

## Restoring lives, relieving burdens: The role of stroke rehabilitation in supporting and empowering caregivers: A review

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### Abstract

Stroke is one of the major causes of morbidity and mortality globally, putting a huge strain on patients, families, and healthcare systems. While stroke rehabilitation is critical for regaining function and improving outcomes for survivors, it also places a significant burden on informal carers. Caregivers play an important role in sustaining rehabilitative improvements and ensuring continuity of care, often at the expense of their own physical, mental, and social health. This review aims to explore the extensive impact of stroke rehabilitation on caregivers by synthesizing information from current research on caregiver burden, coping methods, and quality of life. Key findings show that active caregiver participation in rehabilitation improves patient adherence and outcomes while also increasing caregiver stress and psychological strain. Caregivers also have a substantial burden due to factors such as stroke severity, insufficient training, and restricted support networks. Structured home-based programs, psychoeducation, peer-support groups, and digital health treatments are among the emerging options that show promise for lowering caregiver stress and increasing resilience. This review emphasises the need to incorporate caregiver-centred techniques into rehabilitation frameworks to promote optimal recovery for stroke survivors while reducing caregiver strain.

**Keywords:** Stroke Rehabilitation; Caregiver Burden; Quality of Life; Home-Based Care; Tele-Rehabilitation; Caregiver Support.

### 1. Introduction

Stroke is a devastating neurological condition that not only affects patients but also places significant burdens on their caregivers. According to Global Burden of Disease(2019), stroke is the second leading cause of death and the third most significant cause of death and disability [1,2]. Almost all stroke survivors have physical, psychological, and life-altering consequences [3]. Approximately 75% of stroke patients experience varying degrees of motor, speech, and swallowing difficulties, with approximately 20% of survivors being wheelchair-bound or bedridden. Additionally, more than half of stroke patients are released with neurological sequelae that need long-term, appropriate rehabilitation treatment [4].

Despite this progress in acute stroke care, more patients are surviving strokes but often with significant disabilities, necessitating comprehensive long-term care strategies [5]. Caregivers play a critical role in sustaining stroke survivors' progress in rehabilitation and long-term well-being. The emphasis in stroke rehabilitation has shifted from focusing solely on the stroke survivor to a stroke survivor-caregiver dyad approach, recognizing the critical role caregivers play in recovery [6]. Stroke rehabilitation aims to improve patients' physical capacity, cognitive function, and emotional well-being, all of which are typically compromised after a stroke. Effective rehabilitation can lead to improvements in motor disability, cognitive status, and mood, thereby enhancing the overall recovery process [7]. However, the level of

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disability and presence of comorbidities in patients are critical factors that affect the rehabilitation outcomes and the extent of caregiver burden [8].

Efforts to minimize the worldwide burden of stroke prioritize prevention via awareness programs that target risk factors such as hypertension, obesity, smoking and physical inactivity [9]. Furthermore, programs that focus on getting people to acute care quickly, sophisticated therapies like thrombolytic therapy, and full rehabilitation are very important for reducing the effects of stroke [10]. Addressing the worldwide burden of stroke requires collaboration among governments, healthcare organizations, advocacy groups, and communities. Initiatives aiming at improving access to healthcare, increasing stroke awareness, encouraging healthier lifestyles, and developing rehabilitation services are essential in lowering the burden of stroke globally [11]. To reduce the burden of stroke and improve outcomes for persons suffering from this devastating condition, methods such as prevention, early intervention, access to quality treatment, and comprehensive rehabilitation are essential [5].

By synthesising existing information and emphasising new trends, this review serves as a valuable resource for physicians, researchers, and policymakers involved in stroke care and caregiver support. Rather than following the rigid format of a systematic review, this manuscript adopts a rigorous, integrative approach to literature selection guided by defined inclusion criteria emphasizing relevance, methodological quality, originality, and a focus on recent innovations in stroke rehabilitation that directly or indirectly influence caregiver outcomes. Recognising that stroke rehabilitation is inherently multifaceted, this review covers a wide range of topics, from acute care transitions to long-term community-based interventions, with a focus on carers, who are the foundation of stroke recovery in the home and community setting.

