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Family Caregivers Challenges for Stroke Survivors in the Community: A Literature Review

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Abstract

Stroke is a chronic condition that significantly reduces the patient's quality of life and increases the need for support from family caregivers. This situation places the family as a crucial element in patient care, yet often presents significant challenges for family caregivers. This study aims to identify and describe the various challenges faced by families caring for stroke patients in the community. A literature review design was employed. Relevant articles published between 2020 and 2025 were retrieved from international databases including PubMed and ScienceDirect, using the keywords "family challenges" OR "family burden" AND "stroke" OR "stroke survivor." The inclusion criteria were determined using the PEO framework. A total of 346 articles were identified, and fifteen articles met the inclusion criteria for the review. The findings indicate that family caregivers of stroke patients face various challenges due to the complex demands of care, ranging from emotional stress at the time of diagnosis to physical and social challenges during home care. Challenges are further exacerbated when the patient experiences dysphagia, severe disability, or psychological problems such as depression and anxiety. Factors contributing to these challenges include the family caregiver's employment status, educational level, kinship relationship, social support, knowledge of stroke rehabilitation, the transition process from hospital to home, limited access to healthcare, and limited social activities. Caring for stroke patients presents significant challenges for families, who serve as the primary caregiver system and play a central role in community care. Interventions that support family caregivers through education, psychosocial support, and access to adequate health and rehabilitation services are crucial for community nurses to reduce caregiver burden and improve the quality of life for both family caregivers and stroke patients in the community.

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1. INTRODUCTION

Stroke is a leading cause of long-term disability, affecting not only survivors but also their families, who often serve as primary caregivers in the community. Physical impairments after stroke often range from motor dysfunction to emotional instability, cognitive decline, and limitations in social functioning, ultimately reducing patients' quality of life and increasing their dependence on ongoing family support (Dimunová et al., 2021). Stroke survivors commonly experience long-term disability, post-stroke fatigue, physical weakness, sarcopenia, falls, and psychosocial stress, which contribute to poorer functional recovery, higher rates of rehospitalization, and increased burden on family caregivers (Kotlega, Kobus-kotlega, & Szczuko 2025). Family caregivers have an important and effective role in improving the functional status of patients including reducing prolonged depression in post-stroke patients, preventing recurrent stroke attacks, increasing the motivation and compliance of stroke patients in undergoing treatment and care programs, and increasing the independence of stroke patients in meeting the needs of daily activities in the community (Deepradit et al., 2023; Israfil, 2024). Although the central role of families in maintaining post-stroke recovery is widely recognized, the realities of family caregivers often involve substantial multidimensional challenges, including being required to assume complex and prolonged caregiving responsibilities, often without adequate preparation, structured training, or psychosocial support, which places family caregivers at significant risk of physical exhaustion, increased stress levels, and broader physical and psychological health problems arising from long-term caregiving obligations for stroke patients in the community (Stiexs & Chayati, 2021). Unfortunately, comprehensive syntheses of studies focusing on the challenges faced by family members caring for stroke survivors in the community are still limited.

The World Health Organization reports that approximately 15 million people worldwide experience a stroke each year, resulting in 5 million deaths and another 5 million living with permanent disability (WHO, 2024). Stroke-related disabilities can include paralysis, difficulty speaking and communicating, visual impairment, cognitive decline, emotional disturbance, and reduced independence in performing daily activities. These long-term impairments require ongoing assistance with rehabilitation, medication management, and psychosocial support, increasing dependence on family caregivers (Poomalai, Prabhakar, and Jagadesh, 2023). In Indonesia, the Ministry of Health of the Republic of Indonesia reported a stroke prevalence of 8.3 per 1.000 population in the 2023 Indonesian Health Survey (Ministry of Health of the Republic of Indonesia, 2024). This prevalence reflects not only significant mortality and morbidity but also a reduced quality of life, significant physical, emotional, and financial burdens borne by families and communities (Tiwari et al., 2021)

