



PSYCHOLOGICAL PROBLEMS IN CAREGIVERS OF STROKE PATIENTS SCOPING REVIEW

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ABSTRACT

Stroke is a leading cause of disability. Previous studies revealed that most stroke survivors leave the hospital with varying degrees of disability, often accompanied by limb hemiplegia and other dysfunctions. Caregivers make an important contribution to the health and well-being of stroke patients. This is evidenced by data as much as 25-74% of stroke patients need the help and support of caregivers to assist in various daily activities and to carry out self-management strategies. Therefore the purpose of this study is to identify what psychological problems experienced by caregivers of stroke patients. Methods: The approach used in this article is a scoping review. The purpose of using this approach is to identify findings that have already been done and to identify gaps in the existing literature. Results: Based on the results of the selection of article searches, 1783 literature from PubMed (778 articles), sciencedirect (500 articles) and Ebsco (505 articles) from the results of the analysis of articles that can be taken according to the criteria are 7 articles. Discussion: The 7 articles were selected where there were 14 articles that were the same in the data base to be excluded and the remaining 1769 articles. Of the 1450 articles, 319 articles were excluded because they were not relevant, not original articles and theses. The screening results obtained 312 based on the title and abstract, then excluded articles because they did not fit the inclusion criteria and did not focus on the psychological problems of caregivers of stroke patients, the final selection of full text obtained 7 articles. The sudden job of being a caregiver of a spouse or family member suffering from stroke can have adverse psychological consequences. These findings illustrate the complexity of the challenges faced by caregivers in caring for stroke patients, including psychological impacts such as anxiety, depression and workload experienced by caregivers and associated factors that influence the well-being experienced by caregivers of stroke patients.

Keywords: caregiver; psychological; stroke

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INTRODUCTION

Caregivers make an important contribution to the health and well-being of stroke patients. This is evidenced by data that 25-74% of stroke patients need the help and support of caregivers to assist in various daily activities and to carry out self-management strategies. (Nurse & America, 2014). The earliest research findings in 1981 showed caregivers of stroke patients contributed greatly to the care of stroke patients. The situation of caregivers in Indonesia can be seen from the Central Java Riskesdas data (2018) which shows that stroke patients over the age of 60, as many as 19.44%, experience moderate to severe dependence. This means that stroke patients need care from various parties including caregivers. (Rattani et al., 2022)

Caregivers perform a demanding caregiving role, facing sudden changes in life without fully understanding and preparing for the situation. The acute nature of stroke makes caregivers

insufficiently prepared to adapt to the conditions of the disease and the new role of caring for a family member with a disability. (Em et al., 2017) Caregivers are not only faced with the situation of caring for sick family members but also have to continue to carry out the roles and responsibilities of maintaining the condition of the house that was left behind while accompanying the patient in the hospital. Caring for stroke patients requires caregivers to perform a variety of tasks and feel the difficulty of these tasks. The time needed to care for each day is between 12 to 24 hours. (Ika et al, 2021)

Recent research findings suggest that caregivers experience a range of negative consequences due to the caregiving process. (Bakas T., 2016). Problems arise in the form of significant losses in health and disruptions to life. This is due to the high dependency of patients and changes in patient behavior that require caregivers to provide constant supervision. Other problems arise due to high levels of disabilities, low caregiver care skills, costs related to care and hospitalization costs, long hospitalization times, age and education of caregivers. These conditions can have an impact on the health of caregivers. (Lee Y., 2022)

A reported problem during the first month of caregiving is high levels of emotional stress. (Wu et al., 2022) The patient's prolonged illness plus the patient's disability and additional responsibilities cause excessive stress. (King et al, 2015) and can jeopardize the optimal functioning of the caregiver. The degree of limitation of the patient's activities of daily living and the length of care for stroke patients can also be a burden on caregivers. As a result, caregivers are very vulnerable to health problems, one of which is psychological problems.

Over time, research on caregivers of stroke patients has continued with the aim of understanding various caregiver conditions such as caregiver burden, health problems, and caregiver well-being. (Bakas T., 2016). Other studies show that research on burden risk and psychological health conditions of caregivers is still scarce. (Panzeri et al, 2019) Therefore, the purpose of making a scoping review article is to identify the findings that have been done and the gaps in the existing literature. The step of preparing a scoping review needs to be reviewed to describe what psychological problems experienced by caregivers of stroke patients.

