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Preparedness, Resilience and Support Systems among Family Caregivers of Stroke Survivors: A Scoping Review

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ABSTRACT

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Background: Family caregivers of stroke survivors frequently enter caregiving with limited preparation, while their capacity to adapt is shaped by personal, relational, cultural, socioeconomic, and service resources. This scoping review aimed to map and synthesise recent evidence on how preparedness, resilience, coping, and support systems have been conceptualised and reported among family caregivers of stroke survivors.

Methods: The review followed Joanna Briggs Institute (JBI) methodology and was reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR). Five databases (CINAHL, MEDLINE, Scopus, PubMed, and PsycINFO) were searched for peer-reviewed studies published from 2020 to 2025. Quantitative, qualitative, and mixed methods studies involving adult family caregivers were included. Data were charted and synthesised descriptively and thematically.

Results: Of 2,842 records, 32 studies met inclusion criteria. Three themes emerged: preparedness and challenges, resilience and coping, and support systems. Caregivers assumed their role with limited informational, emotional, and practical preparation. Resilience was shaped by personal, relational, cultural, and socioeconomic resources. Support systems were underused due to structural, financial, and access barriers.

Conclusion: Preparedness, resilience, and support systems are related but conceptually distinct dimensions of post-stroke caregiving. Preparedness describes readiness to meet caregiving demands, resilience reflects adaptation as those demands evolve, and support systems represent contextual resources that may facilitate both processes. Because the evidence base remains dominated by cross-sectional and single-time-point studies, the direction and temporal ordering of these relationships cannot yet be established. Longitudinal, theory-informed, and intervention research is needed, particularly in low- and middle-income settings.

Keywords: Caregivers; Family; Stroke; Preparedness; Resilience; Social support

INTRODUCTION

Stroke remains a major cause of mortality and long-term disability worldwide. The Global Burden of Disease Study reported 12.2 million new strokes in 2021 and approximately 101 million people living with the consequences of stroke (1). Beyond its effects on survivors, stroke frequently transfers substantial rehabilitation and daily-care responsibilities to family members. This reliance on informal care is particularly important in low- and middle-income countries (LMICs), where formal long-term care and community rehabilitation resources may be limited (2,3).

The caregiving transition following stroke may be understood through the concept of biographical disruption (4). Recent qualitative evidence shows that stroke can disrupt not only the survivor's physical functioning but also the identity, social roles, family relationships, daily routines, and future expectations of both survivors and family members (5,6). Family caregivers are often required to assume unfamiliar caregiving responsibilities while simultaneously adjusting emotionally and socially to major changes in family life (5-8). This theoretical lens is useful because it explains why information given at hospital discharge may be insufficient when caregivers are still renegotiating their identity, relationships, and everyday routines after stroke. Therefore, caregiver preparedness should be understood not only as task readiness but also as emotional, relational, and social adaptation to a transformed family life.

In Malaysia, stroke is ranked as the third leading cause of death, with approximately 47,911 new cases recorded in 2019 and an estimated 443,995 individuals living with stroke-related disabilities (9). With limited community-based rehabilitation services, the majority of Malaysian stroke survivors are discharged home under the care of family members, making informal caregiving the backbone of the national stroke rehabilitation system (10). Despite the critical importance of this role, family caregivers frequently begin their caregiving journey without sufficient preparation, training, or access to structured support (10,11).

The literature reveals that insufficient preparedness contributes to caregiver burden, emotional distress, social isolation, and deteriorating physical health (11,12). Emerging

research has begun to shift focus from burden alone toward two interrelated constructs that may explain how caregivers sustain their roles over time: preparedness and resilience. Preparedness was first operationalised as caregivers' perceived readiness to meet role demands (13) and has subsequently been refined as a multidimensional construct encompassing physical, emotional, practical, organisational, and relational readiness (14).

Resilience is recognized as a key protective factor for caregivers. It describes a person's capacity to manage and adjust effectively when faced with difficult situations. Within caregiving, resilience means being able to handle the physical and emotional strains that come with the role. This involves responding constructively to challenges like ongoing stress, changes in work arrangements, traumatic events, and other hardships (15). Key features of resilience include strong problem-solving abilities, effective coping strategies, healthy self-esteem, an optimistic attitude, a sense of purpose, self-control, frustration tolerance, humour, and general life skills (15). Building resilience helps caregivers better engage in self-care and tackle family caregiving issues. When caregivers have higher resilience, they experience fewer perceived difficulties in caregiving, allowing them to navigate these challenges more smoothly.

Support systems in this review are understood as multidimensional resources encompassing three types of support. First, emotional support includes empathy, reassurance, caring relationships, and psychological support. Second, informational support includes advice, education, guidance, training, and clear communication from healthcare providers. Third, instrumental support includes practical assistance, financial support, respite services, transport, and access to community resources. This distinction is important because recent evidence shows that stroke caregivers often experience unmet needs across several domains simultaneously, including caregiving skills, emotional support, service access, and financial assistance (11,16,17). Informational support alone may therefore be insufficient to prepare caregivers adequately if their emotional, practical, and financial needs remain unmet. A multidimensional support approach is needed to strengthen caregiver preparedness, reduce distress, and sustain caregiving capacity over time (18,19).

Preparedness, resilience, and support systems were reviewed together because the literature frequently presents them as related dimensions of the caregiving experience. Preparedness reflects perceived readiness to assume and perform the caregiving role, resilience reflects adaptive capacity during continuing caregiving, and support systems represent external resources available to caregivers. However, the direction, strength, and temporal order of these relationships have not been established. This review therefore maps how the constructs are described and associated across studies without assuming that one causes another.

Despite growing recognition of these constructs, the evidence base remains fragmented across study designs, geographical contexts, and theoretical perspectives. Existing reviews have largely focused on caregiver burden, unmet needs, or individual constructs rather than mapping how preparedness, resilience, coping, and support are conceptualised and connected across quantitative, qualitative, and mixed methods evidence (10,16,17). The present review was restricted to 2020-2025 to map recent evidence and contemporary service contexts; this time window should be retained only if the authors can confirm that it was defined before screening. The review addressed three questions: (a) How has preparedness for caregiving among family caregivers of stroke survivors been described and assessed? (b) What factors are reported to be associated with or to shape caregiver resilience? (c) What formal and informal support systems are reported among family caregivers of stroke survivors, and how are they related to preparedness and resilience?

