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Caregiver Burden, Awareness And Coping Strategies In Stroke Rehabilitation: A Narrative Review

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Abstract:

Background:

Stroke is a leading cause of death and long-term disability worldwide, with a rising burden in low- and middle-income countries like India. As medical advancements improve survival rates, the focus has increasingly shifted toward long-term rehabilitation and support. In this continuum of care, family caregivers play a pivotal yet often under-recognized role. The emotional, physical, and financial burden placed on caregivers can significantly influence not only their own well-being but also the functional recovery and quality of life of stroke survivors. Despite this, caregiver burden, awareness, and coping mechanisms remain under-researched, particularly in the Indian context.

Objective:

This review aimed to explore existing literature on caregiver burden, awareness of stroke-related care, and coping strategies among caregivers of stroke survivors. It also examined how these caregiver factors are associated with the functional independence and rehabilitation outcomes of stroke patients.

Methodology:

A comprehensive narrative review was conducted by systematically searching electronic databases including PubMed, Google Scholar, Science Direct, and Scopus. A total of 112 records were identified, out of which 83 unique studies remained after duplicate removal. After title, abstract, and full-text screening, 10 studies meeting the inclusion criteria were selected and reviewed. These studies included cross-sectional surveys, prospective observational studies, and literature reviews assessing caregiver burden, awareness, coping strategies, and stroke patient outcomes. The selection process followed PRISMA guidelines to ensure transparency and rigor.

Conclusion:

This review highlights that caregivers of stroke survivors often experience moderate to severe burden, driven by emotional strain, time demands, and inadequate support systems. Awareness levels among caregivers were mostly average, indicating a need for structured educational programs to improve stroke-related knowledge and caregiving competencies. Coping strategies were found to be primarily emotion-focused, which may offer temporary relief but are insufficient in addressing long-term caregiver stress. Promoting functional independence in stroke survivors through rehabilitation can significantly reduce caregiver burden. Future efforts should prioritize caregiver-centered interventions, including education, psychosocial support, and policy-level recognition of caregivers as integral stakeholders in stroke care.

Keywords:

Stroke rehabilitation, caregiver burden, awareness, coping strategies, functional independence

