic information will be collected, and data from informal caregivers will be gathered through the administration of the WHOQOL-BREF and the Modified Caregiver Strain Index.

STATISTICS

Descriptive statistics were applied to summarize the baseline characteristics of the participants and to define the variables that were either directly measured or calculated. These analyses were conducted using the SPSS Statistics 23 software for Windows. The Shapiro–Wilk test was run to check the normality distribution. Furthermore, a Pearson correlation test was employed to explore the relationship between caregiver burden and quality of life among informal caregivers of stroke survivors. The statistical significance level was set at $p < 0.05$.

RESULT

The majority of participants were female (57.69%), with males comprising 42.31% of the sample. In terms of age, 75.00% of participants were between 30 and 45 years old, while 25.00% were aged 18 to 30 years. Concerning the Functional Ambulation Categories (FAC) of the stroke survivors, 17.3% of participants were assisting individuals with FAC 1, 53.8% were supporting those with FAC 2, and 28.8% were caring for those with FAC 3.

Table 1: Demographic details of the participants

Demographic variables	No.	Percentage (%)
Gender		
Female	30	57.69
Male	22	42.31
Education detail		
No formal education	0	0.00
Primary	15	28.85
Secondary	19	36.54
Graduate or above	18	34.62
Marital status		
Married	42	80.77
Unmarried	10	19.23
Age		
18-30	13	25.00
30-45	39	75.00
Duration		
3-6 months	31	59.62
6-12 months	21	40.38
FAC		
1	9	17.3
2	28	53.8
3	15	28.8

The data indicates that, on average, 42.02% of caregivers report experiencing certain issues on a regular basis, such as sleep disturbances, physical strain, and emotional adjustments. Meanwhile, 51.92% of caregivers report experiencing these issues sometimes, while 6.05% of caregivers report that these issues do not apply to them. Regular sleep disturbance was reported by 26.9%, while 21.2% found caregiving inconvenient. A majority (63.5%) experienced physical strain, and 36.5% felt caregiving was confining. Family adjustments were reported by 55.8%, and 38.5% had changes in personal plans. Time demands affected 44.2% regularly, and 44.2% made emotional adjustments. 51.9% found the changes in the care recipient upsetting, and 46.2% faced financial strain.

Table 2: Frequency of Caregiver Burden

Sr. No.		Yes, On a Regular Basis = 2 (%)	Yes, Sometimes = 1 (%)	No = 0(%)
1	My sleep is disturbed	26.9	55.8	17.3
2	Caregiving is inconvenient	21.2	75	3.8
3	Caregiving is a physical strain	63.5	30.8	5.8
4	Caregiving is confining	36.5	63.5	0
5	There have been family adjustments	55.8	44.2	0
6	There have been changes in personal plans	38.5	59.6	1.9
7	There have been other demands on my time	44.2	51.9	3.8
8	There have been emotional adjustments	44.2	53.8	1.9
9	Some behavior is upsetting	40.4	55.8	3.8
10	It is upsetting to find the person I care for has changed so much from his/her former self	51.9	48.1	0
11	There have been work adjustments	34.6	61.5	3.8
12	Caregiving is a financial strain	46.2	30.8	23.1
13	I feel completely overwhelmed	42.3	44.2	13.5
	AVERAGE	42.02	51.92	6.05

A Pearson correlation analysis was conducted to examine the relationship between MSCI and WHOQOL-BREF. The results indicated a very weak positive correlation (r = 0.121). However, this correlation was not statistically significant, as the p-value was 0.392. This suggests that there is no significant linear relationship between MSCI and WHOQOL-BREF.

Table 3: Association between MSCI and WHOQOL-BREF

Correlations

		MSCI	WHOQOL-BREF
MSCI	Pearson Correlation	1	.121
	Sig. (2-tailed)		.392
	N	52	52
WHOQOL-BREF	Pearson Correlation	.121	1
	Sig. (2-tailed)	.392	
	N	52	52

The statistical significance level was set at $p < 0.05$.

