

Study Protocol for Development and Validation of a Framework to Promote Preparedness for Caregiving in Family Caregivers of Stroke Survivors

Aniawanis Makhtar^{1*}, Sharifah Munirah Syed Elias¹, Norfadzilah Ahmad², Nor Nadiya Ab Ghani³ & Norliza Suut⁴

¹Department of Special Care Nursing, Kulliyyah of Nursing, International Islamic University Malaysia, Pahang, Malaysia

²Department of Professional Nursing Studies, Kulliyyah of Nursing, International Islamic University Malaysia, Pahang, Malaysia

³Kolej Poly-Tech MARA, Kelantan, Malaysia

⁴Faculty of Medicine and Health Sciences, Universiti Malaysia Sarawak, Sarawak, Malaysia

ABSTRACT

Background: Caring for stroke survivors is a major challenge for many family caregivers in Malaysia who are inadequately prepared for their caregiving responsibilities, particularly during the critical transition from hospital to home. This lack of preparedness often leads to increased stress and burden, which negatively impacts the health and well-being of both the caregivers and stroke survivors. Thus, there is an urgent need to develop a framework to improve family caregiver preparedness in the Malaysian context. The purpose of this study is to develop and validate a framework to promote preparedness for caregiving among family caregivers of stroke survivors.

Methods: This study will be conducted in four phases: a literature review, a quantitative study phase, a framework development phase, and a validation phase. A framework will be developed based on the results of the literature review and the quantitative study. The framework will be validated to ensure its relevance, completeness, and applicability.

Conclusion: The framework will be culturally appropriate and sensitive to the needs of Malaysian family caregivers. It will equip family caregivers with knowledge about the needs of stroke survivors, as well as strategies to manage stress and prevent burnout, ultimately improving caregiving outcomes and the quality of life for both family caregivers and stroke survivors.

Keywords: Preparedness; Family caregivers; Stroke survivors; Framework

*Corresponding author

Aniawanis Makhtar
Department of Special Care Nursing,
Kulliyyah of Nursing,
International Islamic University Malaysia,
Pahang, Malaysia
E-mail: : aniawanis@iium.edu.my

Article History:

Submitted: 23 January 2025

Revised: 14 July 2025

Accepted: 18 July 2025

Published: 31 July 2025

DOI: 10.31436/ijcs.v8i2.430

ISSN: 2600-898X

INTRODUCTION

Stroke is the second leading cause of death and a leading cause of disability worldwide. Its incidence increases as the population ages, with nearly 800,000 people experiencing a new or recurrent stroke each year (1). In Malaysia, stroke is the third leading cause of mortality, and almost half of the stroke survivors have experienced functional dependence at the time of hospital discharge following their first episode of stroke (2,3).

In most developing countries including Malaysia, rehabilitation services for people with stroke are organised in a hospital outpatient unit and provided for less than one year due to resource constraints (4). Domiciliary care in public primary care clinics is only available in four out of thirteen states and is still in the early stages in Malaysia (5). Therefore, family caregivers must take on most of the stroke survivor care responsibilities, for which they are not trained or prepared for. As a result, the recovery of stroke survivors is not as good, and the family caregiver themselves may feel overwhelmed, negatively impacting their health and finances (6).

Due to cultural norms in Malaysia pertaining to family obligation, the family usually assumes the role of caregiver (7). In the case of stroke survivors, the family caregivers provide care and support for the former's therapy and rehabilitation needs (8). This experience can be challenging and impose significant physical, emotional, and financial impacts on the family caregiver (9). Studies have found that family caregivers of stroke survivors experience high levels of stress, depression, and anxiety, with instances of social isolation and financial strain (10).

One of the main challenges they face is the lack of preparation and training for their caregiving role as commonly reported, indicating their need for information and psychosocial support (11). This can lead to caregiver burnout, which may result in a worsening of the patient's outcome (12). In the worst case scenario, stroke survivors receiving care at home are prone to complications such as bedsores, respiratory infections, urinary infections, and joint stiffness; thus, effective prevention of complications can reduce patient pain or suffering, alleviate family expenses, and minimise the country's

expenditures (13). Moreover, research indicates that the caregivers' inadequate preparation creates a second crisis for stroke survivors and their family caregivers as they transition home (6). Preparedness is associated with several positive aspects, such as less burden and anxiety, and can be regarded as a protective factor against negative consequences. Preparedness may also promote stronger feelings of reward, hope, and better health (11). Strategies to improve preparedness not only benefit stroke survivors and family caregivers, but could also reduce hospital readmissions, home care demands, and overall healthcare costs (14). However, it has been documented that Malaysian family caregivers do not receive sufficient preparation for their caregiving tasks, particularly during the transition period from the hospital to home (15).