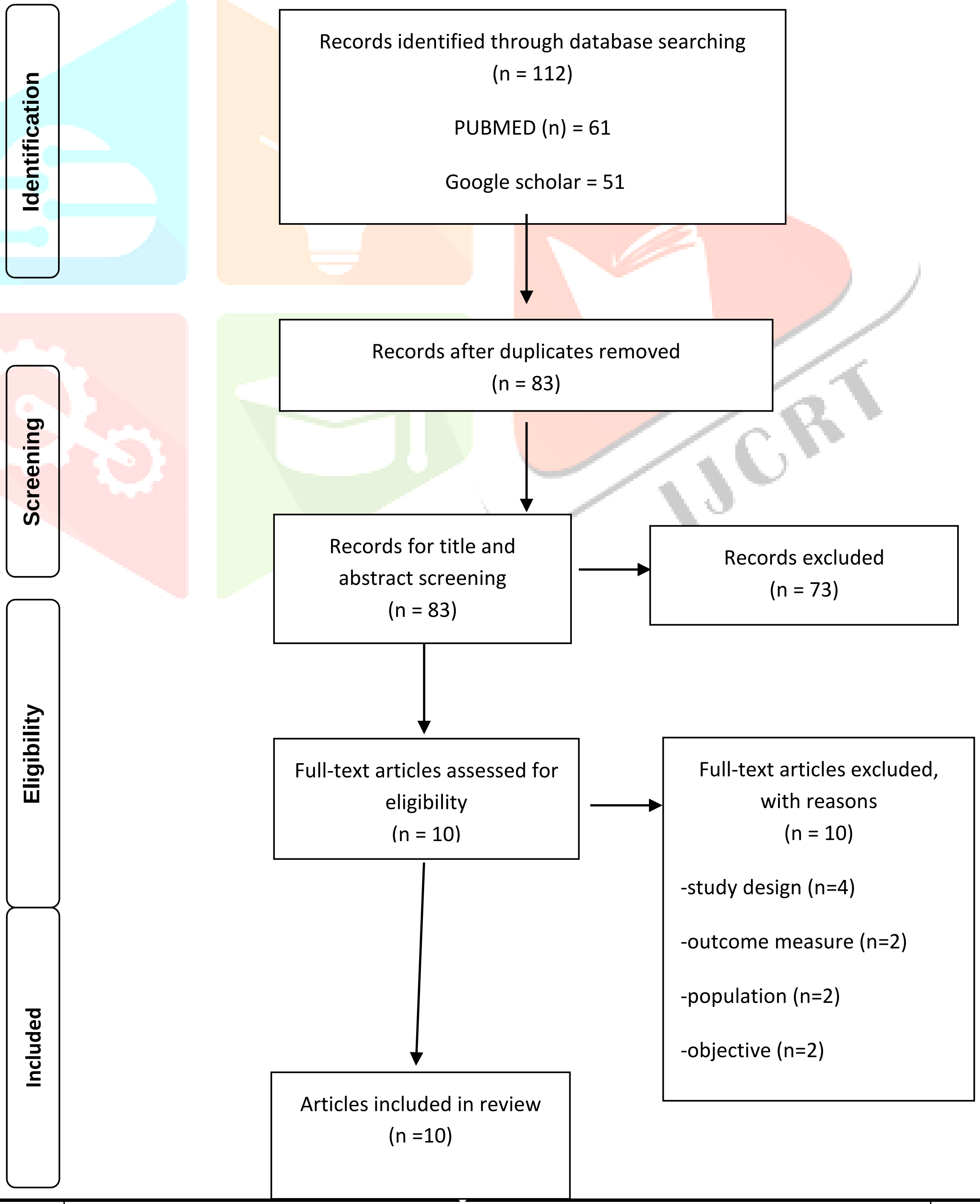
INTRODUCTION

Stroke is one of the leading causes of death and disability worldwide. According to WHO stroke is the second most common cause of mortality. It is estimated that by the year 2050, 80% of stroke attack will occur in low and middle-income countries like India.[1] Stroke burden is also increasing in India day by day and it is now leading as a main cause of death and fifth leading cause of disability. According to research findings, the incidence of stroke in India ranges from 105-152/100,000 and the crude prevalence of stroke has large ranges from 26 to 752/100,000 people per year and per month case fatality ranges are 18-42%.[2] WHO defines stroke as "a clinical syndrome characterized by the rapid onset of focal (or global) neurological dysfunction lasting more than 24 hours or leading to death, which is of presumed vascular origin." [20] Stroke is the most common cause of acquired disability worldwide. In stroke survivors, quality of life (QoL) is variably affected by multiple factors. These include patient characteristics (age, sex) stroke outcome (physical disability, repeat events) stroke-related complications (speech impediment, cognitive impairment, depression), psychological factors (problem-solving versus emotion focused coping style) and changed aspects of daily living (place of residence, dependency on caregivers, mobility, returning to leisure activities). Each of these factors are known to affect Quality of life (QoL), however, no study has investigated the additional or combined effect of these factors.[5] Without proper care and treatment, stroke may result in various secondary complications such as pressure sores, joint contracture, shoulder pain and aspiration pneumonia. To prevent secondary complications and to support the activities of daily living (ADL) in patients, the role of the caregiver is important, particularly if the patients are in an acute stage. The high dependence and specificity of the stroke itself results in a great burden on the caregivers of patients with stroke, which means that the care of patients with stroke often falls into the hands of formal caregivers rather than family members. The care provided by caregivers may affect the outcome and secondary complications in patients, it is important to examine their knowledge base and competencies.[3] The global burden of stroke represents a significant public health challenge, characterized by high morbidity and mortality rates. As one of the leading causes of disability worldwide, stroke not only impacts the patients but also exerts substantial emotional, physical, and financial strains on their caregivers.[1,20] Caregiving may include caring for a loved one in the caregiver's home, the care recipient's home or in an institutional setting. It may include attending to an individual's emotional well-being and/or physical health. It may involve long-term caregiving for an individual with a chronic illness or physical disability, or may be intermittent and sporadic as in the case of caring for someone with an acute illness or an acute episode of a chronic illness.[4] The role of family members who undertake patient care is unarguably important for stroke rehabilitation. Without proper care and treatment, a stroke may result in many secondary complications, such as pressure sores, joint contracture, shoulder pains, and aspiration pneumonia. To prevent secondary complications and to support the activities of daily living (ADL) in patients, the role of the caregiver is important, particularly if the patients are in an acute stage.[4] Caregivers of patients with neurological disease have been found to have higher risk of social isolation, emotional burden and a reduction in quality of life. Burden of care of stroke patients impacts the physical as well as psychological well-being of the caregiver adversely. Caregiving is a difficult task, particularly for untrained primary caregivers who are taking care of an individual with serious, chronic health problems. Unsurprisingly, caregiver stress is common and is caused by the ongoing emotional and physical strain of caregiving. [6] Caregiver burden can be defined as the strain that is experienced by a person who cares for a chronically ill, disabled, or older family member. The burden of care is used to describe the side effects of care that are extremely problematic for the patients and their families. It is a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience. Caregivers are hidden patients who, as a result of their involvement with caregiving responsibilities, may not be able or eager to seek care for their own health needs. Caregiver burden and strain have been associated with increased health-risk behaviours (such as smoking) and higher rates of drug use.[6] Caregiving burden adversely affects the mental health of caregivers and make them vulnerable to even more risk when caregivers perceive that the patient's care needs exceed their caregiving capabilities. Most studies of family caregivers of stroke survivors have reported that caregiving had negative impacts on the caregiver's health and well-being. Due to the abrupt onset of disability and the chronic nature of stroke recovery, caring for a stroke survivor has been found to have a negative impact on the physical, mental, and psychological health of caregivers. Primary caregivers of stroke patients tend to report more somatic and depressive symptoms, sleep disorders, stress and social isolation than general population.[2,7]