Post-stroke care is gradually shifting from hospital-based care to community- and home-based rehabilitation approaches that emphasize the primary role of the family as long-term caregivers. After hospital discharge, families begin to assume primary responsibility for managing the complex and ongoing demands of care. Stroke produces multifaceted impacts that affect not only the patient but also the family as caregivers, making family caregiving a uniquely challenging journey that carries significant emotional burdens and ongoing responsibilities (Yusrini et al., 2019). Several studies have demonstrated a significant relationship between family support and improved quality of life among stroke survivors in community settings. Adequate family involvement increases patient independence in self-care and daily activities, which is crucial for long-term recovery and adaptation (Risal & Sali, 2021). Although existing research largely emphasizes the positive contribution of family support to patient outcomes, the challenges

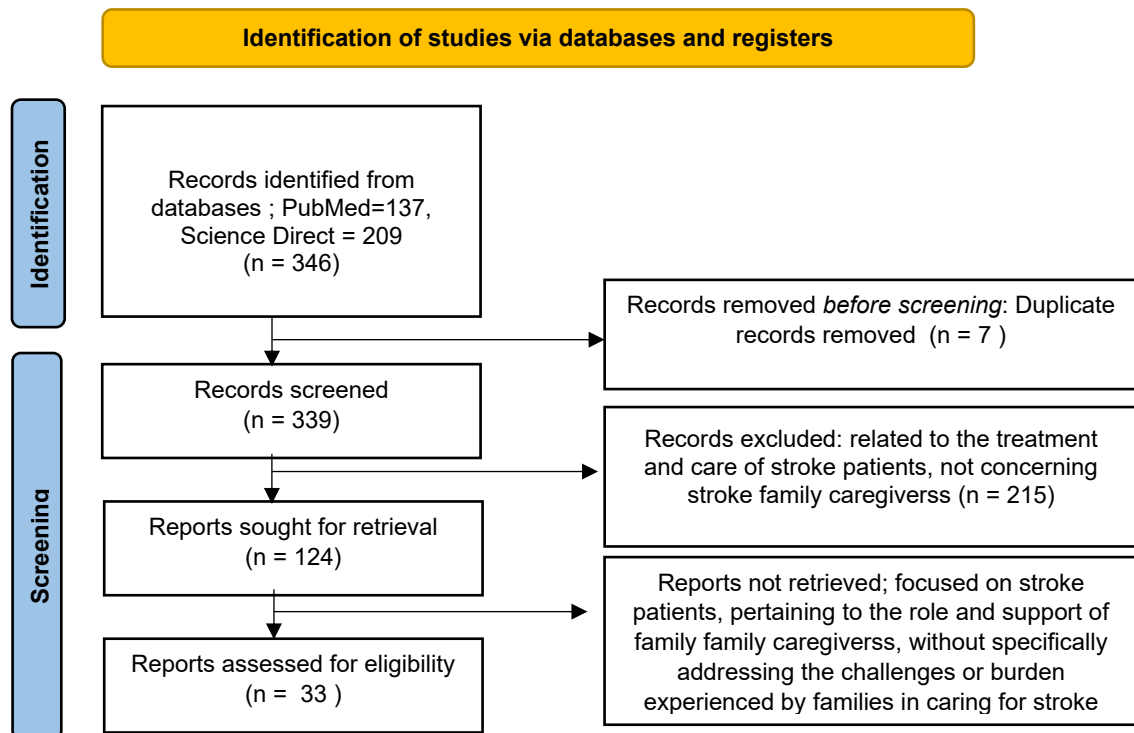
faced by families as primary caregivers of stroke survivors in the community warrant further investigation to inform the development of appropriate family-based nursing care plans in community settings.

Identifying and understanding the challenges faced by families caring for stroke survivors in the community setting is crucial for strengthening ongoing stroke management. Synthesizing current evidence on the challenges of family caregiving can inform the development of family-centered nursing interventions in the community (Wang et al., 2025). Therefore, this study aims to analyze and synthesize relevant current scientific evidence related to the challenges experienced by family caregivers caring for stroke survivors in the community. This study is expected to provide an evidence-based basis for the development of comprehensive family-centered nursing interventions in the community.

2. METHOD

This study was designed using a literature review approach to identify and synthesize recent research findings on the challenges faced by families in caring for stroke patients in the community (Libório et al., 2023). Literature was sourced from the international databases PubMed and ScienceDirect. The search was conducted using keywords combined with Boolean operators AND and OR, specifically: “family challenges” OR “family burden” AND “stroke” OR “stroke survivors.”