Therefore, there is an urgent need to develop a framework directed at family caregivers of stroke survivors to make them better prepared for the situation. The Stroke Caregiver Readiness Model (6) highlights the significance of caregiver preparedness in improving outcomes for both stroke survivors and their caregivers. However, as this model was developed within a Western cultural context, it does not adequately capture the unique cultural dynamics, values, and caregiving expectations prevalent in Asian countries such as Malaysia.

Hence, this study aims to develop and validate a framework that promotes caregiving preparedness among family caregivers of stroke survivors. The proposed framework will be culturally appropriate and sensitive to the needs of family caregivers of stroke survivors in Malaysia. Family caregivers can benefit from learning about the specific needs of the stroke survivors they are caring for, as well as strategies for managing stress and burnout.

METHODS

Study Protocol

This study employs a multiphase design to develop and validate a comprehensive framework for promoting preparedness among family caregivers of stroke survivors. This study will be conducted in four phases: literature review, quantitative study,

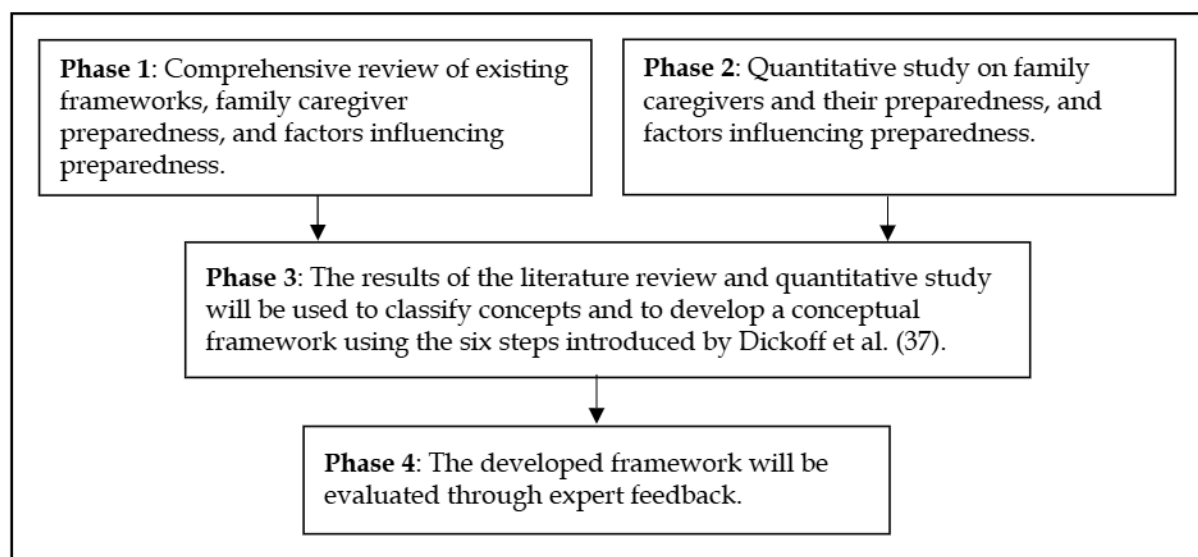
framework development, and validation. A summary of each stage of the project is presented in Figure 1.

Phase 1: Literature Review

This phase aims to explore existing frameworks, describe caregiver preparedness, and identify factors influencing preparedness among family caregivers of stroke survivors. This literature review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (16). Articles will be sourced from several databases including the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (MEDLINE), SCOPUS, PubMed, PsycINFO, and Google Scholar. The inclusion criteria for this literature review are as follows: (1) studies involving family caregivers of stroke survivors; (2) studies conducted with adults older than 18 years old; (3) studies using the terms 'preparedness' or 'readiness';

(4) studies that reported the family caregivers' preparedness to care with no limitations in the assessment scales; (5) studies that included frameworks, models, guidelines, or interventions specifically designed to enhance preparedness among family caregivers; (6) studies that assess the preparedness and factors influencing preparedness in family caregivers; (7) studies employing qualitative and quantitative methodologies; and (8) studies published in English or Malay between 2014 and 2024. Articles that fail to meet the objectives of this review will be excluded. Studies are excluded if they: (1) are based at institutional or formal care facilities; (2) are focused on outcomes without addressing caregiver preparedness; and (3) are focused on digital frameworks to enhance caregiver preparedness. A critical appraisal will be conducted using validated tools such as the Joanna Briggs Institute (JBI) checklist. This step ensures that only high-quality, methodologically sound, and relevant studies are included in the analysis.

Figure 1: Summary of Research Design



Phase 2: Quantitative Research

Study Design

This study will utilise a cross-sectional study design to investigate family caregiver preparedness and the factors influencing the preparedness of family caregivers of stroke survivors.