METHODS

Study Design

This scoping review was conducted in accordance with the Joanna Briggs Institute (JBI) methodology for scoping reviews (20) and was reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (21). The JBI guidance informed the review design, eligibility criteria, search process, study selection, data charting, and synthesis, whereas PRISMA-ScR guided transparent reporting of the review process. A scoping review design was selected to map

the breadth, range, and nature of existing evidence on preparedness, resilience, and support systems among family caregivers of stroke survivors.

A scoping review was considered more appropriate than a systematic review or meta-analysis because the purpose was not to evaluate the effectiveness of a specific intervention or to synthesise homogeneous outcome data (20). Instead, the review sought to clarify key concepts, identify the range of available evidence, examine methodological patterns, and highlight gaps for future research (20). The design also permitted inclusion of quantitative, qualitative, and mixed methods studies, enabling the review to map both measured associations and caregivers' reported experiences across diverse contexts. This approach is consistent with recommendations that scoping reviews are suitable when a field is conceptually and methodologically heterogeneous.

The protocol was not prospectively registered. A preliminary search of PubMed, Scopus, and the Open Science Framework was undertaken before the review, and no scoping review examining preparedness, resilience, and support systems together among family caregivers of stroke survivors was identified. The absence of a publicly accessible protocol limits external verification of decisions made before and during the review and is acknowledged as a methodological limitation.

Eligibility Criteria

Eligibility criteria were developed using the JBI Population, Concept, and Context (PCC) framework (20). The criteria are summarised in **Table 1**.

For synthesis, preparedness was operationalised as perceived or demonstrated readiness to perform the caregiving role; resilience as adaptive capacity or an adaptive process in response to ongoing caregiving adversity; coping as cognitive or behavioural responses used to manage caregiving demands; and support systems as formal or informal interpersonal, professional, material, financial, or service resources available to caregivers. Coping findings were analysed as part of adaptation and were not classified as support unless they explicitly described an external resource.

Table 1: Eligibility Criteria Based on the JBI Population, Concept, and Context Framework

Variable	Eligibility Criteria
Population	Adult family members serving as informal and unpaid caregivers for adult stroke survivors.
Concept	Studies addressing preparedness/readiness, resilience/adaptation, coping responses relevant to adaptation, and/or formal or informal support systems among family caregivers of stroke survivors.
Context	Any healthcare or community setting where family caregivers provide or prepare to provide care for stroke survivors.
Type of sources	Peer-reviewed quantitative, qualitative, and mixed methods primary studies published in English or Malay from January 2020 to December 2025. The 2020-2025 limit should be retained only if confirmed as an a priori decision.
Exclusion criteria	Studies were excluded if they did not provide separate data for family caregivers of adult stroke survivors; focused only on stroke survivors; involved paid or formal caregivers as the target population; were conference abstracts, protocols, review papers, editorials, commentaries, dissertations, or grey literature; focused only on caregiver burden without addressing preparedness, resilience/adaptation, coping, or support; or involved paediatric stroke.

Information Sources and Search Strategy

A literature search was conducted across the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (MEDLINE), Scopus, PubMed, and the American Psychological Association PsycINFO for studies published from 1 January 2020 to 31 December 2025. Search concepts were

developed from the PCC framework and included terms for family caregivers, stroke, preparedness/readiness, resilience/adaptation, and formal or informal support. Controlled vocabulary was combined with free-text terms where appropriate. **Table 2** summarises the working concepts and keywords, while **Table 3** and **Table 4** is intended to reproduce the exact executed search strategy and database yields.

Table 2: Keywords and Related Terms Used in the Search Strategy

Keywords and Synonyms	
Family caregiver	Family caregiver OR informal caregiver OR family carer OR unpaid caregiver
Preparedness	Preparedness OR readiness OR caregiver competence
Stroke survivor	Stroke survivor OR stroke patient OR cerebrovascular accident OR cerebrovascular accident (CVA)
Resilience	Resilience OR family resilience OR adaptation OR coping OR coping capacity
Support systems	Support systems OR social support OR informational support OR emotional support OR instrumental support OR interventions OR rehabilitation support

Table 3: Database Search Dates and Yields

Database	Final search date	Records retrieved
CINAHL	December 2025	490
MEDLINE	December 2025	610
Scopus	December 2025	680
PubMed	December 2025	830
PsycINFO	December 2025	232

Table 4: Complete PubMed Search Strategy

Search line	PubMed query
#1	("Caregivers"[MeSH Terms] OR caregiver*[Title/Abstract] OR "family caregiver*[Title/Abstract] OR "informal caregiver*[Title/Abstract] OR "family carer*[Title/Abstract] OR "unpaid caregiver*[Title/Abstract])
#2	("Stroke"[MeSH Terms] OR stroke*[Title/Abstract] OR "stroke survivor*[Title/Abstract] OR "stroke patient*[Title/Abstract] OR "cerebrovascular accident*[Title/Abstract] OR CVA[Title/Abstract])
#3	(preparedness[Title/Abstract] OR readiness[Title/Abstract] OR "caregiver competence"[Title/Abstract] OR competenc*[Title/Abstract])
#4	("Resilience, Psychological"[MeSH Terms] OR resilience[Title/Abstract] OR "family resilience"[Title/Abstract] OR adaptation[Title/Abstract] OR coping[Title/Abstract] OR "coping capacity"[Title/Abstract])
#5	("Social Support"[MeSH Terms] OR "support system*[Title/Abstract] OR "social support"[Title/Abstract] OR "informational support"[Title/Abstract] OR "emotional support"[Title/Abstract] OR "instrumental support"[Title/Abstract] OR intervention*[Title/Abstract] OR "rehabilitation support"[Title/Abstract])
#6	#1 AND #2 AND (#3 OR #4 OR #5)
#7	("2020/01/01"[Date - Publication] : "2025/12/31"[Date - Publication]) AND (English[Language] OR Malay[Language])
#8	#6 AND #7

Study Selection Process

All retrieved records were deduplicated and screened in two stages: title and abstract screening followed by full-text eligibility assessment. Two reviewers (NS and NNAG) independently screened records, with disagreements resolved through discussion and consultation with a third reviewer (AM) when required. During the present revision, the included-study set was also checked against the stated stroke-specific population criterion.