METHODOLOGY

A comprehensive narrative review was conducted to explore relevant literature on the chosen topic. Electronic databases including PubMed and Google Scholar were searched systematically, yielding a total of 112 records (PubMed = 61, Google Scholar = 51). After removing duplicates, 83 unique records remained. These records underwent title and abstract screening, resulting in the exclusion of 73 studies that did not meet the initial inclusion criteria. The remaining 10 full-text articles were assessed for eligibility. Among these, 10 articles were excluded due to various reasons including inappropriate study design (n=4), irrelevant outcome measures (n=2), non-target population (n=2), and misalignment with the study objective (n=2).

Finally, 10 articles were included in the review based on their relevance and adherence to the inclusion criteria. The selection process followed the PRISMA guidelines to ensure transparency and reproducibility.



Authors and Journal Year	**Objective**	**Design**	**Characteristics of Participants & Sample Size**	**Material and Methods**	**Outcome Measures**	**Result**
Pandian JD et al. (2013)	To review and summarize the current state of stroke in India—specifically its epidemiology (prevalence, incidence, case-fatality) and the availability/ quality of stroke care services across the country	Narrative review	The samples included adults from diverse regions, mainly aged 45 and above, with varied healthcare access.	collection and analysis of epidemiological data from multiple studies that reported on stroke incidence, prevalence, and mortality. Additionally, the authors examined literature related to stroke care infrastructure, such as the presence and distribution of stroke units, the availability and use of thrombolytic therapy (both intravenous and intra-arterial), access to rehabilitation services, and the affordability and accessibility of medications required for secondary prevention.	prevalence and incidence of stroke across urban and rural populations, case fatality rates, the number and distribution of stroke units, the proportion of patients receiving thrombolysis, the availability of post-stroke rehabilitation services, and the level of access to affordable medications for long-term management and prevention of recurrent strokes.	In rural areas, the prevalence of stroke ranged from 84 to 262 per 100,000 individuals, while in urban populations, it was notably higher, ranging from 334 to 424 per 100,000. The incidence of stroke was reported to be between 119 to 145 per 100,000 population per year. Case fatality rates also varied significantly by region, with some areas such as Kolkata reporting rates as high as 42 percent.