This review paper explores the intricate and interdependent relationship between stroke rehabilitation and caregiver well-being, offering a comprehensive overview of current practices, challenges, and future directions. It then critically examines current rehabilitation approaches such as early mobilization, physical therapy, occupational therapy, speech-language therapy, cognitive rehabilitation, and psychosocial support and assesses how these affect caregiver burden, role strain, and adaptation. Special attention is given to how the rehabilitation process influences the emotional, physical, and economic domains of caregivers' lives.

Caregivers in developing countries face heightened challenges due to limited access to structured rehabilitation services, financial constraints, and inadequate health system support. Additionally, the review highlights innovations in caregiver support models such as tele-rehabilitation, peer-support frameworks, culturally adapted education programs, and the use of technology-assisted caregiving tools, which show promise in reducing caregiver burden and improving quality of life. Cultural expectations and lack of formal training further exacerbate caregiver burden, making stroke recovery a complex and demanding responsibility in low-resource settings [12]. Emphasis is placed on the need for caregiver-focused outcome metrics in stroke trials, integration of caregiver training into early rehabilitation phases, and the development of scalable, sustainable home-based rehabilitation programs that acknowledge the pivotal role of informal caregivers. By bridging clinical insights with caregiver realities, this manuscript aims to contribute to a more inclusive, evidence-based rehabilitation framework that restores lives while relieving the burdens placed on caregivers.

This review explores the multifaceted effects of rehabilitation programs on the physical, emotional, and social well-being of individuals caring for stroke survivors. By analyzing original research studies, the review aims to identify key areas where rehabilitation interventions contribute to reduced caregiver burden, improved quality of life, and enhanced coping strategies. Through a synthesis of recent evidence, this review highlights the complex relationship between stroke rehabilitation and caregiver well-being, offering insights for clinical practice and policy development.

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## 2. Stroke Rehabilitation: An Overview

Stroke rehabilitation is an organised process that helps people restore lost abilities, adapt to new difficulties, and maximise their independence and quality of life following a stroke. It involves various therapies, including physical therapy (for improving movement and coordination), occupational therapy (for developing daily living skills), and speech therapy (for enhancing communication), tailored to the individual's needs. It also includes cognitive therapy to improve thinking, memory, and other mental abilities. According to the International Stroke Recovery and Rehabilitation Roundtable, ischaemic stroke has several phases: the hyperacute stroke phase, which begins about 0-24 hours after the stroke; the acute stroke phase, which lasts 1-7 days; the early subacute stroke phase, which occurs within the first 3 months; the late subacute stroke phase, which occurs between 4 and 6 months; and the chronic stroke phase, which begins at 6 months and beyond [13]. Understanding these phases is critical for tailoring rehabilitation strategies.

Stroke teams that work in hospitals typically operate within specific stroke units and comprise stroke doctors, nurses, physiotherapists (PTs), occupational therapists (OTs), speech and language therapists (SLTs), and healthcare and therapy assistants [14]. Rehabilitation can be inpatient (hospital-based) or outpatient (clinic-based) and may involve home-based therapy depending on the patient's needs and the stage of their recovery [12]. Hospital-based rehab offers intensive, multidisciplinary care for those with severe impairments, while outpatient programs provide structured therapy for stable patients. Home-based rehab, including early supported discharge, allows therapy in a familiar environment but may be less intensive [15]. The American Heart Association (AHA) provides recommendations on three key categories of home-based rehabilitation: early supported discharge (ESD), which serves as a substitute for extended acute care; rehabilitation at home, which replaces institutional rehabilitation; and home exercise programs aimed at long-term health maintenance and risk reduction [16].

