

Association of resilience with caregiver burden in caring for the elderly with stroke; a systematic review

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Objective: To review the construct of resilience and related variables in caregivers caring for older adults with stroke and factors influencing caregiver burden.

Methodology: The review included studies published between February 2009 and February 2024, using the Preferred Reporting Items for Systematic Reviews. The PubMed, Web of Science, Scopus, China Academic Journals, Wan Fang Data Knowledge Service Platform, China Science and Technology Journal Database databases were employed.

Results: In all 18 investigations, 14 quantitative and 2 qualitative were found. Resilience was linked to positive impacts on life satisfaction and emotional pain in these studies. Building robust coping skills can be

facilitated by social support and communication. The majority of the chosen papers employed convenience sampling. Semi-structured interviews were utilized to gather qualitative and quantitative data utilizing resilience-related elements and evaluation tools.

Conclusion: Encouraging caregivers to adopt a resilient coping style helps them feel less distressed about changes in their biopsychosocial and spiritual aspects that come with sickness. A resilient coping strategy can help the caregiver adjust while lowering their risk of stress and strain.

Keywords: Resilience, stroke, elderly, caregiver, care burden, systematic review.

INTRODUCTION

Stroke or cerebrovascular accident (CVA) is an acute disorder, which includes ischemic and hemorrhagic stroke, and causes damage to brain tissue as a result of abruptly rupturing blood vessels in the brain or obstructing blood arteries that prevent blood from entering the brain. It one of the second leading causes of death and third leading cause of disability.¹ Its incidence in the elderly is significantly higher than that the younger population.^{2,3}

Stroke not only affects the patient himself, but also places a heavy burden on his family. Elderly stroke patients are often accompanied by other chronic diseases and functional impairments.⁴ Therefore, the care of older stroke patients involves emotional and physical changes. Caregivers face risks associated with care needs that increase stress and undermine personal performance.

Resilience is a powerful social-psychological capacity that can reduce negative emotions during crises while enhancing adaptability, plays an important role in motivating caregivers to maintain mental health, participate in helping them take care of the anxiety and depression caused by stroke patients and ultimately improve their quality of life.^{5,6} By focusing on the cultural aspect, we can understand resilience more systematically.⁷

Despite the impact of diversity, resilience is a key

strength in helping caregivers overcome the difficulties of caring for stroke patients. However, using disparate findings as evidence-based knowledge to attempt to improve caregiver resilience is limited. There is also a lack of comprehensive research specifically targeting caregivers of stroke patients in Malaysia. The lack of in-depth research on the unique challenges faced by Malaysian caregivers creates a significant knowledge gap.

This paper aims to provide a thorough theoretical and practical basis for improving support for caregivers across Malaysia by analyzing the role of elasticity and its associated psychological factors in emotional distress and well-being.

METHODOLOGY

This systematic review used PRISMA statement for guidelines for published articles.

The PubMed, Web of Science, Scopus, China Academic Journals, Wan Fang Data Knowledge Service Platform, China Science and Technology Journal Database databases were used. The review included studies published in the last 15 years, between February 2009 and February 2024. Quantitative and qualitative empirical studies written in English were included. The following Medical Subject Headings terms in English and Chinese were used for the bibliographic search: regarding the