Kamalakannan S et al. (2017)	The systematic review aimed to determine the incidence and prevalence of stroke in India by analyzing published population-based and cohort studies from 1960 to 2015	Systematic search across databases	The review incorporated data from ten community-based studies with populations ranging from tens of thousands to over a million. The sample included adults of all ages, representing diverse rural and urban regions of India .	The authors conducted a systematic search across databases including PubMed, Embase, Ovid, Medline, and IndMED. They screened 3,079 titles and ultimately included 10 population-based cross-sectional and cohort studies .	The cumulative stroke incidence reported ranged from 105 to 152 per 100,000 persons per year. The crude prevalence varied widely, from 44.3 to 559 per 100,000, across different regions of India .	The prevalence ranged from 44.3 to 559 per 100,000, with higher rates in urban areas. The study highlighted a lack of recent, high-quality data, especially from rural regions.
Jones SP et al.(2022)	The study aimed to identify high-quality prospective research on stroke epidemiology in India, focusing on incidence, prevalence, age-adjusted rates, and one-month case fatality	systematic review	These studies represented regions across Mumbai, Trivandrum, Ludhiana, Kolkata, Punjab, and 12 villages in West Bengal. The combined population denominator was 22,479,509, with 11,654 individuals (mean per study 1,294 ± 1,710) identified with incident stroke	The questionnaire contained 48 items across six domains: caregiver demographics, bed positioning, meal provision, position changes and transfers, range-of-motion exercises, and caregiver training .	Researchers measured the percentage of correct responses for each care domain, and recorded whether caregivers received regular training and their sources of information .	Caregivers scored 64.3 % correct on bed positioning, 74.3 % on meal provision, and 62.4 % on position changes and transfers.

Woo Lee K et al. (2015)	The study aimed to assess how much formal caregivers working in hospitals know about caring for stroke patients and whether they apply that knowledge appropriately	cross-sectional survey using self-reported questionnaires among caregivers in eight hospitals in South Korea .	A total of 217 caregivers participated. Of these, 41 % worked in university hospitals, 35 % in rehabilitation hospitals, and 24 % in convalescent hospitals .	An interview schedule was prepared , non participant observations and focus group discussions were adopted as and when required to supplement data.	Face to face communications and interviews are reliable and efficient.	The study revealed that purdah or ghungat plays a significant role in prohibiting women from working for a wage leaving them dependent on their husbands or other family members for financial support and reduce their ability to connect with others.
Shrestha et al. (2018)	The study aimed to assess caregivers' awareness about stroke-related disability and the importance of early rehabilitation.	cross-sectional survey	A total of 105 caregivers participated, with 56 females and 49 males, aged between under 20 to 70 years. Most caregivers were either spouse, children, or offspring, and spent over 12 hours daily caring for the stroke patient .	Researchers conducted a descriptive, cross-sectional survey using a structured questionnaire and convenience sampling of caregivers recruited from the hospital. Each correct answer was scored "1" and incorrect "0," with awareness levels categorized as high (>75%), average (50–75%), or low (<50%)	Overall, 70.5% (74/105) of caregivers demonstrated average awareness about disability and early rehabilitation.	Most caregivers had an average level of knowledge about stroke care and early rehabilitation.
Mishra A K et al. (2016)	The review aimed to assess the financial burden of caring for stroke survivors in	narrative literature review	The review included a small number of studies—many drawing from rural	This was a narrative literature review that systematically searched studies assessing	Key measures included out-of-pocket expenses for hospital stays,	The review reported that caregiving families—especially those from weaker socioeconomic backgrounds—

	India, focusing on socioeconomic impacts on families and caregivers.		community-based investigations—but did not specify a combined numerical sample size. Populations largely comprised low socioeconomic status families across rural and urban India.	direct and indirect costs associated with stroke caregiving in Indian contexts.	rehabilitation, medications, supplies, and loss of income among caregivers. The review also looked at financial strain, unmet economic needs, and socioeconomic differences in caregiving burden.	experienced significant financial stress. Costs related to hospitalization and rehabilitation formed the major share of burden; nearly all caregiver respondents noted unmet financial needs.
Tosun Z.K. & Temel M. (2017)	The study aimed to explore the burden experienced by family caregivers of stroke patients and to assess how perceived social support influences this burden during home care visits	Cross sectional study	The study involved 66 caregivers, predominantly female (86%), with an average age of 51.6 ± 11.6 years. The stroke patients cared for had a mean age of 69.4 ± 18.3 years, and about half had been providing care for 1–5 years .	This was a descriptive, cross-sectional study using home visits. Researchers collected data through structured tools including an identification form, the Barthel Index (BI), Zarit Burden Interview (ZBI), and the Multidimensional Scale of Perceived Social Support (MSPSS) .	Caregiver burden was measured with ZBI (range 0–88), and perceived social support was gauged using MSPSS. The Barthel Index assessed patients' functional dependency.	The average ZBI score was 47.4 ± 11.9, indicating a moderate to high caregiving burden. The mean MSPSS score was 50.7 ± 17.8, with the highest support coming from family (mean subscale = 19.4 ± 6.7). Burden was significantly higher among caregivers with lower income, no financial support, longer caregiving duration, poor caregiver health, and lower perceived social support (especially from friends) . Notably, perceived social support correlated inversely with caregiver burden, with strong negative relationships (e.g., total MSPSS vs.