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### 3. The Role of Caregivers in Stroke Recovery

Informal caregivers are the major support system for stroke survivors after discharge and a vital component of the health care system. An informal caregiver, usually a family member, provides care, often unpaid, to someone with whom they have a personal relationship [17]. Caregivers play a crucial and challenging role in stroke rehabilitation. They help stroke patients recover physically by assisting them with exercises, mobility, and rehabilitation regimens, all of which are essential for restoring lost motor functions. Furthermore, carers offer emotional support to assist patients in managing the psychological effects of the stroke, including anxiety, frustration, and despair that may result from diminished independence or impaired mobility [18]. Caregivers of stroke survivors often endure significant emotional distress (including anxiety and depression), chronic physical exhaustion (such as fatigue and sleep disturbances), and financial hardship stemming from direct care expenses and lost income challenges that are compounded by the intensity and duration of caregiving responsibilities [19,20]. When caregivers actively participate in rehabilitation, they help them by coordinating follow-up appointments and supporting home exercise regimens, which significantly enhance patient adherence, but this involvement also introduces additional financial and time commitments that contribute to caregiver burden [21].

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### 4. Impact of Stroke Rehabilitation on Caregivers

The recovery process of a stroke patient significantly impacts caregiver stress and burden, with both the successes and challenges of rehabilitation directly influencing the caregiver's experience. Many studies have shown that home rehabilitation can be as effective as, or even more effective than, institutional care.

Caregivers may endure stress and strain as a result of giving lengthy care to their patients. This burden is comprised of physical, social, psychological, and economic issues. Caregivers must manage the dual challenge of caring for a disabled stroke survivor while also adjusting their lifestyle. The requirements of a stroke survivor differ widely, encompassing physical needs (such as walking and transferring from bed to chair or chair to toilet), communication needs (both verbal and nonverbal interactions with family and friends), nursing needs (including feeding, changing clothes, and personal hygiene), as well as emotional and psychological adaptations to the effects of the stroke, along with financial concerns (like job loss and medical expenses) [22].

Anxiety and depression can arise quietly. Reports indicate that the prevalence of anxiety and depressive symptoms among primary caregivers of stroke patients ranges from 30% to 45% and 20% to 50%, respectively. Numerous studies have indicated that caregivers' anxiety or depressive symptoms adversely affect their socioeconomic status, physical health, and overall quality of life. When primary caregivers experience anxiety or depression, their ability to offer effective support to stroke survivors may diminish, potentially hindering the patients' rehabilitation process and negatively impacting their disease prognosis [23].

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### 5. Factors Influencing Caregiver Burden

A stroke affects not just the individuals who survive but also the informal caregivers, who are responsible for the majority of care during the recovery period [16]. The effects of stroke adversely influence the physical, emotional, social, and financial health of caregivers, which in turn impacts the health status and quality of life for stroke survivors. Research indicates that 25–46% of caregivers face considerable distress during the initial six months of providing care as they shift from facility-based to home-based environments. Several factors are believed to affect caregiver burden, including the socio-demographics of the caregiver, the nature of their relationship with the patient, duration of caregiving, shared living with the patient, obligations outside the caregiving role, distractions from work, social engagements, and family routines [24].

Globally, depression can be seen not just in the stroke survivor but also in their caregiver. If left untreated, depression can lead to a diminished quality of life and a heightened burden for both the caregiver and the survivor. The increased burden has been linked to higher levels of patient depression, insufficient support and lack of time for themselves [5]. Recent advancements in stroke rehabilitation have effectively decreased severe disabilities and the need for institutional care, resulting in a greater number of disabled individuals living at home, supported by caregivers who often feel unprepared, misinformed, and dissatisfied with the level of assistance available post-discharge [25].