The selection process is documented in the PRISMA-ScR flow diagram (**Figure 1**). Of the 2,842 records identified, 1,547 duplicates were removed before screening, leaving 1,295 records for title and abstract screening. After screening, 136 reports were sought for retrieval and assessed for eligibility. A total of 104 reports were excluded, and 32 studies were included in the final review.

Data Extraction and Management

Data were charted using a standardised form developed by the research team. The charted information included author, year, country or data context, study aim, design, sample size, participant characteristics, data collection method, key construct, and main findings. Two reviewers (NS and NNAG) independently extracted and cross-checked the data, with discrepancies resolved through discussion and

consultation with AM where necessary. Microsoft Excel was used for data management. For the final journal version, the extraction sheet should also be used to add the exact preparedness/resilience/support measure or conceptual framework and caregiving stage.

Quality Appraisal

Formal methodological quality appraisal was not undertaken because appraisal was not required to answer the review objective, which was to map the extent, characteristics, and conceptual patterns of the evidence rather than determine intervention effectiveness. Consequently, studies contributed to the synthesis regardless of methodological rigour, and the findings should be interpreted as a map of available evidence rather than a graded statement about evidence strength (20).

Data Synthesis

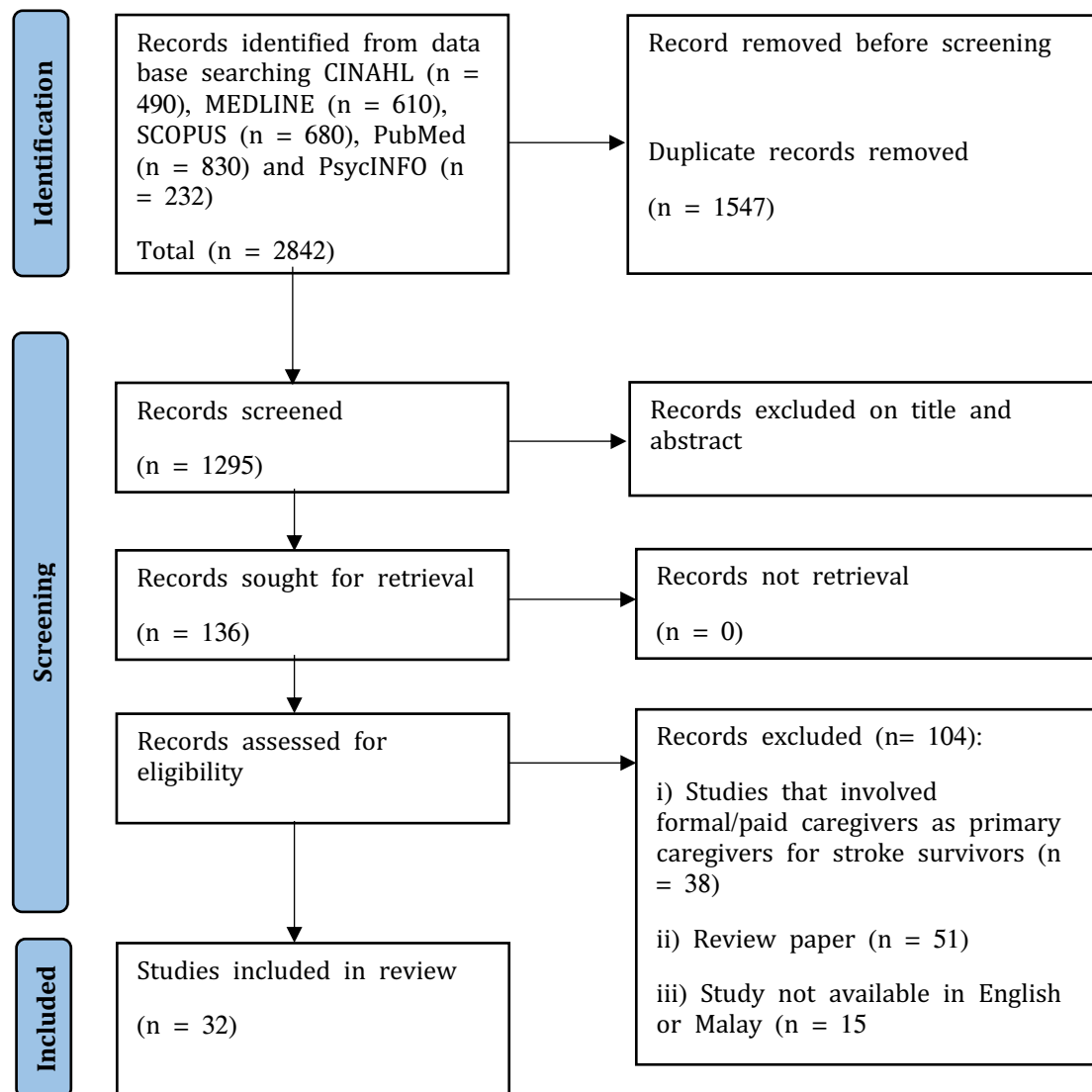
The charted data were synthesised descriptively and narratively. Study characteristics were summarised to describe geographical or data context, research design, sample size, and the distribution of evidence across preparedness, resilience/adaptation, and support.

A combined deductive and inductive approach was used for synthesis. Preparedness,

resilience/adaptation, and support systems were predefined synthesis domains because they reflected the review questions; they were therefore not treated as themes that emerged independently from the data. Within each domain, additional subdomains were developed inductively from the charted findings. NNAG conducted the initial coding,

NS reviewed the coding and domain structure against the extracted data, and disagreements were resolved through discussion, with AM consulted when necessary. Attention was given to separating coping responses from external support resources and to avoiding causal interpretation of associations reported in cross-sectional studies.

