

Family Experience in Caring for Patients with Stroke: An Integrative Review

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ABSTRACT

Introduction

After suffering a stroke, patients may experience limb paralysis, leading to a negative impact on their life and requiring long-term care both in the hospital and at home by the family. This integrative review identified scientific literature regarding family knowledge, roles, and support in caring patients with stroke.

Methods

This study was conducted as an integrative review. Article searches were conducted using ProQuest, Scopus, PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Ebsco, and Garuda for publications from 2015 to 2024, with full text available in English or in Indonesian. This review was referred on the Whittemore and Knafl framework, and for quality control, we utilized the Clinical Appraisal Prospective Study (CAPS) instrument.

Results

Nine qualitative articles were thoroughly checked and carefully extracted to reach a conclusion regarding family experiences in caring for patients with stroke, emphasizing knowledge, support, and family roles. The need for tailored educational and support programs for families caring for patients with stroke emphasizes the importance of enhancing family knowledge and skills, involving them in care decisions, and providing comprehensive support from healthcare professionals.

Conclusions

The role of the family is crucial in caring for family members with stroke at home. However, this review high light several limitations and challenges in caring for patients with stroke, including a lack of knowledge, skills, and significant economic psychosocial burden. Therefore, families need different types of information support and interventions from health providers in order to carry out their responsibilities optimally.

Keyword

Family role; Family caregiver; Family support; Stroke

INTRODUCTION

Stroke is the second leading non-communicable disease that causes death¹. The incidence of stroke in the general population is around 2-2.5 cases per 1000 population. Every year, more than 62% of strokes occur in people aged 49-70 years, and 34% of sufferers die². Furthermore, data at the North Africa, the Middle East, and Southeast Asia show the greatest increase in ischemic stroke incidence by age, mortality, and the highest morbidity rate³. Therefore, stroke requires very special attention.

Stroke is a medical condition that affects the central nervous system due to blockage of blood flow to the brain. This negative incidence frequently occurred as the result of prolonged and uncontrolled hypertension⁴. Consequently, it causes damage to brain cells due to the lack of oxygen supply and nutrients needed for their normal function. Additionally, some brain cells may also be damaged by sudden bleeding around or within the brain area⁵. Some brain cells can die quickly, while others may be damaged or weakened over a period of several hours⁵. These effects can result in paralysis and permanent limb damage.

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After suffering a stroke, patients may experience limb paralysis, leading to a negative impact on their life and requiring long-term care both in the hospital and at home by the family⁶⁻⁸. Physical and cognitive limitations resulting from a stroke mean that patients still require long-term care at home, particularly in the first 3 months following a stroke⁹. Majority of patients with stroke continue to experience impaired physical activity even 3 years after their initial stroke¹⁰. Despite not reaching expected levels of functionality, patients with stroke, as with other chronic diseases, often return home, facing ongoing limitations^{11,12}. Therefore, the family members involvement in caring for patients with stroke is crucial.

Families play an important role in providing the physical and psychosocial needs of patients with stroke¹³. They assist with daily activities, encourage exercise, and provide emotional support¹⁴. When families provide care at home, it can accelerate recovery, prevent complications, reduce recurrence, and enhance the quality of life of patients with stroke. So, it is necessary for nurses to support and educate families who care for patients with stroke at home. Nurses can provide health education and training in care skills to family members taking on caregiving responsibilities¹⁵. With support and guidance from nurses, the burden of families can be lessened, and their ability to care for patients with stroke can improve, resulting in a more positive experience for everyone involved¹⁵.

In a meta-analysis review conducted by Hamzadeh et al¹⁶ on family adaptation, it was found that family members of patients with stroke respond cognitively and practically and try to balance between providing care for patients with stroke and their daily lives. This review article also emphasized the role of caregivers, including the quality of marital relationships, personal characteristics of family caregivers, the needs and reactions of sick individuals, and the family environment of caregivers to ensure the maximum function of the sick person and minimize the negative impact of being a caregiver¹⁷. Additionally, Cheong et al¹⁸ evaluated the effectiveness of various functional and psychosocial aspect for patients with stroke and their family members¹⁸. However, it is worth noting that none of these review studies discussed knowledge, family roles, and family support in caring for family members who suffer from stroke.

METHODS

This study is a synthesis review of the literature using a systematic method that involved five stages. These stages included establishing inclusion and exclusion criteria of included studies to ensure their relevance and quality, conducting a comprehensive literature search strategy using appropriate keywords and databases, selecting studies that met the criteria using the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow chart to describe the selection process, evaluating the methodological quality of each included article using a valid quality assessment instrument, and extracting relevant data from the selected studies, including the quality assessment, for synthesis and analysis. More specifically, we were focused in exploring the following:

1. How is the family's knowledge of caring for patients with stroke?
2. How is the family's role in caring for patients with stroke?
3. How is the family's support for caring patients with stroke?