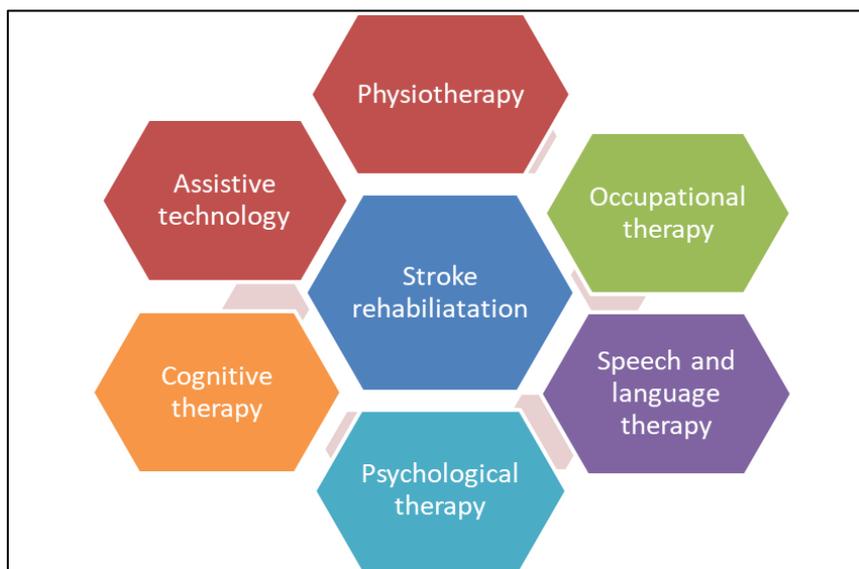
Caregiver requirements differ based on age. Younger caregivers are more likely to seek information and training and tend to express criticism towards the healthcare system, whereas older caregivers require support to foster a positive mindset and are less likely to voice discontent with the healthcare system. Caregivers require support from family or friends for emotional and physical help, and they also depend on healthcare providers to assist them in establishing and sustaining this support over time [5].

## 6. Rehabilitation Modalities and Caregiver Involvement

Rehabilitation interventions for stroke should begin as soon as possible after the event, even during the acute phase, as this is linked to better outcomes. Passive range-of-motion exercises, including mobilisation, and cognitive stimulation activities can all be used as early methods. The goal of these early interventions is to avoid secondary complications, encourage neural plasticity, and prepare for future rehabilitation efforts.

Meanwhile, collaborating with the patient and their caregivers to set rehabilitation goals helps create a clear focus for therapy. These goals are customized, achievable, and geared toward enhancing functional abilities based on recognized impairments. A multidisciplinary team of professionals, including physiotherapists, occupational therapists, speech-language pathologists, psychologists, and social workers, is required.

This collaborative method ensures a comprehensive assessment and recognition of rehabilitation needs from multiple perspectives. Each specialist offers distinct knowledge, aiding in the formulation of a comprehensive rehabilitation plan designed to address the patient's specific impairments and objectives. Additionally, involving family members or caregivers from the outset enables them to understand the rehabilitation process, receive guidance on how to assist the patient, and foster a supportive atmosphere when the patient is discharged. The early identification of stroke rehabilitation requirements through a comprehensive, interdisciplinary strategy establishes the foundation for a focused, tailored, and prompt rehabilitation plan, greatly influencing the recovery journey for stroke survivors [26].



**Figure 1** Multidisciplinary Components of Stroke Rehabilitation. The diagram illustrates the core elements of a comprehensive stroke rehabilitation program, including physiotherapy, occupational therapy, speech and language therapy, psychological therapy, cognitive therapy, and assistive technology