Figure 1: PRISMA-ScR Flow Diagram of Literature Search and Study Selection



RESULT

Characteristics of Included Studies

The 32 included studies were conducted between 2020 and 2025 across diverse geographical regions (**Table 4**). Asian studies were conducted in Malaysia (10,11), Indonesia (25,30,31,38), Thailand (49), Singapore (47), China (23,26,27,32-34,50,51), and Türkiye

(22,28). African studies were conducted in Ghana (36) and Nigeria (37); the Oceanian study was conducted in New Zealand (45); and European studies were conducted in the United Kingdom (42), Spain (24), Sweden (41), Denmark (48), Portugal (44), and Italy (29). Studies from the Americas were conducted in Canada (40), the United States (39), and Brazil (35), while Middle Eastern studies were conducted in Saudi Arabia (46) and Iran (43).

Fifteen quantitative studies were retained: 13 cross-sectional studies (11,22-28,30-34) and two longitudinal studies (29,35). The quantitative evidence therefore remained dominated by single-time-point associations. Fifteen qualitative studies were identified, including phenomenological, qualitative descriptive, grounded theory, participatory action research, and longitudinal qualitative approaches (10,36-49). Two explanatory sequential mixed methods studies were conducted in China (50,51).

Qualitative studies generally used smaller samples than quantitative studies. San et al. included nine Indonesian caregivers (38), while Tyagi et al. included 61 participants in Singapore (47). Quantitative samples ranged from 59 caregivers in Septianingrum et al. (31) to 413 caregiver-survivor dyads in Xu et al. (33). Differences in sample composition, caregiving stage, survivor dependency, and

measurement approach limited direct comparison across studies.

The evidence was also unevenly distributed by construct. Preparedness was examined directly in a smaller subset of studies than resilience/adaptation and support-related experiences, and resilience was variously conceptualised as individual resilience, family resilience, adaptation, coping capacity, or caregiving ability. These variations are important because similarly labelled findings may not represent identical constructs.

Malaysia contributed two included studies, one qualitative (10) and one quantitative study of unmet needs (11). Neither provided longitudinal or intervention-based evidence on how preparedness and resilience change over the caregiving trajectory. The Malaysian evidence therefore remains limited in both the number of available studies and methodological diversity.

Table 4: Characteristics and Primary Synthesis Domains of Included Studies on Preparedness, Resilience, and Support Systems Among Family Caregivers of Stroke Survivors

No.	Author and Year	Country	Design and Sample	Data Collection	Key Findings	Primary synthesis domain(s)
1	Aydın & Karabacak (2024) (22)	Türkiye	Cross-sectional quantitative, 167 caregivers	Self-administered questionnaire	Caregivers reported moderate to low preparedness and moderate stress. Higher patient independence was associated with higher caregiver preparedness and lower perceived stress.	Preparedness
2	Fang et al. (2022) (23)	China	Cross-sectional quantitative, 245 caregivers	Self-report questionnaires	Care burden was positively associated with depressive symptoms and negatively associated with resilience. Resilience partially mediated the relationship between burden and depression.	Resilience
3	Gutierrez et al. (2022) (24)	Spain	Cross-sectional quantitative, 172 caregivers	Self-report questionnaires	Preparedness was positively associated with resilience and negatively associated with burden. Training needs included coping, services information, medication, and technical skills.	Preparedness; Resilience; Support
4	Handayani et al. (2024) (25)	Indonesia	Cross-sectional quantitative, 134 caregivers	Self-report questionnaires	Higher caregiver burden was associated with poorer quality of life. Resilience reduced the negative impact of burden on quality of life.	Resilience
5	Li et al. (2024) (26)	China	Cross-sectional quantitative, 350 caregivers	Self-administered questionnaire	Illness uncertainty and perceived stress were negatively associated with family resilience. Perceived stress partially mediated the relationship between uncertainty and resilience.	Resilience

6	Liu et al. (2020) (27)	China	Cross-sectional quantitative, 306 caregivers	Self-administered questionnaire	Preparedness was negatively associated with disease uncertainty and positively associated with stroke knowledge. Education, caregiving experience, uncertainty, and survivor factors predicted preparedness.	Preparedness
7	Özkan (2024) (28)	Türkiye	Descriptive cross-sectional, 130 caregivers	Self-report questionnaires	Caregivers had moderate preparedness and high spiritual well-being. Spiritual well-being was positively associated with caregiving preparedness.	Preparedness
8	Pucciarelli et al. (2022) (29)	Italy	Longitudinal quantitative dyadic, 222 survivor-caregiver dyads	Self-report questionnaires	Caregiver preparedness protected survivor quality of life by moderating the effects of depressive symptoms on communication, mobility, and daily activities.	Preparedness
9	Rusti et al. (2022) (30)	Indonesia	Cross-sectional quantitative, 229 caregivers	Self-report questionnaire	Socioeconomic status and ethnicity were significant determinants of family resilience. Values, beliefs, and rules were the weakest resilience component.	Resilience
10	Sidek et al. (2022) (10)	Malaysia	Phenomenological, caregivers and healthcare providers	In-depth interviews	Caregivers felt overwhelmed and unprepared. Key needs included stroke care information, psychological support, rehabilitation access, and stronger community-based services.	Preparedness; Support
11	Mohd Zawawi et al. (2023) (11)	Malaysia	Quantitative, 263 caregivers	Self-administered questionnaire	91% of caregivers reported at least one unmet need. Financial support (72.5%) and professional support for caregiver well-being (59.2%) were most prevalent.	Support
12	Septianingrum et al. (2024) (31)	Indonesia	Cross-sectional quantitative, 59 caregivers	Self-report questionnaires	Caregiver readiness was moderate. Age, gender, income, occupation, marital status, and knowledge were associated with readiness, with gender as the strongest factor.	Preparedness
13	Wang et al. (2022) (32)	China	Cross-sectional quantitative dyadic, 306 dyads	Self-report questionnaires	Higher resilience was linked to lower illness uncertainty and better caregiving ability. Education, income, age, and health influenced resilience and caregiving ability.	Resilience
14	Xu et al. (2024) (33)	China	Cross-sectional quantitative dyadic, 413 dyads	Self-administered questionnaires	Higher caregiver burden was associated with lower family resilience and lower caregiver capacity. Family resilience mediated the burden-capacity relationship.	Resilience
15	Zhu et al. (2024) (34)	China	Cross-sectional descriptive, 119 caregivers	Self-administered questionnaire	Caregivers of survivors with poorer function reported higher burden and lower family resilience. Care burden was negatively associated with family resilience.	Resilience
16	Day et al. (2023) (35)	Brazil	Longitudinal quantitative, 48 family caregivers	Structured questionnaires	Spouse and non-spouse caregivers experienced burden over time. Non-spouse caregivers reported higher isolation and general strain; functional dependency influenced burden profiles.	Support/context
17	Atsu et al. (2023) (36)	Ghana	Descriptive phenomenology, 37 family caregivers	One-to-one interviews	Caregivers had limited stroke knowledge, felt poorly prepared, and experienced emotional, physical, social, and	Preparedness; Resilience; Support