Setting

The study will entail various sources, including the Sultan Ahmad Shah Medical Centre (SASMEC@IIUM), several branches of the National Stroke Association of Malaysia (NASAM) in Kuantan, Petaling Jaya, Ampang, Melaka, Johor Bahru, and Ipoh, as well as through official social media pages such as the Stroke Caregiver Support Group Malaysia and Stroke Survivors Malaysia.

Population and Sampling

Family caregivers of stroke survivors will be recruited using convenience sampling. The required sample size for this study was calculated using the sample size calculator developed by Arifin (17), based on the outcome parameters reported by Aydin and Karabacak (18), who identified an estimated mean score of 19.47 and a standard deviation (σ) of 7.40. With a 95% confidence level ($Z = 1.96$) and a desired margin of error (d) of 1.0, the minimum required sample size is determined to be 211 participants. To accommodate a potential non-response or dropout rate of 20%, the sample size is adjusted accordingly. As a result, a total of 264 participants will be targeted for recruitment to ensure sufficient statistical power and precision in estimating the population mean.

Inclusion Criteria

The following inclusion criteria should be met to ensure the eligibility of the family caregivers to participate in this study: (a) aged 18 years or older; (b) actively provide care to a stroke survivor diagnosed with any type of stroke (ischemic, haemorrhagic, or transient ischemic attack) including those with recurrent strokes over an extended period; (c) identified as the primary caregiver for the stroke survivor; and (d) provided care for at least one month.

Exclusion Criteria

Family caregivers are excluded if they: (a) provided care as part of paid employment or as professional caregivers; (b) are unable to read or communicate in either English or Malay; (c) are unwilling to participate for the full duration of the study period; (d) are unwilling or unable to provide informed consent; and (e) cared for a stroke survivor institutionalised in nursing homes, long-term care facilities, or rehabilitation centres.

Research Instruments

A bilingual questionnaire in Malay and English will be employed to assess factors associated with caregiver preparedness. The research instruments are detailed as follows:

For Family Caregivers

Sociodemographic Data

Sociodemographic characteristics will be collected, including age, gender, marital status, education level, health status, income, caregiving duration, and other relevant demographic information.

Preparedness for Caregiving

The Preparedness for Caregiving Scale (PCS) developed by Archbold et al. (19) will be used to measure the level of preparedness that the family caregivers perceive in carrying out caregiving activities, including physical care. The scale consists of eight items, each rated on a 5-point Likert scale, ranging from 0 (not at all prepared) to 4 (very well prepared) (19).

The total score ranges from 0 to 32, with higher scores indicating a greater sense of preparedness. The validity and reliability of the tool had been established in the original study, with a Cronbach's alpha of 0.72, indicating acceptable internal consistency (19). This questionnaire has not yet been translated into Malay and will be translated for use in this study.

Quality of Life (QoL)

The Adult Carer Quality of Life Questionnaire (AC-QoL) developed by Elwick et al. (20), is a valid and reliable tool for assessing the quality of life among caregivers. The questionnaire consists of eight domains, each containing five questions, for a total of 40 items. Items are rated on a 4-point Likert scale: Never = 0, Some of the time = 1, A lot of the time = 2, Always = 3. The total score ranges from 0 to 120, with higher scores indicating better quality of life (20).

The AC-QoL has been translated and validated into Malay following standard procedures, including forward and backward translation, pilot testing, and psychometric evaluation to ensure cultural appropriateness and reliability (21).

Caregiving Needs

The Understanding the Needs of Stroke Caregivers questionnaire developed by Mohd Zawawi et al. (22), will be utilised in this study to assess the needs and unmet needs of stroke caregivers. The questionnaire consists of 23 items, of which 10 specifically address unmet needs. These unmet needs are organised into four categories: help with caregiving skills (3 items), support for caregiving and non-caregiving tasks (4 items), emotional support for caregivers (2 items), and financial assistance (2 items) (22). The remaining items explore information provision, changes in relationships after stroke, and participation in stroke support groups (22).

The tool has undergone content validation by four experienced post-stroke care providers and face validation through in-person interviews with stroke caregivers, confirming its content relevance and clarity (22).

Anxiety and Depression

The Hospital Anxiety and Depression Scale (HADS) will be used to assess psychological distress, specifically anxiety and depression, through two subscales. The tool consists of 14 items, with 7 items each for the anxiety and depression subscales. Each item is rated on a 4-point Likert scale, and subscale scores are calculated separately. Each subscale yields a total score ranging from 0 to 21, with higher scores indicating greater levels of anxiety or depression (23).

The Malay version of the HADS has been translated and validated among Malaysian caregiver samples. It demonstrated good psychometric properties, with a Cronbach's alpha of 0.88 for the anxiety subscale and 0.79 for the depression subscale (24).