Eligibility criteria

The inclusion criteria were determined as follows: 1) Published in English or Indonesian, 2) Original study, 3) Published within 2015 to 2024, 4) Focused on family experiences in caring for patients with stroke, including aspects of knowledge, family roles, and family support, 5) Research participants were adults aged over 18 years. The exclusion criteria were: 1) Review article, 2) Studies related to the development of assessment tools, and 3) Unpublished studies.

Article quality evaluation

Theory from Whittemore & Knafl¹⁹ from Cooper²⁰ was chosen to increase the accuracy of the integrative review. Integrative review allows various study designs to be brought together, thus providing a comprehensive description of a phenomenon¹⁹. The authors jointly assessed the quality of methodological aspect of the 9 selected studies using a critical appraisal tool (Clinical Appraisal Prospective Study [CAPS]) developed by Bowling²¹.

Search strategy

The review method, as updated by Whittemore & Knafl¹⁹



from Cooper²⁰, was selected to ensure the accuracy of this integrative review, as we used in previous review studies²²⁻²⁴. Integrative reviews allow for the inclusion of various study designs, thereby providing a comprehensive description of a phenomenon¹⁹. This review adhered to guidelines for improving accuracy in study searches. An article search was performed in six online databases in December 2023. The databases included ProQuest, Scopus, PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Ebsco, and Garuda. The keywords inserted for the search were “experience”, “family caregiver OR family support” cerebrovascular accident OR stroke”. For Garuda, a database recommended by the Ministry of Education, Culture, Research and Technology, the keywords used were “stroke”, “family experience”, “support”, “role”, and “knowledge”.

Data extraction and quality appraisal

The first search conducted by both authors resulted in 1,353 articles. Titles and abstracts were examined and checked by both authors based on inclusion criteria, focusing on family experiences in caring for patients with stroke. A total of 45 studies were removed, leaving 1304 studies for next screening. Each author was assigned to review the articles and input the relevant information into the extraction table using the Mendeley application. Studies whose titles did not mention family experiences in caring for patients with stroke but referenced related knowledge, support, and family roles were considered acceptable. For duplicate articles, only one version was retained, and the authors reviewed only full-text articles. Ultimately, 9 studies met the inclusion criteria, according to the sampling flow of the selected articles (Figure 1).

We used a tool developed by Bowling²¹, to assessed quality appraisal of the nine selected studies. The ratings were recorded in a table for evaluation and interpretation using a scale of ‘Yes’, ‘Not reported’, and ‘Poor’. The ability to assess both quantitative and qualitative articles was the reason why we chose this evaluation method. As the result, all nine studies were considered to be of high quality. Therefore, we decided that the selected studies were appropriate to be included in the review (Tables 1 and 2).

Ethical clearance: No ethical approval required for review study.

RESULTS

Nine qualitative articles were carefully examined and synthesized to reach conclusions regarding family experiences in caring for patients with stroke, focusing on family knowledge, support, and roles. The studies were conducted in various parts of the world: Indonesia (n=5)²⁵⁻²⁹, China (n=1)³⁰, Thailand (n=1)³¹, Singapore (n=1)³², and Scotland (n=1)³³.

Family knowledge

Of the nine studies analyzed, seven discussed family knowledge in caring for patients with stroke^{26,29,31,32,34,35}. Most studies indicated that family knowledge in this area is still limited and needs improvement^{29,31,35,30}. Important aspects for families to understand include the needs of patients, appropriate treatment methods, prevention of complications, and a comprehensive understanding of the concept of stroke itself.

The role of the family

Explicitly, five articles mention that the role of family is very important in caring for patients with stroke at home^{28-32,35}. The family plays a crucial role in providing care to their members^{26,28-32,34,35}. They help fulfil the daily activity needs of patients with stroke²⁹. However, families often face limited knowledge and skills in providing care, which impacts the physical, psychological, social and economic burden they experience.

Family support

Four articles describe family support as essential for patients with stroke both during their hospital stay and afterwards^(26,27,29,32). This support includes emotional, spiritual, informational, and practical assistance in meeting daily needs²⁹. As a result, family caregivers often face significant challenges due to limited knowledge, skills, physical conditions, and psychological and socio-economic pressures³².

DISCUSSION

The aim of this review is to describe the knowledge, role, and support of families in caring for their family members with stroke.