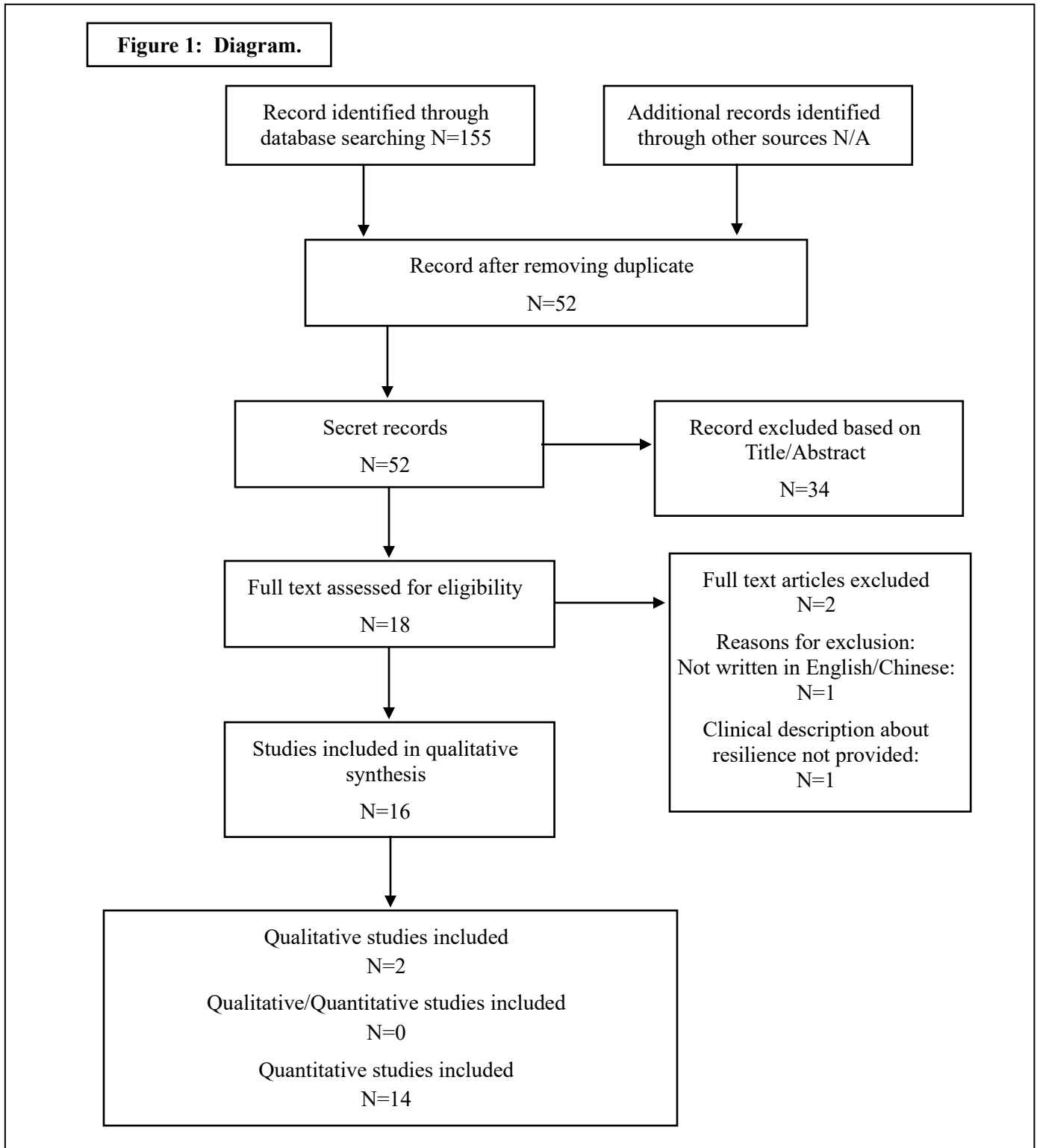


Fig. 1: Prisma diagram.

population, “cares,” caregivers” “caregiver,” and “nursing staff”; regarding the problem, “stroke,” “first stroke,” “Cerebrovascular accident,” and regarding processes, “resiliency,” “resilience”.