						ZBI: $r = -0.512$, $p < 0.001$)
Tsai Yu-Hsia et al. (2018)	The study aimed to investigate predictors of quality of life (QoL) among caregivers of first-time stroke patients and to determine whether caregiver burden mediated these effects	Cross sectional survey	126 family caregivers aged over 20 participated. They were the primary caregivers in nursing first-time stroke survivors at home.	this was a cross-sectional survey conducted via home visits. Researchers enrolled caregivers of patients discharged within one year, using structured questionnaires to collect data.	Caregiver burden was measured using the Caregiver Strain Index (CSI). Quality of life was assessed with the Caregiver Quality of Life Index (CQLI). Patient and caregiver characteristics, income, education, and health were also recorded.	Higher caregiver burden, lower education (elementary or below), poorer self-rated health, and lower income were significant predictors of poorer quality of life. Poor health and low education affected QoL indirectly through caregiver burden. Spouses paying medical bills and low income had direct negative effects on QoL.
Dewilde et al. (2019)	The study aimed to evaluate how patient disability, caregiver dependency, and coping strategies together affect quality of life after ischemic stroke.	Cross sectional study	The study included around 100 ischemic stroke patients. The average patient age was approximately 68 years, and about 60% were male. Most caregivers were the patients' spouses or close family members.	It was a prospective, observational, cross-sectional study. Researchers recruited post-stroke patients with ischemic stroke and their primary caregivers. They collected data using structured interviews and standardized questionnaires. Disability was measured with a recognized clinical	The primary outcome was the patient's quality of life. Higher levels of disability and increased caregiver dependency were associated with poorer quality of life. Positive coping strategies partially offset these negative impacts.	The study found that greater disability and reliance on caregivers significantly reduced quality of life, whereas effective coping strategies helped mitigate these effects.

				scale, caregiver dependency was assessed using appropriate metrics, and coping strategies were evaluated with a coping scale. Quality of life was measured as the main outcome using a standardized quality-of-life instrument.		
Kazemi et al. (2021)	The study aimed to explore how the severity of caregiver burden relates to coping strategies among Iranian caregivers of older stroke patients, and whether coping differs between men and women.	cross-sectional survey	110 caregivers (mean age 32.09 ± 8.70 years) participated; 70% were female, over two-thirds were married, most were unemployed, about half had at least diploma education, and nearly all care recipients were elderly stroke survivors (mean age ~69.9 years).	It employed a descriptive, cross-sectional survey using convenience sampling. Caregivers completed the Zarit Burden Interview (ZBI) and the Lazarus coping strategies questionnaire.	The study measured caregiver burden via ZBI scores and coping strategies across eight domains via the Lazarus scale.	Most caregivers (67.3%) reported mild to moderate burden (mean ZBI ≈ 32.8). The most common coping strategies were positive reappraisal and seeking social support. Male caregivers used positive reappraisal and accepting responsibility more than females ($t = 2.76$, $p = 0.007$; $t = 2.26$, $p = 0.026$). Caregiver burden positively correlated with negative, emotion-focused strategies: escape-avoidance ($r = 0.245$, $p = 0.010$) and distancing ($r = 0.204$, $p = 0.032$).