Family knowledge

Our integrative review revealed that families often have limited knowledge and skills in caring for patients with stroke. This lack of essential knowledge and



information can lead to poor treatment outcomes and inadequate care delivery. Additionally, caregivers often experience physical and emotional changes when caring for patients with stroke. Home care is crucial during the transition period after hospitalization, and caregivers require social support from both the government and family members. Based on these findings, the theory posits that a lack of family knowledge can result in failure to care for patients with stroke at home, leading to negative attitudes among family members ³⁶. Caregiver support and empowerment systems highlight the importance of tailoring interventions and education to meet the specific needs of different caregiver identities. Education and training provided by health professionals can significantly improve family knowledge and skills in caring for patients with stroke ³⁷.

Therefore, families need to receive education and training from health professionals to provide optimal care for patients with stroke, including risk factors, stroke management and secondary prevention as well ³⁸. Interventions and education must be tailored to the specific needs of each family, necessitating the development of customized education and training programs for families or caregivers of patients with stroke involving health professionals. These programs should be designed with the specific needs of each family in mind. The government and related institutions should provide adequate social support for families, including counseling services, information, and other resources. Improved family knowledge and skills in caring for patients with stroke can enhance the quality of care and prevent recurrence through healthy lifestyle practices.

Family role

This review indicated that the families are involved in making care decisions and meeting the physical, financial, and daily needs of patients. However, it does not detail the specific roles of families in caring for members suffering from a stroke, including the types of physical needs and care provided, which are critical aspects of care. Family care theory emphasizes the importance of including families in the care process and in making decisions regarding the care of ill family members ³⁹. A strong family role in caring for patients with stroke can improve the patient's self-concept ⁴⁰. Therefore, families should

be actively involved in decision-making for the care of sick family members, as they are well-acquainted with the patient's condition and needs. The role of the family in meeting the patient's physical needs is crucial, particularly in home care or after discharge from the hospital. Financial support from the family is also necessary to cover the costs of care and treatment, especially for families with limited economic resources. Raising awareness and educating families about their roles and responsibilities in caring for sick family members is essential. Families should be involved in the decision-making process for care and treatment and should receive the necessary support and training. The government and related institutions need to provide access to affordable health services for families with limited economic means. Developing programs or interventions that focus on empowering families in the care of sick family members, especially in meeting physical needs and home care, is also very important.

Family support

The results of the article review indicated that families provide emotional, spiritual support, practical, and psychological assistance to patients. However, the articles did not fully explain the spiritual, psychological, and social support provided by families to patients with stroke. Families also play a role in seeking traditional or spiritual treatment support for patients, but the reviewed articles did not detail the types of traditional and spiritual treatments families provide to patients with stroke. Family care theory supports the importance of family involvement in providing holistic support, encompassing physical, emotional, social, and spiritual aspects ^(41,42).

In addition, family support is crucial for life achievement and can significantly increase patient motivation during the treatment process ⁴³. Emotional, social and spiritual support from the family is crucial for helping patients with stroke in their healing process and adaptation to new conditions. Families need to be equipped with the knowledge and skills to provide appropriate support according to the patient's needs. Support from the broader social environment, such as the community and related institutions, is also necessary to assist families in providing optimal care. Therefore, it is essential to develop education and training programs for families to improve their ability to provide spiritual, psychological, and social



support to patients with stroke. Health professionals should involve families in the care process and provide guidance on the types of support that patients need. The government and relevant agencies need to provide accessible social and psychological support services that can for families and patients with stroke. Developing collaboration between health professionals, families, and communities to provide holistic support to patients with stroke is also important.

The literature provides several important implications for improving the care quality for patients with stroke by families. The review results indicate the need for increased education and regular training for family members to ensure that they have adequate knowledge, skills, and capacity to provide care. Additionally, intensive and continuous psychosocial support from health workers is essential to help families overcome the challenges they face. Developing innovative care models with a collaborative approach among various stakeholders is also crucial for providing holistic support to patients and families. Moreover, more comprehensive quantitative research is needed to precisely map family problems, enabling more targeted interventions. The utilization of digital technologies, such as telehealth and online educational applications, also has the potential to strengthen the family roles in caring for patients with stroke. By addressing these implications, it is hoped that the overall care quality for patients with stroke can be further improved.

This review has some limitations. Few studies explore solutions or interventions to improve family knowledge and support capacity. Additionally, there is limited in-depth understanding of the specific roles of different family members. In addition, quantitative research to comprehensively map the patterns and prevalence of problems faced by families is still very rare. The utilization of modern technology or innovative collaborative care models that can strengthen the role of families is also not optimal.