18	Farombi et al. (2024) (37)	Nigeria	Qualitative, 18 family caregivers	Focus group discussions	financial strain. Coping included prayer, fasting, and other informal strategies. Caregivers reported insufficient information and training, emotional and physical challenges, and the need for structured caregiver education and support.	Preparedness; Support
19	San et al. (2024) (38)	Indonesia	Phenomenological, 9 caregivers	In-depth interviews	Caregivers experienced sleep deprivation, physical exhaustion, social isolation, and financial strain. Support needs included respite care, financial assistance, and education.	Preparedness; Support
20	Zara et al. (2023) (39)	United States	Qualitative phenomenological, 10 caregivers	Semi-structured interviews	Social support and support groups helped caregivers cope with changed responsibilities, stress, work-life balance issues, and family expectations.	Support
21	Garnett et al. (2022) (40)	Canada	Qualitative, 22 caregivers and 18 healthcare providers	In-depth interviews	Service use was influenced by financial constraints, transport issues, trust in providers, limited-service information, and informal support networks.	Support
22	Kristensson et al. (2020) (41)	Sweden	Qualitative, 14 family caregivers	Semi-structured interviews	Caregivers reported changing information needs, lack of continuity, and the importance of being acknowledged by healthcare providers.	Support
23	Malewezi et al. (2022) (42)	United Kingdom	Qualitative, 16 caregivers	Face-to-face interviews	Caregivers experienced emotional and physical effects, financial strain, information gaps, lack of respite, and unmet emotional support needs.	Preparedness; Support
24	Nooreddini et al. (2025) (43)	Iran	Qualitative, 15 caregivers	In-depth interviews	Resilience was reflected in stress management, spiritual and cognitive self-care, healthy lifestyle, social relationships, and help-seeking.	Resilience
25	Pereira et al. (2023) (44)	Portugal	Longitudinal qualitative, 24 participants	In-depth semi-structured interviews	Adaptation after discharge involved managing change, balancing support, and shifting priorities over time. Ongoing tailored professional support was important.	Preparedness; Resilience; Support
26	Qureshi et al. (2022) (45)	New Zealand	Qualitative, family caregivers of stroke survivors	Semi-structured interviews	Resilience was affected by emotional distress, sudden role changes, financial stress, exclusion from care planning, and the need for coping and communication skills.	Resilience; Support
27	Tunsi et al. (2025) (46)	Saudi Arabia	Descriptive exploratory qualitative, 20 caregivers	Semi-structured interviews	Caregivers experienced emotional strain, healthcare navigation barriers, disrupted daily living, social isolation, and resilience through faith, meaning, and social connections.	Resilience; Support
28	Tyagi et al. (2021) (47)	Singapore	Qualitative descriptive, 61 participants	Semi-structured interviews	Support systems were shaped by culture, caregiver identity, family roles, and relationship dynamics. Spouse and adult-child caregivers used different support arrangements.	Support
29	Lobo (2023) (48)	Not geographically bounded	Grounded theory using literature and social-media-derived caregiver data	Literature and social-media data	Caregiver needs were grouped into information, involvement, self-care, and support. Tailored information and caregiver involvement were emphasised.	Support
30	Chaknum et al.	Thailand	Participatory action research,	Group discussions,	The caring model emphasised problem assessment,	Resilience; Support

	(2023) (49)		14 family caregivers	observations, home visits, telephone, LINE app, field notes	collaborative strategies, caregiver self-care, and healthy family dynamics.	
31	Han et al. (2024) (50)	China	Explanatory sequential mixed methods, 242 family caregivers	Questionnaires and semi-structured interviews	Family resilience was above medium level. Family functioning, social support, self-efficacy, and caregiver burden shaped resilience.	Resilience; Support
32	Ye et al. (2024) (51)	China	Explanatory sequential mixed methods, 379 survivors and 15 dyads	Questionnaires and semi-structured interviews	Social support strengthened family resilience through self-perceived burden and self-efficacy. Adaptation moved from shock to reorganisation and future-oriented coping	Resilience; Support

Preparedness for Caregiving

Conceptualisation and Reported Preparedness

Across the included studies, preparedness involved more than having information about stroke. It included practical caregiving skills, emotional readiness, confidence in providing care, decision-making, medication management, communication with healthcare professionals, and coordination of care (11,27,31,37,41,42,44,47,48). Several studies reported that caregivers felt unprepared when they first assumed the caregiving role, particularly because stroke occurred suddenly, discharge education was limited, or they had little experience managing care at home (10,22,27,31,36-38,41,44,45). Caregivers also reported uncertainty, fear of making mistakes, psychological distress, sleep problems, physical exhaustion, reduced social activities, and financial difficulties. These experiences were reported alongside limited preparedness, but the available studies do not establish that inadequate preparedness directly caused these problems.