METHOD

This article uses a scoping review approach. The purpose of a scoping review article is to identify existing findings and gaps in the literature. The scoping review followed the five stages described in Arksey & O'Malley's framework. Stage 1: Identifying the research question. The research question used in this scoping review was "what are the psychological problems experienced by caregivers of stroke patients?" Stage 2: Identifying relevant research. The studies used as a review were those that met the following inclusion criteria: a) the participants in the study were caregivers of stroke patients, b) the results of the study were psychological problems experienced by caregivers of stroke patients, c) the research article was quantitative research, d) the year of publication of the research in the 2019-2023 timeframe, and e) research in English and Indonesian. The electronic databases used were Science Direct, ebsco and pubmed. The search for research articles was conducted in September 2023. The keywords used in the search were stroke and caregivers and psychological.

Stage 3: Research selection The first selection was done by looking at relevant titles, while irrelevant ones were excluded and eliminating duplication of articles by using the reference manager, Mendeley. Next, the abstracts of the articles were reviewed and those that met the

inclusion criteria were identified. The full text of the abstracts was read to determine which studies were included in the review. Stage 4: Mapping the data Data extraction was performed in Microsoft Word by creating a table containing several components namely researchers, year of publication, study objectives, study design, study location, interventions used, technology used, participant characteristics, measurement methods, outcome measures and relevant key findings. Stage 5: Compile, summarize and report results. The research is summarized descriptively and compares the review articles. More specific summaries include significant and non-significant outcomes; type of intervention (single or complex); length of intervention; intervention methods and measurement tools used. (Caro, 2018)