Initially, 155 articles were identified. After screening according to the inclusion/exclusion criteria, 18 articles were preselected. In case of disagreement, 3 of the 6 researchers attempted to reach consensus on included

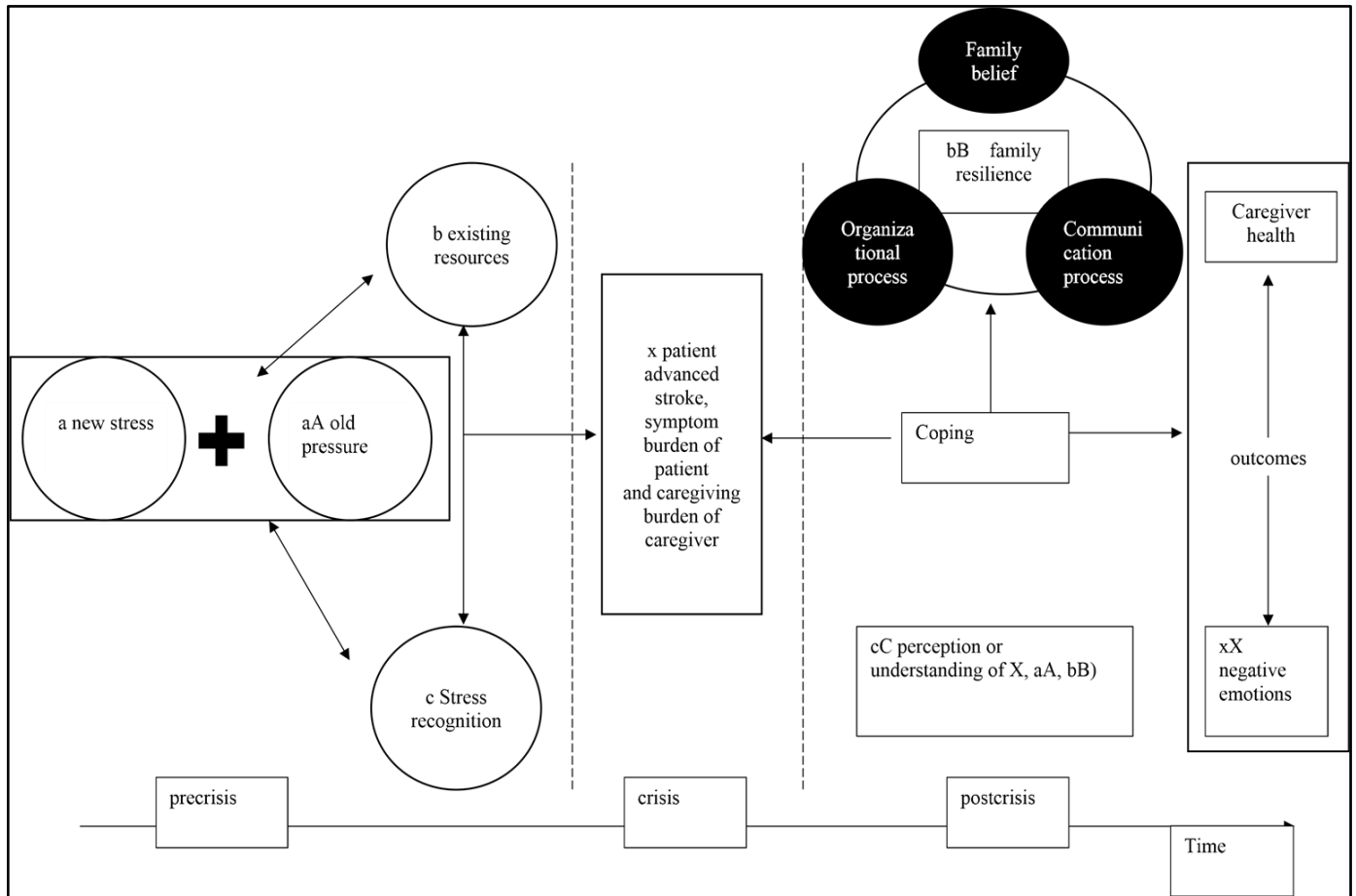


Fig. 2: Family strength and resources.

studies. 1 non-English/Chinese study was excluded. One study was excluded because they did not examine the positive effects of resilience in a clinical context, The full texts of preselected studies were reviewed by a single researcher. Finally, a total of 16 articles were included.⁸⁻²³ (Fig. 1).