Factors Associated with Preparedness

Quantitative studies identified several factors associated with caregiver preparedness, including survivor independence, stroke knowledge, uncertainty, perceived stress, spiritual well-being, caregiver burden, and caregiver or survivor quality of life (22,27-29,31). Higher survivor independence and greater stroke knowledge were generally associated with higher preparedness. In contrast, greater uncertainty, stress, and caregiver burden were associated with lower preparedness. Most of these studies were cross-sectional; therefore, the direction of these relationships cannot be determined. For example, caregivers may feel more prepared

because caregiving demands are lower, or better preparedness may help caregivers manage those demands more effectively.

Transition and Ongoing Preparation Needs

Caregivers reported a need for education that was relevant to their individual caregiving responsibilities, opportunities to practise caregiving skills, involvement in care planning, continued guidance from healthcare professionals, and support after hospital discharge (10,11,37,41,42,44,47,48). These findings indicate that caregiver preparation may need to continue beyond discharge because new needs can arise after caregivers begin providing care at home. One longitudinal dyadic study found that caregiver preparedness moderated the relationship between survivor depressive symptoms and some aspects of stroke-specific quality of life (29). However, this finding alone is not sufficient to conclude that preparedness has a protective effect. Overall, the studies suggest that preparedness should be assessed and supported at different stages of the transition from hospital to home.

Resilience, Adaptation and Coping

Resilience and Associated Factors

Resilience was described as the caregiver's ability to adjust to changing caregiving demands rather than simply the ability to remain emotionally strong. Quantitative studies reported that higher resilience was associated with stronger social support, better family functioning, greater caregiving ability, higher self-efficacy, and more favourable socioeconomic circumstances (23,25,26,30,32-34,50,51). Lower resilience was associated with greater caregiver burden, illness uncertainty, perceived stress, survivor dependency, and poorer caregiver health.

Several studies also examined whether resilience explained relationships between caregiver burden, depression, caregiving capacity, self-efficacy, and quality of life. However, most of these analyses were based on cross-sectional data and cannot determine which factor occurred first.

Coping, Spirituality, and Relational Adaptation

Qualitative studies described several ways caregivers managed the demands of caregiving, including seeking support from family members, engaging in religious or spiritual practices, accepting caregiving as a moral responsibility, finding meaning in the caregiving role, seeking help, practising self-care, and reorganising daily activities (36,39,43,45,46,49). Prayer, fasting, and religious meaning were particularly reported in studies conducted in Ghana, Iran, and Saudi Arabia (36,43,46). In this review, these practices were considered coping strategies or sources of meaning rather than direct measures of resilience. Family and cultural expectations also influenced how caregivers responded to caregiving responsibilities. Some caregivers sought help from others, whereas others viewed caregiving as a family or personal responsibility that should be managed without outside assistance.

Evidence Gaps in Resilience Research

The studies did not use the concept of resilience consistently. Some measured individual resilience, while others examined family resilience, caregiving ability, adaptation, or coping. This variation makes direct comparison across studies difficult. In addition, few studies followed caregivers over time. As a result, it remains unclear whether resilience develops with caregiving experience, helps reduce later distress, changes as the survivor's condition improves or worsens, or depends mainly on family, financial, and healthcare resources.

Support Systems

Forms of Support Reported by Caregivers

Caregivers reported needing several types of support, not only information about stroke. These included practical caregiving education, supervised skills training, clear and individualised information, emotional and psychological support, peer support, respite

care, financial assistance, involvement in care decisions, continued communication with healthcare professionals, and access to community services (10,11,37-42,44,47,48). Family members, friends, and other informal social networks also provided practical and emotional support that helped some caregivers manage changes in daily responsibilities, social isolation, and stress (39,47).

Barriers to Access and Continuity

Several factors affected caregivers' ability to use formal support services. These included limited knowledge of available services, financial cost, transport difficulties, lack of trust in providers, poor continuity of care, limited-service availability, and services that did not match caregivers' individual or cultural needs (40-42,44,47). Therefore, the availability of a service did not necessarily mean that caregivers could access or use it. In Malaysia, one multicentre study found that 91% of caregivers reported at least one unmet need, with financial assistance and professional support for caregiver well-being among the most frequently reported needs (11).

Relationship of Support to Preparedness and Resilience

Participatory and mixed methods studies reported that collaborative care planning, family functioning, self-efficacy, and continued communication with healthcare professionals were relevant to caregiver adaptation and support (49-51). However, the available evidence does not show that support directly causes greater preparedness or resilience. Support may help caregivers manage their responsibilities, but caregivers who are already more confident or able to cope may also be more likely to seek and use available support. Longitudinal and intervention studies are needed to clarify how these relationships develop over time.

Relationships Across the Synthesis Domains

Across the included studies, preparedness, resilience, and support were closely related but represented different aspects of caregiving. Preparedness referred to how ready caregivers felt to provide care. Resilience referred to how caregivers adjusted to caregiving demands over time. Support systems referred to the formal and informal

resources available to help caregivers carry out their role.

The studies did not establish a single sequence in which one of these factors led directly to another. Instead, caregiver experiences appeared to be influenced by several interacting factors, including the level of care required by the stroke survivor, caregiver knowledge and health, coping strategies, family relationships, cultural expectations, financial resources, and access to healthcare and community services. These findings suggest that preparedness and resilience should be understood within the wider caregiving situation rather than as individual caregiver characteristics alone.

DISCUSSION

This scoping review examined recent evidence in three areas: caregiver preparedness, resilience and adaptation, and support systems. The findings show that these areas are related but represent different aspects of caregiving. Preparedness refers to how ready caregivers are to provide care, resilience refers to how they adjust to caregiving demands and changes over time, and support systems refer to the formal and informal resources available to help them. Because most quantitative studies were cross-sectional and most qualitative studies explored experiences at only one point in time, the available evidence cannot determine whether one factor leads directly to another.

Family Caregiver Preparedness

The findings show that being prepared for caregiving involves more than receiving information before hospital discharge. Caregivers needed to manage mobility, medication, feeding, communication problems, behavioural changes, personal care, and possible emergencies after the stroke survivor returned home (10,22,27,31,36-38,41,44,45,48). Therefore, preparedness includes practical caregiving skills, confidence, emotional readiness, decision-making, and the ability to adjust care when the survivor's condition or needs change.