Coping Strategies

The Brief-COPE (Coping Orientation to Problems Experienced) is a 28-item self-report questionnaire designed to assess effective and ineffective coping responses to stress. It consists of three subscales: problem-focused coping, emotion-focused coping, and avoidant coping. Each item is rated on a 4-point Likert scale, typically ranging from 1 (I haven't been doing this at all) to 4 (I've been doing this a lot). Scores are calculated for each coping

subscale, with higher scores indicating greater use of the respective coping strategy (25).

The Malay version of the Brief-COPE has been psychometrically tested and demonstrated good reliability and validity (26).

Burden

The Zarit Burden Interview (ZBI) is a 22-item self-report instrument used to assess the subjective burden experienced by caregivers. Each item is rated on a 5-point Likert scale, typically ranging from 0 (Never) to 4 (Nearly always). The total score ranges from 0 to 88, with higher scores indicating greater caregiver burden (27).

The Malay version of the ZBI (MZBI) has demonstrated good psychometric properties in assessing caregiver burden among the Malaysian population, with a high internal consistency (Cronbach's $\alpha = 0.898$) (28).

Mutuality

The Mutuality Scale (MS) is used to assess the emotional connection and relationship satisfaction between the caregiver and the care recipient. It consists of 15 items, each rated on a 5-point Likert scale, typically ranging from 1 (not at all) to 5 (a great deal). Higher total scores indicate greater levels of mutuality in the caregiver-care recipient relationship (19).

The MS has been widely used in caregiving research, including studies involving stroke survivors and their caregivers (29). It has shown adequate reliability and validity, with high internal consistency, reporting Cronbach's alpha values between 0.90 and 0.93 in various studies (29). This questionnaire has not yet been translated into Malay and will be translated and culturally adapted for use in this study.

Social Support

The Multidimensional Scale of Perceived Social Support (MSPSS) is a 12-item instrument used to evaluate perceived social support from three sources: family, friends, and significant others. Each item is rated on a 7-point Likert scale, ranging from 1 (Very Strongly Disagree) to 7 (Very Strongly Agree). The total score ranges from 12 to 84, with

higher scores indicating greater perceived social support (30).

The Malay version of the MSPSS has been validated and widely used for assessing social support in Malaysian populations (31). It demonstrated excellent internal consistency with a Cronbach's alpha of 0.85 and good concurrent validity (32).

Religious Beliefs

The Belief into Action Scale (BIAC) is a tool used to assess religious beliefs and their application in daily life. It consists of 10 items, where the first item is scored as either 1 or 10 depending on the response, and the remaining nine items are each rated on a 1 to 10 scale. The total score ranges from 10 to 100, with higher scores indicating greater religious involvement (33).

The Arabic version of the BIAC has demonstrated good psychometric properties, including high internal consistency with a Cronbach's alpha of 0.80, and strong test-retest reliability, with an intraclass correlation coefficient (ICC) of 0.88 (34). This questionnaire has not yet been translated into Malay and will be translated and culturally adapted for this study.

For Stroke Survivors

Sociodemographic Data

Data will be collected on the age, gender, marital status, educational background, stroke subtype, and recurrence history of the stroke survivors.

Level of Dependency

The Modified Barthel Index (MBI), developed by Collin et al. (35), is used to evaluate the physical functional ability of individuals with disabilities, including stroke survivors. It comprises 10 domains: bowel control, bladder control, grooming, toilet use, feeding, transfers, walking, dressing, climbing stairs, and bathing. Each domain is scored on a scale from 0 to 3, based on the level of independence in performing the task. The total score ranges from 0 to 20, with higher scores indicating greater independence (35).

The Malay version of the MBI, included in the Comprehensive Geriatric Assessment Questionnaire, has been translated and validated by Harith and Tan (36). It demonstrated good internal consistency reliability, with a Cronbach's alpha greater than 0.70 (36).

Data Collection Procedure

In Phase 2, the family caregivers will be identified and recruited through three ways. First, family caregivers who accompany stroke survivors to follow-up appointments at the Medical Clinic or Rehabilitation units at SASMEC@IIUM will be approached. Second, contact information for the family caregivers will be obtained through NASAM records. Third, Facebook pages such as the Stroke Caregiver Support Group Malaysia and Stroke Survivors Malaysia will be requested to promote the research via their online networks and newsletters. The researcher will then contact these family caregivers, and those who are interested and meet the study criteria will be invited to participate.

The purpose and format of the questionnaire will be explained to the participants. A cover letter detailing the study and a consent form will be attached to each questionnaire. Family caregivers who agree to participate will be asked to sign the informed consent before completing the questionnaire, which will be returned on the spot. Additionally, other methods, such as telephone calls and Google Forms, will be used. Verbal consent will be obtained from family caregivers who agree to participate. Participants will then have the option to complete the questionnaire through self-administration, a telephone interview, or a Google Form, which will be collected by the researcher.