DISCUSSION

Stroke remains one of the most prevalent neurological disorders worldwide, with a growing incidence in low- and middle-income countries, including India. While pharmacological and acute medical interventions are crucial in the early management of stroke, the role of physical therapy and long-term rehabilitation strategies is equally significant for functional recovery. However, a major yet often overlooked dimension in stroke management is the impact on caregivers, whose burden, awareness, and coping strategies directly affect both their well-being and the rehabilitation outcomes of the stroke survivor.

The current narrative review highlights critical findings from a study conducted in Haryana, India, aimed at evaluating the caregiver's burden, awareness, and coping strategies in relation to the functional independence of stroke patients. Unlike the extensive body of research in Western countries addressing caregiver support and burden, there is a notable scarcity of such studies in Indian settings, particularly in Haryana. This underscores the importance of the present study as a step forward in addressing this research gap and drawing attention to the psychosocial dimensions of stroke care.

The demographic data reflect that caregivers are often younger family members, with sons and spouses predominantly assuming caregiving roles. This familial responsibility, while rooted in cultural expectations, contributes to significant mental, physical, and emotional stress, especially in the absence of formal caregiving training or institutional support.

Findings from the Caregivers' Burden Scale (CBS-IP) indicate that a significant portion of caregivers experience moderate to severe burden, primarily driven by emotional and time-related demands. This aligns with the existing literature, including studies by Kavga et.al (2021) [15] and Hu P et.al (2018) [16], which emphasize the role of patient dependency in caregiver exhaustion and emotional distress. These caregivers, often termed the "second patient," bear the cumulative burden of managing daily care, navigating healthcare systems, and maintaining their own personal and professional lives.

The awareness levels among caregivers, assessed through a structured questionnaire, were found to be average in most cases. Although this level of awareness may seem satisfactory, the complexity of stroke rehabilitation demands a higher degree of knowledge and engagement for optimal outcomes. Previous studies, such as those by Sharma et.al (2014)[14], have reported similar findings in South Asian countries, suggesting a regional pattern of limited awareness and highlighting the urgent need for structured caregiver education programs.

Coping strategies employed by caregivers were predominantly emotion-focused, followed by problem-solving approaches, while avoidant strategies were the least used. This trend reflects the psychological adaptation process in caregiving, where emotional regulation becomes a primary mechanism to handle chronic stress. While emotion-focused coping such as acceptance and reappraisal may provide short-term relief, studies suggest that without adequate problem-solving support and social reinforcement, these strategies may become maladaptive, leading to burnout or depressive symptoms.[10]

Global studies, including those by Schmidt et.al (2022)[11] and Boonen et.al (2018)[19], which have shown that improving patient autonomy through rehabilitation mitigates the intensity of caregiving tasks and, consequently, the perceived burden. This supports the broader idea of family-centered rehabilitation, where patient recovery is approached as a shared outcome between healthcare providers and caregivers.

Implications and Future Directions

The implications of these findings are both practical and policy-oriented:

- Integrating caregiver education into stroke rehabilitation programs is essential. Educational sessions focusing on stroke pathology, rehabilitation protocols, patient handling techniques, and self-care strategies for caregivers should be routinely offered.
- Psychosocial interventions, including counseling, support groups, and stress management workshops, can help caregivers build resilience and reduce emotional fatigue.
- Community-based stroke care models, involving home visits and tele-rehabilitation, should be explored, especially in resource-constrained settings like rural Haryana.
- Policy frameworks must recognize caregivers as stakeholders in the rehabilitation process and provide financial, social, and emotional support systems to sustain their role effectively.

CONCLUSION

This narrative review underscores the significant and multifaceted impact of stroke on both patients and their caregivers. It highlights how caregiver awareness, burden, and coping strategies are intricately linked with the functional independence of stroke survivors. The findings suggest that caregivers often bear substantial physical, emotional, and financial strain—particularly in settings with limited formal support systems like India.

Improving caregiver knowledge and psychological resilience through structured training and emotional support can positively influence rehabilitation outcomes. Moreover, integrating caregiver-centered interventions into stroke rehabilitation programs is critical to fostering patient independence and enhancing the quality of life for both caregivers and stroke survivors.

Future research should focus on developing and evaluating region-specific caregiver support models that address the unique sociocultural and economic challenges faced by families in low- and middle-income settings. A holistic, family-centered approach is essential for comprehensive stroke management and sustainable long-term outcomes.

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