Quantitative studies found that preparedness was associated with stroke knowledge, survivor independence, uncertainty, perceived stress, spiritual well-being, caregiver burden, and quality of life (22,27-29,31). However, these findings do not show that greater

preparedness directly reduces burden or improves resilience. For example, caregivers of survivors who are more independent may have fewer difficult caregiving tasks and may therefore feel more prepared. Similarly, caregivers with better family support or easier access to healthcare services may report greater preparedness because they have more help available. Preparedness should therefore be understood in relation to both the caregiver's abilities and the level of care required by the stroke survivor.

One longitudinal dyadic study found that caregiver preparedness moderated the relationship between survivor depressive symptoms and some aspects of stroke-specific quality of life (29). This finding suggests that caregiver preparedness may also be relevant to survivor outcomes. However, evidence from one longitudinal study is not sufficient to conclude that preparedness has a general protective effect. More studies that follow caregivers over time are needed to determine whether preparedness leads to better outcomes, improves through caregiving experience, or changes as the survivor recovers or becomes more dependent.

The concept of biographical disruption may help explain why providing information alone does not necessarily make caregivers feel prepared (4). Stroke can suddenly change family roles, relationships, daily routines, employment, and expectations about the future while caregivers are also learning new caregiving skills (5-8,44). Caregivers therefore need to adjust both practically and emotionally to their new responsibilities. Their level of preparedness may also differ according to health literacy, previous caregiving experience, relationship with the survivor, financial resources, stroke severity, time since discharge, access to rehabilitation, and communication with healthcare professionals.

The Malaysian studies reported unmet needs related to caregiving skills, emotional support, professional guidance, financial assistance, and access to rehabilitation services (10,11). These findings suggest that caregiver preparation should not end when the survivor is discharged from hospital. Caregivers may require follow-up assessment, further education, and professional support after they begin providing care at home. However, current Malaysian evidence does not establish which type of support is most effective, when

it should be provided, or how frequently caregivers should receive it.

Factors Associated with Caregiver Resilience

The findings suggest that resilience should not be understood simply as an individual's ability to remain emotionally strong. Caregivers' ability to adapt was associated with their family relationships, available support, caregiving ability, self-efficacy, socioeconomic circumstances, and the demands of caregiving. Higher resilience was reported among caregivers with stronger social support, better family functioning, greater caregiving ability, higher self-efficacy, and more favourable socioeconomic circumstances. In contrast, greater caregiver burden, illness uncertainty, perceived stress, financial difficulties, survivor dependency, and poorer caregiver health were associated with lower resilience (23,25,26,30,32-34,45,50,51).

These findings are important because lower resilience should not automatically be interpreted as a lack of personal strength. A caregiver who has financial security, supportive family members, previous caregiving experience, good access to healthcare services, or a survivor who requires less assistance may find it easier to adapt to the caregiving role. In contrast, caregivers managing severe disability with limited financial, family, or professional support may find adaptation more difficult. Therefore, efforts to strengthen resilience should address not only the caregiver's psychological coping but also practical, financial, family, and healthcare needs.

Several quantitative studies examined whether resilience explained relationships among caregiver burden, depression, caregiving capacity, self-efficacy, and quality of life (23,25,33,51). These statistical models showed possible indirect relationships between the variables. However, most of the studies collected data at only one point in time. It is therefore not possible to determine whether resilience reduces later burden, whether lower burden makes it easier for caregivers to remain resilient, or whether both are influenced by other factors such as caregiver health, survivor dependency, family functioning, and available support.

A similar issue applies to the relationship between social support and resilience. Family,

friends, peers, and healthcare professionals may help caregivers adjust to caregiving demands. At the same time, caregivers who are more confident, have higher self-efficacy, or cope more effectively may be more willing or able to seek help and maintain supportive relationships (39,50,51). Future studies should therefore examine not only whether support is available but also whether caregivers seek, receive, and find that support useful.

Religion and spirituality were also important in several qualitative studies. Caregivers in Ghana, Iran, and Saudi Arabia described prayer, spiritual practices, moral responsibility, family commitment, and religious meaning as ways of managing caregiving demands (36,43,46). These beliefs may provide comfort, motivation, and meaning. However, strong beliefs about family or religious duty may also make some caregivers reluctant to admit difficulty or seek outside help. Future studies should therefore examine both the supportive and potentially limiting effects of religious beliefs and family obligations in different caregiving situations.

Support Systems Associated with Preparedness and Resilience

The findings show that caregivers require several forms of support. These include practical caregiving education, opportunities to practise caregiving skills, clear and tailored information, emotional and psychological support, peer support, respite care, financial assistance, involvement in care decisions, continued communication with healthcare professionals, and access to community services (10,11,36-42,44,47,48). Providing information alone may therefore be insufficient. A caregiver may understand how care should be provided but still struggle if there is no physical assistance, transport, respite care, financial support, or access to professional advice when problems arise.

Caregiver support needs also changed after hospital discharge. As caregivers began providing care at home, they faced new difficulties related to the survivor's condition, daily care, family responsibilities, and their own well-being (37,41,42,44). This suggests that support should continue after discharge and should be adjusted according to changing needs. However, the included studies did not determine the most effective type, frequency, intensity, or duration of follow-up support.

The ability to use healthcare and community services was affected by several practical barriers. These included cost, transport, limited awareness of available services, lack of trust in providers, poor continuity of care, limited-service availability, and whether services were appropriate for caregivers' individual and cultural needs (40-42,44,47). Therefore, having a service available does not necessarily mean that caregivers can access or benefit from it. Future interventions should consider whether services are affordable, easy to reach, acceptable to caregivers, consistently available, and responsive to their needs.

The Malaysian evidence demonstrates this problem. In one multicentre study, most caregivers reported at least one unmet need, particularly financial assistance and professional support for caregiver well-being (11). The qualitative Malaysian study also identified difficulties related to rehabilitation access, psychological support, and community-based services (10). Together, these studies indicate that some Malaysian caregivers continue to have substantial support needs after stroke. However, only two Malaysian studies were included, so there is currently insufficient evidence to determine which programmes are most effective for improving preparedness, resilience, or longer-term caregiver outcomes.