Understanding the limitations of the current literature can guide future research to significantly contribute to enhancing family knowledge, support, and roles in post-stroke care. This research should aim to produce recommendations that can increase the capacity of family support for patients with stroke.

CONCLUSION

The family role is crucial in caring for family members of patients with stroke at home. However, this review mentioned various limitations and challenges in caring for patients with stroke due to a lack of knowledge, skills, and heavy economic and psychosocial burden. For this reason, families need various forms of information support and interventions from health workers in order to carry out their responsibilities optimally. It is hoped that through collaboration between health professionals, families, patients, and other stakeholders, the best quality of care and support for patients with stroke at home can be achieved. This collaboration will positively impact the quality of life and the development of the patient's condition. By understanding the family perspective through existing research, appropriate and meaningful intervention programs can be developed to achieve optimal family support and holistic patient well-being.

Conflict interests

The author states that there is no conflict of interest.

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AUTHOR'S CONTRIBUTION

Data gathering: NN, AMI

Study design: NN, AMI

Manuscript writing: NN, AMI

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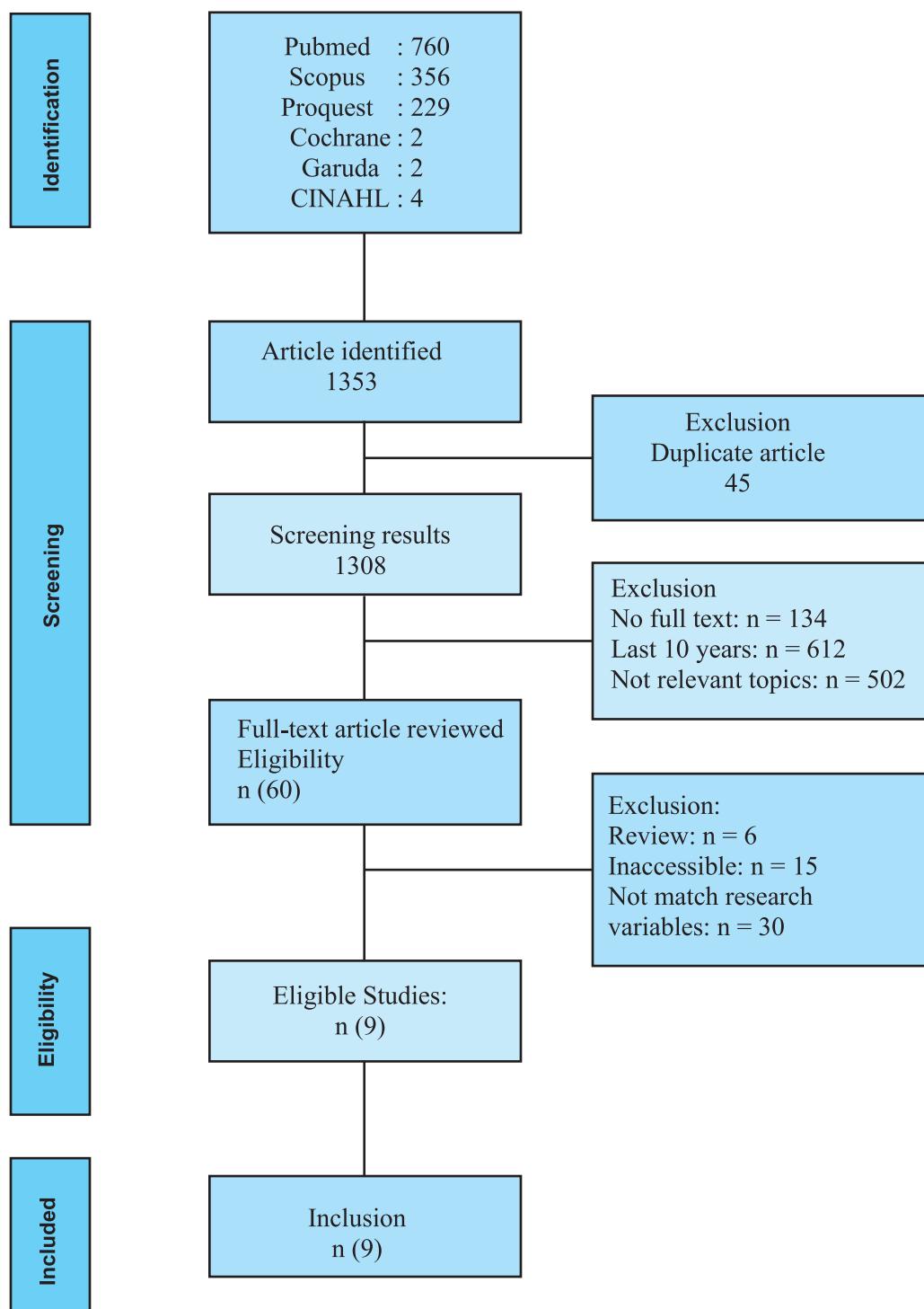