Only one summary of the literature¹⁶ is states that the resilience of caregivers. Most used convenient sampling. The samples included the primary caregiver of stroke survivors, most of whom were women. Qualitative studies (n=2) mainly use semi-structured interviews to gather relevant information from caregivers of strokes. By contrast, quantitative studies (n=13) mostly use cross-sectional surveys and vertical studies to describe the data, while summary studies (n=1) are interventions that use a literature summary to evaluate caregiver resilience.

Objective and quality of the studies

A related study²² of the resilience of caregivers in strokes found five dimensions: psychology, social support, personality, psychological elasticity, and cognition. One study⁸ showed a lower level of care burden and a higher quality of life for caregivers with higher psycho-elasticity

scores, response methods and spirituality, while another study¹² identified a regulating role of caregiver resilience in adaptation, significantly lower incidence of primary stroke than recurrence of recurrent stroke, and Wang Jing Yao¹⁸, in the study of family caregivers who survived the primary stroke, had a significant partial indirect impact on their care capabilities through disease uncertainty and recovery.

Resilience of caregiver caring for elderly with stroke

The theoretical framework was built based on the Double ABC-X Model of Family Stress and Coping by McCubbin et al, and Walsh’s Family resilience Framework. The Double ABC-X Model of Family Stress and Coping is a theoretical framework used to understand the process families go through when they experience stress. Developed by Reuben Hill, this model highlights the factors that influence a family's response to stressors. The model consists of four major components: the stressor, the family’s resources and coping strategies, the family’s definition of the stressor, and the family’s ability to manage and cope with the stressor.

The original ABC-X model was expanded to the Double ABC-X model by McCubbin and Patterson, which emphasizes the importance of the “pile-up” of stressors and the family's ability to handle them. which emphasizes that the effect of cognitive appraisal and coping on individual outcomes, also a crisis (X) is not solely determined by the stressor (A) itself, but rather by the interplay of three key factors.

The second is Walsh's Family Resilience Framework, which consists of three key processes in family coping, including family belief, organizational process, communication process. Overall, the framework highlights the importance of family strengths and resources in promoting resilience in the face of challenges. The theoretical framework of this study is shown in Fig. 2. Variables affecting resilience

Most of the research finds that the following five dimensions mainly affect the resilience of caregivers. The mental health of the caregiver is one of the important indicators for assessing their resiliency, covering mental health indicators such as anxiety, depression, and stress levels. Their response strategies are also key factors, including positive response (such as problem-solving, seeking social support) and negative response (e.g. escape, denial).²⁴ Some studies have shown that high resilience scores are linked to positive response strategy.²⁵

In addition, social support from family, friends, communities or professional institutions also has an impact on their resilience.²⁶ Assessing the burden of caregivers in providing care services and their available response resources, such as time, money, energy, etc., are factors that must be taken into account. Individual factors of caregivers include genetic, gene, gender, age, health, etc. can also affect caregiver's resilience levels, some of whom are innately more resilient, and others may need more time and resources to adapt and respond to challenges. Self-efficacy reflects the degree of confidence that caregivers are able to deal with difficulties and challenges effectively.²⁷

Determine factors of resilience

Wang²⁰ discovered a favorable relationship between caregiver quality of life and resilience, indicating that resilience enhances mental health and survival while sharply lowering the risk of stress, anxiety, and depression. A study by Fang et al,¹¹ stated that resilience acts as an intermediary between the care burden and the symptoms of depression, suggesting that more resilient caregivers are less susceptible to the adverse effects of care stress. Resilience can reduce caregiver's negative emotions, such as anxiety, depression, emotional distress,

and can help them adapt actively to the challenges of stroke and help them develop effective response strategies.²⁸

Social support from family, friends and healthcare providers appears to be the cornerstone of the resilience of caregivers.^{17,19,22} Epidemiological studies²⁹ showed that resilience plays a major role in increasing interpersonal and perceptual social support. Several studies included in this review emphasize the protective role of resilience in mitigating the negative psychological consequences of care.^{11,20,21}

A systematic review by Qureshi et al,¹⁶ showed that interventions combining information provision, problem-solving skills training and psychoeducation contributed to improving the resilience of caregivers. Taking everything into account, the reviewed research indicate that resilience is a dynamic phenomenon that arises from the interplay of various personal and environmental elements and may lessen the adverse consequences of providing care for elderly stroke victims.