Participatory and mixed methods studies identified collaborative care planning, family involvement, self-efficacy, and continued communication with healthcare professionals as potentially useful aspects of caregiver support (49-51). Support groups and informal networks may also provide emotional reassurance and practical knowledge from others with similar experiences (39,47). However, most of the available evidence is descriptive. Intervention studies are therefore needed to determine whether these approaches actually improve caregiver preparedness, resilience, and well-being and whether different caregivers benefit from different forms of support.

Methodological, Cultural, and Gender Considerations

The findings should be interpreted in light of the methods used in the included studies. Twelve of the 14 quantitative studies were cross-sectional, while only two quantitative studies followed participants over time (29,35). Only one qualitative study explicitly used a

longitudinal design (44). Most studies therefore described caregiver experiences or relationships between variables at a single point in time. This provides useful information about the difficulties caregivers experience and the factors associated with preparedness and resilience, but it provides limited information about how these factors change during the caregiving journey.

Another limitation is that the studies did not define or measure the main concepts consistently. Preparedness, individual resilience, family resilience, adaptation, coping, caregiving capacity, and support were measured and described in different ways. As a result, two studies may use the same term but measure different aspects of caregiving, while studies using different terms may actually be examining similar experiences. Future research should clearly define each concept and report the instruments used to measure it so that findings can be compared more accurately across studies.

Cultural factors were also evident across the included studies. Studies from Ghana, Iran, and Saudi Arabia described religion, faith, and moral responsibility as important parts of caregiver adaptation (36,43,46). Studies from Asian settings highlighted family roles, obligations to relatives, shared decision-making, and family functioning (30,47,49-51). Similar factors may influence caregiving in Malaysia, where caregiving responsibilities may be affected by filial expectations, religion, extended-family relationships, employment, and financial circumstances (52-55). However, caregivers from the same ethnic or religious group should not be assumed to have identical experiences. Their beliefs, family resources, financial circumstances, and willingness to seek support may differ considerably.

Women made up a large proportion of caregivers in several included studies (11,31,35,38,42,47,52). However, few studies examined whether caregiving experiences differed between women and men beyond reporting gender as a participant characteristic. Future studies should examine whether preparedness, resilience, caregiving demands, access to support, and caregiver outcomes differ by gender while also considering employment, income, relationship to the stroke survivor, caregiving hours, and responsibility for other family members.

Overall, the findings show that caregiver preparedness and resilience cannot be understood separately from the conditions in which caregiving takes place. The amount of care required by the stroke survivor, caregiver knowledge and health, coping strategies, family support, cultural expectations, financial circumstances, and access to healthcare services may all influence the caregiving experience. Preparedness reflects how ready caregivers are to provide care, resilience reflects how they adjust when caregiving demands change, and support systems provide resources that may assist both processes. Future longitudinal and intervention studies are needed to determine how these factors influence one another over time and which forms of support are most helpful for different groups of caregivers.

CONCLUSION

This scoping review maps recent evidence showing that family caregivers of stroke survivors frequently report limited preparedness, while resilience and support are shaped by interacting personal, relational, cultural, socioeconomic, and service factors. The synthesis clarifies that preparedness, resilience, coping, and support should not be used interchangeably: preparedness concerns readiness for caregiving demands, resilience concerns adaptation as demands evolve, coping concerns specific responses to those demands, and support systems concern external resources. The current evidence base is insufficient to establish temporal or causal relationships among these domains. Longitudinal, mixed methods, theory-informed, and intervention studies are needed to determine how readiness and adaptation develop across the stroke trajectory and which forms of support are effective for different caregiver groups.

LIMITATIONS AND RECOMMENDATIONS

This review has several limitations. First, it was restricted to English and Malay publications, which may have excluded relevant research published in other languages. Second, the 2020-2025 publication period prioritised recent evidence but excluded foundational studies published earlier. Third, the breadth of the scoping review constrained the depth of synthesis within each construct. Fourth, formal methodological quality appraisal was not undertaken, so the findings represent a map

of available evidence rather than a graded assessment of evidence strength. Fifth, the included studies were highly heterogeneous in country, culture, design, sample characteristics, caregiving stage, and measurement of preparedness, resilience, and support. This heterogeneity limited direct comparison across studies and precluded pooled estimates or firm conclusions about the relative importance of factors across settings. Finally, the protocol was not prospectively registered, which limits transparency regarding decisions made before and during the review.

The findings suggest several directions for future research rather than definitive priorities. Longitudinal qualitative, quantitative, and mixed methods studies could examine how preparedness and resilience change across the caregiving trajectory. Theory-informed studies may help clarify relationships among caregiving demands, coping resources, support, preparedness, and resilience. Researchers should consider ethnicity, religion, gender, socioeconomic status, family structure, caregiver experience, survivor severity, and service access as potential contextual influences. Culturally validated measures may improve comparability in Malaysian and other Southeast Asian populations. Intervention studies are also needed to determine whether tailored education, skills training, psychological support, respite, or service-navigation programmes improve caregiver outcomes.

CONFLICT OF INTEREST

The authors declare no conflicts of interest related to this study.

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AUTHOR CONTRIBUTIONS

NS: Conceptualization, methodology, literature search, study selection, data extraction, formal analysis, data interpretation, visualization, and writing original draft.

AM: Conceptualization, methodology, validation, supervision, and writing review and editing.

SMSE: Methodology, validation, data interpretation, and writing review and editing.

NA: Methodology, validation, and writing review and editing.

NNAG: Conceptualization, methodology, validation and writing review.

DECLARATION OF GENERATIVE AI USE

During the preparation of this manuscript, the authors used Grammarly, QuillBot, and ChatGPT to enhance spelling, grammar, language, and punctuation. Following the use of these tools, the authors thoroughly reviewed and revised the content as necessary and assume full responsibility for the final version of the manuscript.

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