The inclusion criteria of literature followed the PEO (Population, Exposure, Outcome) framework (Capili, 2020) include Population: stroke patients and their family caregivers, Exposure: experiences encountered by family caregivers in providing care, Outcome: burden, stress, difficulties, coping, and adaptation. Only research articles published between 2020 and 2025 were included in this review. Article selection involved multiple stages: identification of articles from databases, title screening, abstract screening, and full-text review (Page et al., 2021). Data were analyzed descriptively through a data extraction process that recorded the author and year of publication, country, study design, sample size, and key findings.



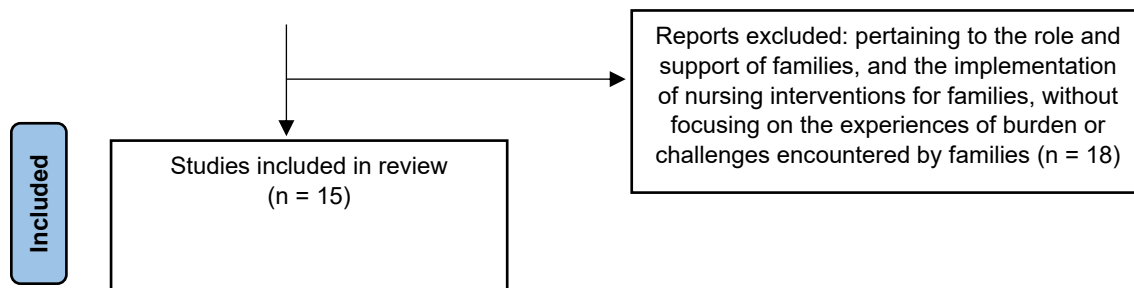


Figure 1. PRISMA Flow Diagram of Article Selection (Page et al., 2021).

3. RESULTS AND DISCUSSION

A total of 346 articles were identified from the databases. After removing duplicates, titles and abstracts were screened, and irrelevant articles were excluded. Full-text assessment was then conducted resulting in 15 articles that met the inclusion criteria and were included in this review (Figure 1). The reviewed studies encompassed a wide range of research designs, sample sizes, and geographic settings, demonstrating the global challenges in understanding the challenges of family caregiving for stroke patients. These studies were conducted in countries including Ireland, China, Indonesia, Italy, Poland, Saudi Arabia, Iran, and Zimbabwe, highlighting diverse cultural and healthcare contexts (Table 1).

Table 1. Summary of Studies on Family Caregiving Challenges for Stroke Survivors in the Community.

No	Author (Year)	Country	Study Design and Sample Size	Findings
1	Giray et al., 2023 (Giray et al., 2023)	Ireland	Study Design: Multi-center, cross-sectional (prospective) study. Sample Size: 120 stroke patients and informal family caregivers (57 with dysphagia, 63 without dysphagia)	Family caregivers of stroke patients with dysphagia face higher challenges and greater burden compared to those without dysphagia. Family caregivers' burden is correlated with patients' swallowing-related quality of life and stroke-specific quality of life. Significant factors influencing burden include family caregivers' employment status (high workload), low education, close kinship, severe dysphagia, and low patient quality of life.
2	Ye et al., 2024 (Ye et al., 2024)	China	Study Design: Mixed-method explanatory sequential design.	Family caregivers experience emotional burden and stress from the early phase of stroke diagnosis. Family resilience is influenced by social support,