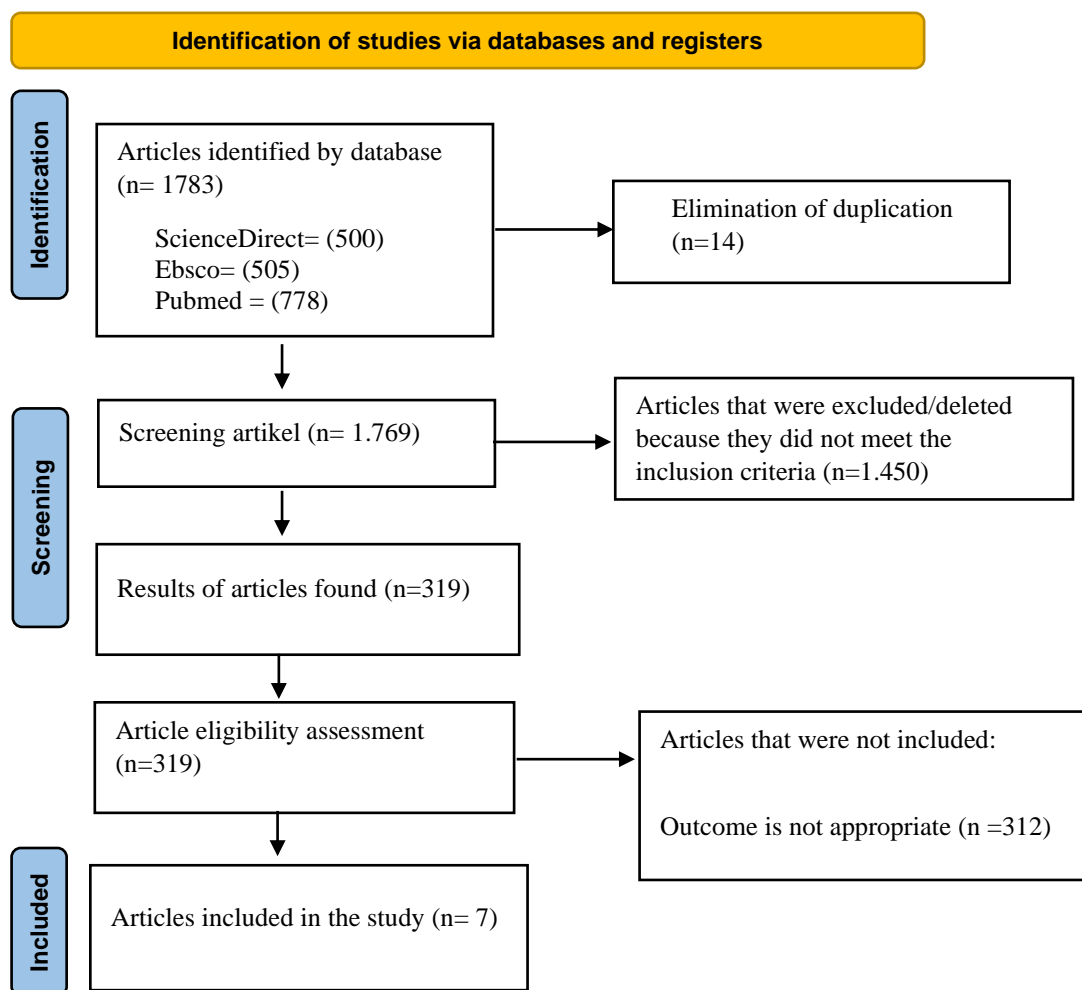


Figure 1. Flow Chart

RESULTS

Based on the results of the selection of article searches obtained 1783 literature from PubMed (778 articles), science direct (500 articles) and Ebsco (505 articles) from the results of the analysis of articles that can be taken according to the criteria are 7. There are 14 articles that are the same in the data base to be excluded and the remaining 1769 articles. Of the 1450 articles, 319 articles were excluded because they were not relevant, not original articles and theses. The screening results obtained 312 based on the title and abstract, then excluded articles because they did not fit the inclusion criteria and did not focus on the psychological problems of caregivers of stroke patients, the final selection of full text obtained 7 articles.

Table 1.
Article Analysis

Article Author Year of publication	Article Title	Methods	Respondents	Results
Ozdalifah omar et al (2021)	Caregiver Depression Among Home-Bound Stroke Patients in an Urban Community	cross-sectional	n=123 Caregivers of post-stroke patients	Respondents who experienced depression were 20.3% (n=25). Depression was associated with caregiver age (CI=42.23-50.09, p=0.016), presence of illness (p=0.001), and being the sole caregiver (p=0.001). There was also an association found between caregiver depression and longer post-stroke duration (CI= 12.75-16.13, (p<0.001) longer time spent caregiving (CI= 117.73-135.87, p=0.004), and more functionally dependent patients (p=0.002).
Kruithof WJ (2019)	Caregiver burden and emotional problems in partners of stroke patients at two months and one year post-stroke: Determinants and predictions	Prospective cohort study	n=183 Caregivers of post-stroke patients	The results of this study indicate that most stroke spouses or caregivers experience heavy burden, anxiety and post-stroke depress symptoms. 1-month post-stroke spouse anxiety symptoms found in this study 53.3% and heavy burden, anxiety and post-stroke depress symptoms after two months of stroke 44.0%.
Sohkhlet G (2023)	Stress in Caregivers of Stroke Patients During Rehabilitation	Quantitative	n=76 Caregivers of stroke patients	The findings showed that out of the total 76 caregivers involved, 51.32% were female, while the remaining 48.68% were male. The average age of the caregivers was 42 years, while the average age of the patients reached 55 years. The duration of care delivery had an average of six months. The perceived caregiver burden score results showed a low level, with an average score of 19.61, indicating that not all forms of assistance were associated with stress levels. This finding was found in the correlation between each measure of burden with the Modified Rankin Scale and the level of disability, which was found to be significantly correlated (r=0.7, P<0.0001). Further investigation showed that caregivers experienced higher levels of stress when patients required physical activities such as exercising, walking, or using restroom facilities.
Wu X, Liang Y (2020)	Care stress in caregivers of disabled stroke patients: a cross-sectional survey	Qualitative	n=242 Caregivers of stroke patients	Most family members experienced high stress when caring for stroke patients with disabilities. Family members' care stress was moderately positively correlated with financial stress (r=0.476, P<0.01). Family members' educational background, financial pressure, hospitalization time, stroke patient dependency, and the degree of family