DISCUSSION

This study provides a detailed insight into the challenges faced by caregivers, particularly those caring for individuals who have suffered strokes. The findings highlight significant physical, emotional, and financial burdens experienced by caregivers. Despite these challenges, the study found a weak and statistically insignificant correlation between caregiving-related burden and overall quality of life, suggesting that the impact of caregiving burden on caregivers' quality of life may be more complex than previously assumed. The caregiver sample in this study was predominantly female (57.69%), with the majority (75%) falling within the 30-45 age range. These findings align with trends observed in previous studies, which suggest that caregiving roles are more commonly assumed by women, especially in the middle-age range **[14]**.

Caregiving Challenges

The majority of caregivers reported significant challenges, particularly related to physical strain (63.5%), sleep disturbances (26.9%), and emotional strain (44.2%). These results mirror those of previous studies, which have consistently found that caregiving is associated with increased physical fatigue, disrupted sleep, and heightened emotional strain.[15] The high levels of physical strain reported in this study are consistent with research indicating that caregivers often experience higher levels of physical burden due to the demands of providing hands-on care **[14]**.

Additionally, a significant number of caregivers reported family adjustments (55.8%) and financial strain (46.2%). Changes in family dynamics and financial pressures are common stressors for caregivers, especially when caregiving duties interfere with work and personal plans **[16]**. These findings underscore the broader societal implications of caregiving, where caregiving responsibilities often extend beyond the physical and emotional demands to include financial burdens and shifts in family roles.

Correlation between MSCI and WHOQOL-BREF

The weak positive correlation between the MSCI and WHOQOL-BREF results ($r = 0.121$, $p = 0.392$) suggests that there is no significant linear relationship between caregiving burden and overall quality of life. This finding is oppose with previous research that has stated caregivers' psychological health and care burden influenced their QoL **[17]**. A study by Pinquart and Sörensen (2003) found that while caregiving is associated with higher stress levels, the overall impact on quality of life varies significantly depending on personal factors such as coping strategies, social support, and personality traits. Similarly, this study suggests that the effects of caregiving stress on quality of life may be mediated by factors that were not captured in this analysis.

The Role of Coping Strategies and Social Support

Coping strategies and social support are critical in shaping caregivers' experiences. Research has shown that caregivers with strong social support networks tend to report higher levels of well-being, despite the stresses associated with caregiving **[18]**. This finding suggests that the availability of family support or community resources might buffer the negative effects of caregiving burden. Conversely, caregivers who experience high levels of burden but lack social support are at greater risk of experiencing adverse health outcomes **[15]**.

In this study, caregivers who reported regular emotional adjustments (44.2%) and changes in personal plans (38.5%) may indicate that emotional and social resources are crucial to managing caregiving burden. Additionally, a majority of participants experienced disruptions in their daily routines, highlighting the need for targeted interventions that address these practical and emotional demands.

Financial Strain and its Impact on Caregiving

Financial strain was reported by 46.2% of caregivers in this study, which is a significant concern, as it can exacerbate other forms of burden. Financial strain is a well-documented stressor that can lead to both physical and emotional health problems **[19]**. The impact of financial burden on caregivers' quality of life has been highlighted in several studies, indicating that caregivers who face economic hardships often experience worse mental health outcomes, including depression and anxiety **[20]**. Providing financial support through government assistance programs or workplace accommodations could reduce the financial burden on caregivers, potentially alleviating some of the stress associated with caregiving. This could, in turn, improve overall well-being and quality of life.

This study also has some limitations, such as: The study was conducted in specific setting sites that may reflect regional cultural values and caregiving practices, limiting the applicability of the findings to other areas with different healthcare systems or cultural norms. It also does not account for variations in caregiver training, prior experience, or personality traits, which could influence caregiver strain and quality of life.

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CONCLUSION

Informal caregivers of stroke survivors experience physical exhaustion, emotional strain, sleep disruptions, and financial difficulties. Despite these stressors, the relationship between caregiving-related stress and overall quality of life was found to be weak and statistically insignificant. Future studies are needed to examine caregiver burden across different populations and regions to better understand its variations and the factors influencing these differences. Encouraging family collaboration and community support can help share caregiving duties, reducing stress and improving quality of life.

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