			Sample Size: 379 stroke patients, 15 family caregivers	perceived burden, and family caregivers' self-efficacy. Demographic factors such as age, education, occupation, and income also affect family adaptation. Interviews revealed that families gradually adapt, build social support, and develop positive perspectives in managing patient care.
3	Lin et al., 2022 (Lin et al., 2022)	China	Study Design: Qualitative longitudinal study Sample Size: 23 stroke survivors and 23 family caregivers	The transition from hospital to home is dynamic and challenging, divided into three phases: Survived (optimism and hope), Living in the Mist (emotional concerns before discharge, lack of knowledge and home care information, care difficulties, and expectation of pre-discharge support), and Crisis at Home (high post-discharge stress, limited access to rehabilitation and health support, interpersonal disruptions, lifestyle changes, and financial burden).
4	Khomarun et al., 2025 (Khomarun et al., 2025)	Indonesia	Study Design: Exploratory qualitative study Sample Size: 30 informal stroke family caregivers	Family caregivers face burdens in daily patient care. The main coping strategy is devotion, encompassing family bonds (pride, sincerity, acceptance, destiny, responsibility) and physical capacity (ability, spirit). This strategy helps maintain care continuity despite emotional and physical challenges.
5	Rago et al., 2025 (Rago et al., 2025)	Italy	Study Design: Qualitative phenomenological study Sample Size: 19 stroke survivors	Thematic analysis revealed four main themes: The Homeward Odyssey (complex journey home with physical and emotional challenges), A New Dawn: Perspectives on Rehabilitation Continuity (importance of rehabilitation continuity and professional support post-discharge),

				Isolated at Home: The Solitary Journey of Stroke Survivors (feelings of loneliness, social isolation, and limited support at home), and The Shades of Life (changes in life perspective and emotional adaptation post-stroke)
6	Li et al., 2025 (Li et al., 2025)	China	Study Design: Cross-sectional study Sample Size: 517 family members of stroke patients	Families show positive attitudes and proactive practices in supporting rehabilitation, but face challenges due to limited knowledge of specific rehabilitation processes, including stroke rehabilitation networks that may hinder effective family involvement
7	O'Callaghan et al., 2024 (O'Callaghan et al., 2024)	Ireland	Study Design: Qualitative descriptive study Sample Size: 16 participants (9 stroke survivors, 7 family caregivers)	Stroke survivors and family caregivers face significant challenges during hospital-to-home transition, including a lack of timely and tailored information, insufficient emotional support, feelings of uncertainty and being "left in limbo," and unequal access to services. Participants desired a multifaceted approach to reduce anxiety, minimize delays, and optimize recovery.
8	Jaracz et al., 2024 (Jaracz et al., 2024)	Poland	Study Design: Longitudinal follow-up study Sample Size: 40 stroke patient-family caregivers dyads	Ten years post-stroke, 47.5% of family caregivers experienced significant burden, higher than 5 years (17.5%) and comparable to 6 months post-stroke (37.5%). Predictors of high burden included long caregiving duration, low family caregivers coherence, stroke severity, and family caregivers anxiety.
9	Yuliana et al., 2023 (Yuliana et al., 2023)	Indonesia	Study Design: Cross-sectional study	Stroke-related disabilities affect family caregivers' quality of life (QoL). Patient depression, anxiety, and

			Sample Size: 183 stroke patients and family caregivers	stress also impact family caregivers' QoL. Family caregivers experience emotional and psychological burden, indicating mutual influence between patients and family caregivers during care. Interventions should target psychosocial support for both family caregivers and patients.
10	Tunsi et al., 2025 (Tunsi et al., 2025)	Saudi Arabia	Study Design: Descriptive exploratory qualitative study Sample Size: 20 family caregivers	Family caregivers face four main challenges: emotional and psychological burden, barriers to accessing health services, disruption of daily activities and social isolation, and resilience through coping mechanisms.
11	Pourhasan & Vasli, 2025 (Pourhasan & Vasli, 2025)	Iran	Study Design: Qualitative study Sample Size: 17 stroke family caregivers	Four main themes emerged: challenges and struggles, religious coping strategies, psychological coping strategies, and social and relational dynamics.
12	Muhrodji et al., 2022 (Muhrodji et al., 2022)	Indonesia	Study Design: Qualitative study Sample Size: 7 stroke family caregivers	Family caregivers play a key role in connecting patients with healthcare providers and family, and maintaining patients' physical and psychological health. Main challenges include a lack of stroke knowledge, insufficient family attention, suboptimal medical services (physiotherapy, pharmacy, administration), physical limitations, burnout, and uncooperative patients.
13	Kaseke et al., 2024 (Kaseke et al., 2024)	Zimbabwe	Study Design: Longitudinal study Sample Size: 188 stroke survivors and family caregivers	Family caregivers' burden increased among those experiencing anxiety or depression, adjusting to work, or feeling overwhelmed. Poor patient outcomes and dependence on health