A caregiver-led exercise program holds promise for enhancing body function, activities, and participation in individuals who have experienced a stroke. Furthermore, caregivers become more actively engaged in the rehabilitation process,

which may boost their sense of empowerment, lessen caregiver burden, and support the move from rehabilitation settings (such as hospitals, rehabilitation centres, or nursing homes) to a home environment [27]. Various interventions aimed at aiding stroke caregivers, such as offering education, counselling, emotional support, or assistance in accessing services through information packages, social workers, specialist nurses, or family support workers, have yielded minimal benefits for patients and only slight improvements in the psychological and social aspects for caregivers. Providing training for caregivers in essential skills needed for daily management of disabled stroke survivors may help alleviate the caregiving burden [25]. The findings from the controlled trial in Bradford indicate that physiotherapy conducted at home for stroke patients is more successful than hospital rehabilitation in decreasing disability. Patients who received home care had reduced depression levels, experienced fewer complications, and were more likely to stay at home [28]. A collaborative effort among healthcare disciplines is critical for delivering comprehensive education and helping stroke survivors and caregivers. Addressing these challenges, healthcare professionals can work along with caregivers toward reducing stroke recurrences and minimizing long-term disability [29].

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## 7. Interventions to Support Caregivers

Caregivers face a significant challenge when caring for stroke patients, which can lead to feelings of burden both physically and mentally. The worse the health condition of stroke patients, the more strain is experienced by caregivers, impacting their physical, emotional, social, and financial well-being. Between 30% and 68% of caregivers looking after stroke patients report experiencing psychological strain in the form of anxiety and depression. Providing psychoeducation to caregivers can notably alleviate anxiety, serving as a therapeutic method to address psychosocial issues commonly faced in hospitals and lessen caregivers' stress and burden. Psychoeducation, along with caregiver training programs, aims to ease the demands on caregivers of stroke patients, ensuring that the care provided remains effective and that caregivers maintain their health [30].

Families of stroke survivors are at a significant risk of experiencing depressive symptoms, burden, stress, and a decline in quality of life due to the responsibilities associated with caregiving [31]. Problem-solving strategies have proven effective in assisting caregivers in home settings, yet they are often not utilized enough because they require considerable staff time and can be challenging for caregivers. To address these challenges, programs for stroke caregivers need to offer low-cost, practical solutions that can be integrated into standard clinical practice [32]. Tailored, individualized problem-solving and support initiatives are more likely to promote changes in health behaviours and enhance self-efficacy compared to generic programs [33]. Researchers have consistently indicated that interventions designed to help caregivers tackle issues are the most effective in supporting caregivers at home [34].

Structured home-based rehabilitation is an efficient approach that seeks to enhance the involvement of patients and their families in recognizing their needs and delivering essential education [35]. It aims to preserve and restore patients' well-being and independence while minimizing the disability associated with stroke [36]. These services play a crucial role in addressing the health requirements of individuals in need of rehabilitation and are regarded as highly valuable due to their cost-effectiveness, practicality, comfort for the client, reduction of frequent hospital admissions, and the establishment of a connection between the hospital and the community [37].

For numerous survivors and their caregivers, the perception of social support is linked to effective coping strategies [38]. Individuals who feel they have ample social support tend to adjust better to daily life changes resulting from new disabilities and evolving roles [39]. Peers serve as a key source of social support. Peer support groups offer stroke survivors and caregivers valuable psychological and social support, distinguished by shared experiences that foster mutual understanding and facilitate the exchange of emotional, affirmational, and informational support [38]. For stroke survivors, offering support to peers has been shown to bring about benefits, as those who provide support often find enjoyment in the process, experience personal growth, and feel they are positively impacting another's life [40]. Numerous research studies indicate that stroke survivors and their caregivers often do not have sufficient knowledge about the community support resources available to them. Providing timely and effective education and information will undoubtedly help the caregivers [41]. The participation of community health centres in enhancing physiotherapy and providing emotional support to caregivers can be beneficial [42].

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## 8. Caregiver Burden in Developing Countries

In Asian countries, including India, the responsibility of caring for stroke patients can be challenging because about one-third of them remain at home instead of being in care facilities, as is common in developed countries. The traditional joint family system is prevalent in rural regions, where there is plenty of room, while in urban areas, many family members often share cramped living spaces with limited infrastructure [43].