Data Analysis

Descriptive statistics will be used to summarise participant characteristics and study variables. Normality of continuous data will be tested using the Kolmogorov-Smirnov and Shapiro-Wilk tests. Depending on the distribution, results will be reported as mean $\pm$ SD (normal) or median (IQR) (non-normal). Categorical variables will be presented as frequencies and percentages. For bivariate analysis, t-tests or ANOVA will be used for normally distributed variables, and Mann-

Whitney U or Kruskal–Wallis tests for non-normally distributed ones. Correlations will be assessed using Pearson’s or Spearman’s methods based on data distribution. Multiple linear regression will be conducted to identify predictors of caregiver preparedness. Covariates include sociodemographic factors, caregiving context, psychological variables, social support, and stroke survivor characteristics. Multicollinearity will be checked using VIF, and model fit evaluated with adjusted R^2 , ANOVA, and residual diagnostics.

Phase 3: Development of a Framework

The aim of the study is to develop a framework to promote preparedness for family caregivers of stroke survivors. Framework development will involve classifying concepts based on the literature review and quantitative findings on caregiver preparedness and related factors. The classification of concepts will be

performed using the six steps developed by Dickoff et al. (37) as outlined in Table 1.

To ensure that the framework is culturally appropriate and relevant to the Malaysian context, it incorporates religious perspectives of caregiving, including Islamic values and coping strategies such as prayer and trust in faith, as well as the general recognition of spiritual needs of caregivers from other major religions in Malaysia such as Christianity, Buddhism, and Hinduism. It also respects traditional beliefs and caregiving practices that are common in Malaysian communities. The framework provides for the use of bilingual teaching materials in Malay and English to cater for different literacy levels and language preferences. In addition, it takes into account the dynamics of multi-generational households that are typical in Malaysian families and of which influence caregiving responsibilities and decision-making processes.

Table 1: Steps of Framework Development

Steps	Explanation of steps	Who or what are those?
Step 1: Agency	Who or what performs the activity	People who will implement the framework
Step 2: Recipient	Who or what receives the activity	People who will receive the framework
Step 3: Context	In what context is the activity performed	The place where the framework will be implemented
Step 4: Procedure	The guiding procedure, technique, or protocol of the activity	The path or steps to be taken when implementing the framework
Step 5: Dynamics	Power sources such as agents, recipients, and context to ensure success of the framework	Activities to be performed to ensure success of the framework
Step 6: Terminus	The end point or accomplishment of activity	The end product or outcome of the framework

Phase 4: Validation of a Framework

In the final phase, the developed framework will be evaluated through expert feedback input to ensure its validity, applicability, and effectiveness. The validation will be conducted using a content validation approach through an expert panel review, which involves gathering feedback from professionals with relevant expertise to ensure the framework’s comprehensiveness, applicability, and effectiveness.

Selection of Experts

The selection of experts for the validation process will be based on specific criteria to ensure that the framework is reviewed by individuals with relevant expertise. It has been recommended that there should be at least five members on the panel to avoid chance agreement (38). Experts will be chosen based on their professional experience and knowledge in stroke care, caregiving, mental health, and other related fields. Preference will

be given to professionals with a minimum of five years of experience in clinical practice, research, or education related to stroke rehabilitation and caregiving, as their insights will be critical in evaluating the comprehensiveness and applicability of the framework.

Procedure

The validation process will follow a structured procedure to ensure a thorough evaluation of the developed framework. Initially, the framework will be compiled into a comprehensive document detailing each component, its theoretical foundation, and the anticipated outcomes. This document will be supplemented with relevant materials including guidelines for implementation and a summary of empirical findings from previous research phases. Following the preparation of the review materials, the experts will be formally invited via email. An initial briefing session, conducted either online or in person, will be arranged to explain the purpose of the review, introduce the framework, and clarify expectations regarding their feedback.

The experts will then be given a period of two to four weeks to review the materials provided and submit their evaluations. A structured feedback form will be used to facilitate systematic assessment, focusing on key aspects such as clarity, relevance, comprehensiveness, and applicability of the framework. Specifically, the experts will assess whether the framework's components are clearly defined and understandable, whether they adequately address the preparedness of family caregivers of stroke survivors, whether all essential elements of caregiving preparedness are included, and whether the framework is practical and feasible for real-world implementation.

Content Validity Assessment

The five experts will be asked to rate the content relevance of each item in an instrument using a 4-point rating scale as follows: 1 = not relevant; 2 = unable to assess relevance without item revision or item is in need of such revision that it would no longer be relevant; 3 = relevant but needs minor alteration; and 4 = very relevant.