Figure 1. Study Identification, screening, and selection flowchart

**Table 1.** Quality Appraisal

Author	Goals are clearly explained	Study design explained	Appropriate research method	Adequate Description, sample, and exclusion criteria	Ethics presented	Results are clearly Retrieved	The results are in accordance with the study questions and literature	Limitations presented	Implications discussed	Value/level
(Susanti et al., 2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9 High
(Agustiani et al., 2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9 High
(Jiu et al., 2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9 High
(Visvanathan et al., 2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9 High
(Kadarwati et al., 2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9 High
(Tyagi et al., 2021)	yes	yes	yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9 High
(Audia et al., 2017)	yes	yes	yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9 High
(Utaisang et al., 2021)	yes	yes	yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9 High
(Mei et al., 2020)	yes	yes	yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9 High

Table 2. Data Extraction

No.	Author	Country/ Year	Aim	Methods	Sample	Family knowledge	Family role	Family support
1	Susanti et al.	Indonesia/ 2022	Exploring family experiences of patients with stroke.	Qualitative with a phenomenological approach design	12 Patient's family.	Pre- hospital stroke management, its impact on the timing of bringing patients with stroke to the hospital.	-	-
2	Agustiani et al.	Indonesia / 2023	Exploring in depth the family's experience in caring for non-hemorrhagic stroke patients.	Qualitative with a phenomenological approach design	5 family members who have treated patients with stroke at Pangkalpinang Timah Hospital.	Patient needs, medication adherence, non-pharmacological treatments, signs and symptoms of stroke, and the concept of stroke itself.	Healing process and meeting the daily needs and overall well-being of the patient.	Spiritual, psychological, and social support.
3	Jiu et al.	Indonesia /2023	Exploring the experience of family caregivers in caring for patients with stroke.	Qualitative with a phenomenological approach design	14 family members who are caring for patients with stroke.	-	-	Emotional support, spiritual support
4	Visvanathan et al.	Scotland/ 2020	Exploring what support needs the family has during the decision-making process.	Qualitative with semi- structured interviews	24 family members of severe stroke patients were interviewed for the study.	-	Decision-making for the care of family members	-



No.	Author	Country/ Year	Aim	Methods	Sample	Family knowledge	Family role	Family support
5	Kadarwati et al.	Indonesia /2019	Exploring in depth the family's experience of caring for patients with stroke.	Qualitative with a phenomenological approach design	9 family members who provide care to patients with stroke at home in the Jambi city area	Family knowledge in caring for patients with stroke is limited, and this study suggests that families need education and training from health professionals to improve their knowledge and skills in caring for patients with stroke.	Fulfilling physical, and financial needs, as well as meeting the daily needs of the patient.	Social support, practical and psychological assistance from caregivers.
6	Tyagi et al.	Singapore/ 2021	Knowing family support	Qualitative with semi-	26 family caregivers of patients	Caregiver support systems and empower, and emphasize the importance of tailoring	Fulfilling physical needs	Spiritual support, information support, and
				structured interviews	suffering from stroke	interventions and education to address the specific needs of different caregiver identities.		Practical assistance support
7	Audia et al.	Indonesia/2017	Knowing the family experience	Qualitative with a phenomenological approach design	6 Banjar family members and the patients with stroke herself, as well as other family members who acted as secondary informants.	The experience of physical and emotional changes in caregivers, the importance of home care in the transition period after hospitalization, and the social support received by caregivers from the government and family members.	-	Emotional support, seeking traditional medicine support, and spiritual support.
8	Utaisang et al.	Thailand/2021	To understand the experiences of stroke family caregivers and to improve healthcare readiness for patients with stroke and their caregivers.	Qualitative with a phenomenological approach design	16 families	Lack of knowledge and information is important for poor treatment outcomes and care delivery...	-	-
9	Mei et al.	China /2020	Exploring the benefits felt by family caregivers of patients with stroke in Chinese communities	Qualitative with semi-structured interviews	31 primary family for patients with stroke	Knowledge of preventing recurrence through healthy lifestyle practices and acquiring knowledge about stroke and health.	-	Stroke care and social support.



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