Care burden experienced by caregivers

Caregivers may suffer from physical exhaustion, pains in their muscles, and injuries as a result of the strain of helping with everyday tasks or transfers. Anxiety, sadness, and a sense of loneliness might be psychological effects of the ongoing stress of providing care. Socially, caregivers who find their spare moments taken by taking care of others may find it difficult to maintain connections and may ignore personal hobbies. When they see their loved one deteriorate or deal with the difficulties of being a caregiver, they might experience feelings of shame, rage, and frustration.

Caregiver burden in stroke care

The elderly have a higher chance of complications from stroke and a more difficult recovery process due to the prevalence of other chronic diseases and health issues. As a result, some elderly persons may pass away or have permanent incapacity.³⁰ The recurrent stroke occurs more frequently in older individuals due to risk factors such as diabetes and high blood pressure. Therefore, in order to prevent recurrence, senior citizen individuals with stroke require long-term monitoring and care.

Factors influencing caregiver burden

The discussion begins with caregivers' own conditions, such as psychological resilience, health level, and social support, may affect their ability to withstand the stress of caregiving. More recent evidence^{8,9,11-13,15,17-19,21-23} has confirmed that caregivers with higher levels of resilience are generally better able to cope with the stress of

caregiving. Positive coping mechanisms including accepting reality, actively seeking out assistance, and seeking solutions to issues are common among those caregivers, and they also have a higher chance of maintaining mental health. In addition, the poor health of caregivers can lead to problems such as physical exhaustion and depression, which will increase the physical and mental burden on caregivers.¹¹

Several studies^{13,19} have reported that the degree of social support caregivers feel is closely related to their level of burden. The support of social networks also plays a positive role in reducing the burden on caregivers.¹⁹ Secondly, the condition and degree of functional impairment of stroke patients are also important factors affecting caregiver burden. Several studies^{13,17} report that the lower the patient's ability to perform daily activities, the higher the need for care, which results in more effort and time required for caregivers, thereby increasing their burden.

A number of studies reported^{11,12,21,23} relationship between the length and severity of a patient's care requirements and the caregiver load that follows. Long-term caregivers tend to experience higher levels of depression and anxiety.

Finally, socioeconomic factors also influence caregiver resilience and burden.^{22,23} Educational level, income, and religious affiliation may influence caregiver burden levels. People with religious beliefs have lower levels of caregiver burden than people without religious beliefs. Current research has uncovered the iceberg tip of the factors affecting the care burden of elderly stroke patients. We need more research to develop effective support to help caregivers cope with stress, improve quality of life, and ultimately provide better care for stroke patients.

Limitations

Firstly, most studies employ a quantitative approach, limiting in-depth understanding of the experiences and perspectives of caregivers. The cultural context of caregiving is not always addressed. Last, most studies focused on caregivers in China, and the generalizability of these findings to other populations needs further investigation.

CONCLUSION

Caregiver resilience is a vital factor in promoting positive outcomes for both stroke patients and their caregivers. By incorporating strategies to assess and promote resilience into routine clinical practice, healthcare professionals can empower caregivers to cope more effectively with the challenges they face and improve the overall well-being of the stroke caregiving dyad.

Future directions

Further research is needed to explore the effectiveness of different resilience-building interventions for stroke caregivers. Additionally, longitudinal studies can provide a deeper understanding of the long-term impact of resilience on caregiver well-being and stroke patient outcomes. Finally, including qualitative research can offer richer insights into the experiences of caregivers and the factors that contribute to their resilience.

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