In this study, the content validity of the framework to promote preparedness among family caregivers of stroke survivors will be determined using the item content validity index (I-CVI) and scale content validity index (S-CVI). The I-CVI will be computed as the number of raters, rating either 3 or 4 on the 4-point relevance scale, divided by the number of experts, that is, the number in agreement on the level of relevancy (39). To achieve acceptable content validity, the I-CVI of the questionnaire should be 1.00 when there are five or fewer content experts, and if there are six or more experts, the recommended I-CVI is at least 0.78 (38,39). As such, revision or deletion of items is recommended if the I-CVI is lower than 0.78 (39). On the other hand, an S-CVI value of at least 0.80 indicates that the scale has acceptable content validity. If the S-CVI value is 0.90 or higher, the content validity of the scale is considered excellent (39).

Ethical Considerations

Ethical approval for this study will be obtained from the Kuliyah of Nursing Postgraduate & Research Committee (KNPGRC), the IIUM Research Ethics Committee (IREC), and the Department of Education and Research, SASMEC@IIUM. An application letter will also be submitted to the NASAM headquarters to seek their approval. Additionally, permission will be requested from the administrators of the Stroke Caregivers Support Group Malaysia and the Malaysia Stroke Survivor social media groups, informing them about the study's purpose, data collection process, and duration. Participants' informed consent will be obtained prior to data collection, tailored to the specific mode of data collection: face-to-face, telephone, and online (Google Form).

DISCUSSION

This study addresses a critical gap in stroke care by developing and validating a framework aimed at enhancing preparedness among family caregivers of stroke survivors. Stroke remains a major cause of mortality and disability globally, and its impact on families in Malaysia is particularly pronounced due to limited rehabilitation services and the heavy reliance on family caregivers.

Existing frameworks, such as the Stroke Caregiver Readiness Model (6), provide important insights into caregiver preparedness, emphasising aspects such as caregiver commitment, capacity, and readiness to manage post-discharge care. However, this model was primarily developed within a Western cultural context, making it less applicable to non-Western settings like Malaysia, where cultural practices, social expectations, and healthcare infrastructures differ significantly.

In contrast, the framework proposed in this study aims to address these gaps by integrating psychological, spiritual, social, and functional dimensions of preparedness throughout the care process that extends beyond the immediate post-discharge phase. By incorporating these broader elements, the framework supports caregivers to better manage the ongoing emotional stress, cultural expectations, and everyday caregiving challenges more effectively.

While existing frameworks have shown effectiveness in reducing caregiver stress and enhancing preparedness for caregiving (6, 40), their long-term applicability in Malaysia remains limited. These models often rely on structured healthcare support, which may be challenging to implement in Malaysia's resource-constrained and culturally diverse caregiving contexts. Moreover, essential elements such as spirituality, local cultural values, and informal support systems are frequently underrepresented, despite their significant role in sustaining caregiver preparedness and mitigating caregiver burden over time. The strength of the proposed framework lies in its comprehensive, culturally sensitive, and integrative approach. The multiphase design, which includes a literature review, quantitative analysis, framework development, and validation ensures thoroughness and rigour. The literature review synthesises existing evidence on caregiver preparedness, while the quantitative phase identifies key factors influencing preparedness, including quality of life, psychological well-being, coping strategies, and social support. Using the six-step approach developed by (37), concepts derived from these phases inform the development of the framework, which is further refined through expert feedback

during validation, ensuring practical relevance.

Specifically, this framework addresses emotional, cognitive, and spiritual aspects of caregiver preparedness and recognises religiosity and family obligations as important motivational factors. It also takes into account unique Malaysian caregiving contexts, such as multigenerational living arrangements and informal support networks, and employs validated instruments specifically adapted to the Malaysian cultural environment. Cultural sensitivity is deeply embedded in this framework through the inclusion of Islamic values and religious coping mechanisms, adaptation of assessment tools and educational resources to local languages and cultural norms, and respect for traditional caregiving beliefs and shared familial responsibilities.

By integrating global caregiving knowledge with local cultural considerations, this framework enhances existing caregiving models, ensuring greater relevance, applicability, and sustainability within Malaysia. Ultimately, this culturally congruent approach contributes significantly to informing policy, shaping practice, and developing caregiver support services that effectively address the long-term well-being of family caregivers.

CONCLUSION

This study contributes significantly to stroke caregiving research by addressing the urgent need for structured and culturally relevant support for family caregivers in Malaysia. The proposed framework provides a practical and evidence-based approach to enhancing family caregiver preparedness, addressing physical, emotional, and financial challenges while promoting better outcomes for both family caregivers and stroke survivors. By integrating cultural considerations, the framework is well-positioned to support Malaysia's caregiving practices and healthcare goals.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

FUNDINGS

This paper is part of research funded by the Ministry of Higher Education Malaysia under the Fundamental Research Grant Scheme (FRGS) IUM/504/14/3/2/FRGS23-313-0922.

ACKNOWLEDGEMENTS

The authors would like to thank the staff and colleagues from the Kulliyah of Nursing, International Islamic University Malaysia, for their input and support in the development of this research protocol.