A recent study highlights the stroke burden among older populations. The overall age-adjusted prevalence rates of strokes in rural and urban regions range from 84 to 262 per 100,000 and 334 to 424 per 100,000, respectively, across various parts of the country over the last ten years, which is comparable to rates observed in developed nations [44]. In India, there is a significant lack of rehabilitation facilities within the government healthcare sector. The rehabilitation services offered by the private sector are costly and unaffordable for many individuals. Most stroke survivors stop engaging in physical therapy after just a few weeks due to challenges with transportation and expenses. Consequently, many of them end up being bedridden. As a result, stroke survivors tend to adopt a sedentary lifestyle that restricts their ability to perform daily activities, raises the risk of falls, and may lead to an increased likelihood of experiencing another stroke or developing cardiovascular disease [45]. Previous research has shown that stroke survivors are capable of improvement and has documented the advantageous physiological, psychological, sensorimotor, strength, endurance, and functional outcomes from various forms of exercise [46].

The increasing global challenge posed by strokes, in both developed and developing countries, will result in a greater strain on caregivers. According to research findings, factors such as financial worries, extended caregiving hours, and emotional strain all contribute to caregiver stress. To alleviate caregiver burden and enhance patient recovery, stroke rehabilitation services should also focus on addressing caregiver challenges through training in practical nursing skills and providing counselling sessions [47].

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## 9. Gaps, Challenges, and Opportunities

Many studies have pointed out a considerable gap in family caregivers' ability to effectively support and maintain the health of stroke patients [48]. Research indicates that caregivers frequently feel unprepared for the responsibilities of post-discharge care, largely due to insufficient knowledge and skills. This challenge is compounded by the need for caregivers to independently seek information and assistance, often without adequate guidance or support [49]

The cost and accessibility of stroke rehabilitation services were found to be the primary barriers at the service level. Many individuals who could not afford these rehabilitation services ended up staying at home, where they did not receive adequate care from their families. When stroke survivors do not have access to suitable rehabilitation services, the risk of post-stroke complications and the severity of their disabilities increase, leading to a significant demand for services that are both accessible and affordable [50].

In response to these challenges, digital health innovations have significantly transformed the field of rehabilitation medicine. Wearable technologies, smartphone apps, health information systems, telehealth services, and mobile health are included in the broad range of digital health.

Among these innovations, telehealth for stroke care has become increasingly accessible, supporting both acute treatment and community-based services by facilitating connections between healthcare providers and caregivers. Tele-neurorehabilitation consultations, in particular, have proven to be practical and effective for delivering coordinated care to patients in rural hospitals. Since internet connectivity and smartphone ownership are widespread in rural areas, the use of smartphones to educate patients and their families about stroke and offer assistance for functional skills training without having the direct involvement of a therapist or rehabilitation professional is becoming more and more prevalent [49].

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## 10. Conclusion

This review highlights the critical connection between carer well-being and stroke therapy. Although rehabilitation treatments are essential for enhancing patient outcomes, they frequently put a significant financial, emotional, and physical strain on carers, especially in low-income environments. Stress and psychological strain are exacerbated by a lack of formal training, inadequate preparation, and a lack of systemic support. Innovative approaches that show promise for lowering caregiver stress and promoting sustainable care models include structured home-based programs, problem-solving training, peer support groups, and telemedicine platforms. Finally, a successful stroke recovery depends on empowering and supporting carers as active participants in care, in addition to the patient's rehabilitation journey. To ensure full, equitable, and successful outcomes, caregiver-inclusive strategies must be strengthened.

## Compliance with ethical standards

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### *Author Contributions*

Contributor	Concept	Study Design	Data Collection	Statistical Analysis	Literature Overview	Discussion	Fund Generation
Mrs. Neethu M	√	√	-	-	√	√	-
Dr. Sindhu J Vayalil	√	√	-	-	√	√	-

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