				insurance further increased the burden on family caregivers. Caring for married stroke patients was associated with reduced family caregivers' burden.
14	Xu et al., 2025 (Xu et al., 2025)	China	Study Design: Cross-sectional study Sample Size: 222 stroke family caregivers	Family caregivers experienced high levels of social alienation. Significant factors influencing social alienation included family caregivers' marital status, living with the patient, disease knowledge, social support, family caregivers' burden, and loneliness.
15	Paryono et al., 2022 (Paryono et al., 2022)	Indonesia	Study Design: Qualitative study Sample Size: 10 healthcare professionals and 8 stroke family caregivers	Families family caregivers had limited knowledge and independence, indicating the need for regular homecare monitoring to ensure post-stroke care meets expected standards.

Table 1 shows that family caregivers of stroke patients face a variety of complex challenges, ranging from emotional distress at the time of diagnosis to physical and social difficulties during home care. The burden of caregiving is particularly high for patients with dysphagia, severe disabilities, or psychological problems such as depression and anxiety. Factors contributing to these challenges include the caregiver's employment status, education level, kinship, social support, and knowledge of stroke rehabilitation. The transition from hospital to home also poses significant stress for family caregivers, limited access to healthcare, and social isolation due to their caregiving responsibilities. Despite the challenges, caring for a family member who has suffered a stroke is considered a form of family devotion that requires substantial emotional adaptation.

The findings of this review indicate that family caregivers of stroke patients face multiple challenges due to the complex and multidimensional nature of caregiving, encompassing emotional, psychological, physical, and social aspects. Emotional and psychological burdens emerge from the early phase of stroke diagnosis, when families first experience worry, anxiety, and stress related to the patient's condition. Patients' psychological issues, such as depression and anxiety, exacerbate the stress experienced by family caregivers and negatively impact their quality of life. Psychological disorders, dysphagia, and/or severe disabilities represent the most significant challenges for families in caring for stroke patients in the community.

Family caregivers encounter various challenges, including emotional and psychological burdens, barriers to accessing healthcare services, disruptions in daily activities, social isolation, and the need to maintain resilience through coping mechanisms (Tunsi et al., 2025). Family caregivers of stroke patients with dysphagia face particularly significant challenges, as their caregiving burden is higher compared to family caregivers

of patients without dysphagia. This burden is closely associated with the patient's quality of life, both regarding swallowing ability and stroke-specific quality of life (Giray et al., 2023). Emotional strain and stress from the early stages of diagnosis represent major challenges in patient care. Family resilience in managing these situations is influenced by social support, perceived caregiving burden, and family caregivers' self-efficacy, while demographic factors such as age, education level, employment status, and income further affect families' adaptive capacity (Ye et al., 2024). Predictors of high caregiving burden include prolonged caregiving duration, low family caregivers coherence, severity of the patient's stroke, and family caregivers anxiety regarding the patient's condition (Jaracz et al., 2024). Furthermore, the patient's disability and psychological conditions, including depression, anxiety, and stress, directly influence family caregivers' quality of life, who often experience substantial emotional and psychological burden throughout the caregiving process (Yuliana et al., 2023). Additional challenges include a lack of knowledge about stroke, limited family attention, suboptimal medical services (e.g., physiotherapy, pharmacy, and administrative support), physical limitations, family caregivers' burnout, and uncooperative patients (Muhrodji et al., 2022). Conditions like this can be controlled with various nursing interventions, for example autogenic relaxation therapy is a therapeutic intervention that can improve adaptation, mobilization, and quality of life of stroke patients in the community with family support as the main support system (Israfil et al., 2024).