AUTHORS CONTRIBUTION STATEMENT

AM: contributed to the conception of this theoretical work and critically revised the manuscript.

SMSE: refined the manuscript for final version.

NA: refined the manuscript for final version.

NNAG: performed the literature review and wrote the first draft of the manuscript.

NS: performed the literature review and wrote the first draft of the manuscript.

REFERENCES

- Oza R, Rundell K, Garcellano M. Recurrent ischemic stroke: strategies for prevention. *American family physician*. 2017 Oct 1;96(7):436-40.
- Tan KS, Venketasubramanian N. Stroke burden in Malaysia. *Cerebrovascular diseases extra*. 2022 Mar 24;12(2):58-62.
- Chen XW, Shafei MN, Aziz ZA, Sidek NN, Musa KI. Trends in stroke outcomes at hospital discharge in first-ever stroke patients: observations from the Malaysia National Stroke Registry (2009–2017). *Journal of the Neurological Sciences*. 2019 Jun 15; 401:130-5.
- Azlin N, Aziz NA, Saperi BS, Aljunid SM. Functional limitation and health-related quality of life, and associated factors among long term stroke survivors in a Malaysian community. *The Medical Journal of Malaysia*. 2016 Dec 1;71(6):313-21.
- Ahmad Zubaidi ZS, Ariffin F, Oun CT, Katiman D. Caregiver burden among informal caregivers in the largest specialized palliative care unit in Malaysia: a cross-sectional study. *BMC palliative care*. 2020 Dec; 19:1-5.
- Lutz BJ, Young ME, Creasy KR, Martz C, Eisenbrandt L, Brunny JN, Cook C. Improving stroke caregiver readiness for transition from inpatient rehabilitation to home. *The Gerontologist*. 2017 Oct 1;57(5):880-9.
- Jawahir S, Tan EH, Tan YR, Mohd Noh SN, Ab Rahim I. The impacts of caregiving intensity on informal caregivers in Malaysia: findings from a national survey. *BMC health services research*. 2021 Apr 27;21(1):391.
- Gérain P, Zech E. Informal caregiver burnout? Development of a theoretical framework to understand the impact of caregiving. *Frontiers in psychology*. 2019 Jul 31; 10:466359.
- Gaur R, Asthana SS, Gonnade NM, Ranjan A, Morvadiya D. Repercussions of Caregiving on Caregivers of Stroke Survivors: A Cross-Sectional Study. *Cureus*. 2023 Dec;15(12).
- Tziaka E, Tsiakiri A, Vlotinou P, Christidi F, Tsiptsios D, Aggelousis N, Vadikolias K, Serdari A. A Holistic Approach to Expressing the Burden of Caregivers for Stroke Survivors: A Systematic Review. *InHealthcare* 2024 Feb 29 (Vol. 12, No. 5, p. 565).
- Alvariza A, Häger-Tibell L, Holm M, Steineck G, Kreicbergs U. Increasing preparedness for caregiving and death in family caregivers of patients with severe illness who are cared for at home—study protocol for a web-based intervention. *BMC palliative care*. 2020 Dec; 19:1-8.
- Avcı YD, Gözümlü S. Effect of transitional care model-based interventions for patients with stroke and their caregivers on increasing caregiver competence and patient outcomes: a study protocol for a randomized controlled trial. *Florence Nightingale Journal of Nursing*. 2021 Jun;29(2):176.
- Utaisang A, Pearkao C, Junsevg K, Sangsaikaew A, Boonkong D, Korcharoenyos C. Experiences of family members in caring of stroke patients: a case study in the border provinces of the upper northeast of Thailand. *Open Access Macedonian Journal of Medical Sciences*. 2021 Oct 19;9(G):172-9.
- Lin S, Wang C, Wang Q, Xie S, Tu Q, Zhang H, Peng M, Zhou J, Redfern J. The experience of stroke survivors and caregivers during hospital-to-home