The transition of stroke patients from hospital to home is a dynamic and challenging process for families, encompassing three distinct phases: the survival phase, the phase of living in uncertainty, and the home crisis phase. During the survival phase, families experience optimism and hope, which can be reinforced through informational support and education provided by healthcare professionals. The phase of living in uncertainty is characterized by emotional concerns, insufficient caregiving knowledge, and difficulties in providing care at home; effective solutions include pre-discharge guidance, home-care training, and access to adequate information. In the home crisis phase, families face high levels of stress, limited access to rehabilitation services, interpersonal disruptions, lifestyle changes, and financial burdens (Lin et al., 2022). Additional challenges in the community include the need for continuity of rehabilitation and professional support, as well as feelings of loneliness and social isolation at home (Rago et al., 2025), limited knowledge regarding specific rehabilitation processes, and restricted access to stroke rehabilitation networks (Li et al., 2025). Timely and tailored information deficits, lack of emotional support, uncertainty or feelings of neglect, unequal access to services (O'Callaghan et al., 2024), insufficient knowledge and patient independence (Paryono et al., 2022), social alienation factors such as family caregivers' marital status, co-residence with the patient, disease knowledge, social support, family caregivers' burden, loneliness (Xu et al., 2025), and reliance on health insurance further exacerbate family caregivers' burden (Kaseke et al., 2024)

Families express the need for a multifaceted approach that reduces anxiety, minimizes delays in care, and optimizes patient recovery (O'Callaghan et al., 2024). Positive strategies employed by families to address these challenges include emotional adaptation, development of a positive life perspective alongside the post-stroke patient, engagement with professional healthcare support, establishment of adequate social networks, and psychosocial adaptation strategies to enhance well-being (Rago et al., 2025). Families gradually undergo an adaptation process, building social support networks and cultivating a positive perspective in managing patient care (Ye et al., 2024), while addressing challenges such as coordination with primary healthcare and rehabilitation

services and managing family resources (Lin et al., 2022). The primary coping strategy employed by families in caring for stroke patients in the community involves perceiving their caregiving role as a form of sincere devotion, encompassing family bonds (pride, sincerity, acceptance, destiny, responsibility) and physical strength (ability, determination) (Khomarun et al., 2025), demonstrating a positive attitude and proactive practices in supporting rehabilitation (Li et al., 2025). Religious coping, psychological coping, and social-relational dynamics are also important considerations (Pourhasan & Vasli, 2025). Effective solutions include comprehensive psychosocial support interventions for both patients and family caregivers to reduce burden, enhance well-being, and improve overall care quality (Yuliana et al., 2023), as well as the development of homecare services (Paryono et al., 2022). These findings reinforce the need for community-based stroke care to recognize the family as an integrated care system with a central role in long-term recovery. Addressing caregiver burden through structured and holistic support remains fundamental to maintaining the quality of patient care and the quality of life of family caregivers of stroke survivors.

This study has several limitations. The search was limited to PubMed and ScienceDirect, which may have excluded relevant studies from other databases. The restriction to articles published between 2020 and 2025 may have omitted earlier research. Most of the included studies were observational, limiting causal interpretation, and the analysis was descriptive in nature. Nevertheless, this study provides important information for nurses regarding the challenges faced by families in caring for stroke patients in the community, which may inform the development of appropriate nursing interventions.

These findings emphasize that community-based stroke care must adopt a family-centered and holistic approach, positioning the family not only as a provider of care but also as a recipient of support. Community nurses should routinely screen caregiver burden, strengthen discharge planning and hospital-to-home transitions, and provide structured rehabilitation skills education and training. Psychosocial support and community services are crucial for increasing family resilience, reducing caregiver burden, and optimizing the continued recovery of stroke patients in the community.

4. CONCLUSION

Family caregivers of stroke patients face multidimensional challenges that include emotional, psychological, physical, social, and financial burdens that arise from the initial diagnosis and are further exacerbated by patient conditions such as dysphagia, severe disability, depression, anxiety, and stress. Additional burdens for family caregivers are influenced by demographic factors, length of care, low coherence of family caregivers, limited access to healthcare services, and lack of knowledge about specific rehabilitation processes. The transition from hospital to home in a community setting is a critical phase that presents emotional, social, financial, and rehabilitation coordination challenges. Effective strategies to support families as family caregivers involve a multifaceted and holistic approach, including pre-discharge education, guidance in home care, access to rehabilitation services, psychosocial support for family caregivers and patients, and strengthening social and professional networks. Families also need to develop personal coping strategies rooted in genuine devotion, family bonding, physical resilience, emotional adaptation, and the development of a positive perspective. Community nurses play a crucial role in supporting family caregivers of stroke patients through holistic interventions aimed at reducing family caregiver burden, enhancing family resilience, improving the quality of care, and optimizing patient recovery within the community.

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