- transitional care: a qualitative longitudinal study. *International journal of nursing studies*. 2022 Jun 1; 130:104213.
15. Tan CE, Hi MY, Azmi NS, Ishak NK, Aziz AF. Caregiving self-efficacy and knowledge regarding patient positioning among Malaysian caregivers of stroke patients. *Cureus*. 2020 Mar;12(3).
16. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, Shamseer L, Tetzlaff JM, Akl EA, Brennan SE, Chou R. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*. 2021 Mar 29;372.
17. Arifin WN. Sample size calculator (web) [Internet]. 2025 [cited 12 July 2025]. Available from: <http://wnarifin.github.io>
18. Aydin A, Karabacak BG. Preparedness of caregivers giving care to stroke patients for caregiving and the stress they perceive. *Turkish Journal of Cerebrovascular Diseases*. 2024;202430(2):104-10.
19. Archbold PG, Stewart BJ, Greenlick MR, Harvath T. Mutuality and preparedness as predictors of caregiver role strain. *Research in nursing & health*. 1990 Dec;13(6):375-84.
20. Joseph S, Becker S, Elwick H, Silburn R. Adult carers quality of life questionnaire (AC-QoL): development of an evidence-based tool. *Mental Health Review Journal*. 2012 Jun 22;17(2):57-69.
21. Khan EE, Arifin WN, Musa KI. Translation, validity and reliability of the Malay version of the Adult Carer Quality of Life Questionnaire (AC-QoL) in informal caregivers of stroke survivors in Kelantan, Malaysia. 2024,
22. Zawawi NS, Abd Aziz NA, Fisher R, Ahmad K, Omar MA, Walker MF. The Unmet Needs of Caregiving Skills, Support, Emotions, and Finances of Stroke Caregivers: A Multicenter Study. *Cureus*. 2023 Aug;15(8).
23. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta psychiatrica scandinavica*. 1983 Jun;67(6):361-70.
24. Yahya F, Othman Z. Validation of the Malay version of hospital anxiety and depression scale (HADS) in Hospital Universiti Sains Malaysia. *Int Med J*. 2015 Apr 1;22(2):80-2.
25. Carver CS. You want to measure coping but your protocol's too long: Consider the brief cope. *International journal of behavioral medicine*. 1997 Mar;4(1):92-100.
26. Yusoff N, Low WY, Yip CH. Reliability and validity of the Brief COPE Scale (English version) among women with breast cancer undergoing treatment of adjuvant chemotherapy: a Malaysian study. *Medical Journal of Malaysia*. 2010;65(1):41-4.
27. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *The gerontologist*. 1980 Dec 1;20(6):649-55.
28. Shim VK, Ng CG, Drahan I. Validation of the Malay version of Zarit burden interview (MZBI). *Malaysian Journal of Psychiatry*. 2017 Dec 1;26(2):3-18.
29. Pucciarelli G, Buck HG, Barbaranelli C, Savini S, Simeone S, Juarez-Vela R, Alvaro R, Vellone E. Psychometric characteristics of the mutuality scale in stroke patients and caregivers. *The Gerontologist*. 2016 Oct 1;56(5):e89-98.
30. Zimet GD, Dahlem NW, Zimet SG, Farley GK. The multidimensional scale of perceived social support. *Journal of personality assessment*. 1988 Mar 1;52(1):30-41.
31. Ng CG, Siddiq AA, Aida SA, Zainal NZ, Koh OH. Validation of the Malay version of the Multidimensional Scale of Perceived Social Support (MSPSS-M) among a group of medical students in Faculty of Medicine, University Malaya. *Asian Journal of Psychiatry*. 2010 Mar 1;3(1):3-6.
32. Din HM, Adnan RN, Akahbar SA, Chin A, Abdullah SA, Minhat HS. Validation of Multidimensional Scale of Perceived Social Support (MSPSS) in Malay Language among Older Adults Living in Community. *Asian Journal of Research in Education and Social Sciences*. 2024 Apr 30;6(1):851-60.
33. Koenig HG, Wang Z, Al Zaben F, Adi A. Belief into Action Scale: A comprehensive and sensitive measure of religious involvement. *Religions*. 2015 Aug 25;6(3):1006-16.
34. Alakhdhair S, Sheets V, Geib R, Alkhuwaili A, Koenig HG.

- Psychometric properties of the Arabic version of the Belief into Action Scale. In *Assessment of Mental Health, Religion and Culture* 2018 Oct 8 (pp. 104-115). Routledge.
35. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. *International disability studies*. 1988 Jan 1;10(2):61-3.
 36. Harith S, Tan SL. Translation and validation of the Malay version of Comprehensive Geriatric Assessment Questionnaire for older adults in Malaysia. *Annals of geriatric medicine and research*. 2020 Jun 10;24(2):115.
 37. Dickoff J, James P, Wiedenbach E. Theory in a practice discipline. I. Practice oriented theory. *Kango kenkyu. The Japanese Journal of Nursing Research*. 1970 Jan 1;3(3):340-66.
 38. Zamanzadeh V, Ghahramanian A, Rassouli M, Abbaszadeh A, Alavi-Majd H, Nikanfar AR. Design and implementation content validity study: development of an instrument for measuring patient-centered communication. *Journal of caring sciences*. 2015 Jun 1;4(2):165.
 39. Polit DF, Beck CT, Owen SV. Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Research in nursing & health*. 2007 Aug;30(4):459-67.
 40. Mohammadi S, Zabolypour S, Ghaffari F, Arazi T. The effect of family-oriented discharge program on the level of preparedness for care-giving and stress experienced by the family of stroke survivors. *Iranian Rehabilitation Journal*. 2019 Jun 10;17(2):113-20