				members' participation in treatment decision-making during hospitalization were the main sources of care stress (P<0.01).
Serda Em et al (2017)	Psychological health of caregivers and association with functional status of stroke patients	Quantitative	n=76 caregivers of stroke patients	The mean levels of caregiver anxiety (9.73 ± 4.88) and depression (9.81 ± 5.05) in the caregiver group were significantly higher than the control group (p<0.001 each). Significant impairment was seen in their mental and physical health. Regression analysis also showed a significant negative correlation between BI (functional state) scores and HADS (hospital anxiety and depression scale) scores.
Eeeseung Byun ddk (2019)	Depressive symptoms in caregivers immediately after stroke	Quantitative	n=63 Caregivers of stroke patients	Caregivers on average reported mild depressive symptoms at T1 and T2. Each of the following characteristics was independently associated with caregiver depressive symptoms during the first 6 weeks post-stroke: caregiver uncertainty (p < 0.001), perceived stress (p < 0.001) but not cortisol level (p = 0.858 upon waking, p = 0.231 night), coping (p < 0.001), social support (p = 0.006), race (p = 0.022), income (p = 0.001), time spent on care (p = 0.039), and stroke survivor race (p = 0.033) and functional status (p = 0.003). At T2, caregiver depressive symptoms correlated with nighttime cortisol levels (p = 0.001).
Jianting Zhao et al (2021)	Effect of main family caregiver's anxiety and depression on mortality of patients with moderate/severe stroke	a multicenter prospective study	n=111 caregivers of stroke patients	Based on HARS results, 297 (36.26%) primary family caregivers experienced anxiety. The results showed that the age of the caregiver, the patient's NIHSS, the duration of treatment time, treatment time per day>8 hours and self-financing had an effect on the anxiety of the primary family caregiver and showed a significant difference (P<0.05). While the results of the HDRS, 192 (23.44%) primary family caregivers experienced depression. The results showed that caregiver age, patient NIHSS, duration of care time, care time per day >8 hours and self-financing had an effect on depression, and the difference between the two groups was statistically significant (P<0.05).

DISCUSSION

Stroke is a leading cause of disability. Previous studies revealed that most stroke survivors leave the hospital with varying degrees of disability, often accompanied by limb hemiplegia and other dysfunctions. Many patients who survive the acute phase of stroke still experience physical or cognitive impairment and require assistance from professional and/or family caregivers. After a stroke, the life of the spouse often also changes significantly. Caring for a family member requires time as well as physical and emotional effort, and partners may experience heaviness, anxiety or depressive symptoms. Many partners are able to adjust to their new situation. However, some of them show clinically relevant levels of distress and may require some form of support and that may also persist over time. (Camak D, 2015)The sudden job of being a caregiver for a spouse or family member who has suffered a stroke can have adverse psychological consequences. In Indonesia, the majority of stroke patients return home to be

cared for by family members and continue rehabilitation as outpatients. In most urban communities, shared caregiving practices occur among stroke caregivers out of necessity or out of kinship. A single caregiver or primary caregiver sharing a home with a stroke patient will be more physically and psychologically challenged compared to a secondary or combined caregiver. Sharing caregiving responsibilities is believed to ease the burden experienced. (Law S, 2021)

The findings illustrate the complexity of the challenges faced by caregivers in caring for stroke patients, including the psychological impact and associated factors that influence the well-being experienced by caregivers of stroke patients. Articles one and seven provide results that caring for stroke patients provides complex challenges for caregivers, involving psychological impact and associated factors that affect their well-being. The prevalence of depression in caregivers reached 20.3%, and its association was related to factors such as caregiver age, presence of illness, and status of being a sole caregiver. Primary family caregivers also experienced significant levels of anxiety and depression, with caregiver age, patient NIHSS, duration of care time, care time per day of more than 8 hours, and self-financing influencing caregiver anxiety and depression levels of stroke patients. (Guo Y, 2015)

Articles two and five provided results where the levels of burden, anxiety, and depressive symptoms in post-stroke caregivers were high, with most experiencing heavy burden and anxiety symptoms. Factors such as longer post-stroke duration, longer caregiving time, and functional dependency of the patient were associated with higher levels of caregiver depression. The mean levels of anxiety and depression in caregivers were significantly higher compared to the control group. A significant negative correlation was found between patient functional state scores and caregiver anxiety and depression levels. (Saban KI, 2012) Articles three, four and five suggest that caregiver stress increases when patients require physical activities, such as exercise or walking. Caregiver stress was positively correlated with financial pressure, educational background of family members, hospitalization time, patient dependency, and family members' participation in treatment decision-making. (Opara JA, 2017). Factors correlated with depressive symptoms in caregivers included uncertainty, perceived stress, coping strategies, social support, race, income, treatment time, stroke survivor race, and patient functional status. In the next stage, depressive symptoms correlated with nighttime cortisol levels. (Lenonn et al. 2015)

CONCLUSION

Stroke is a leading cause of disability, and most stroke patients require the assistance of caregivers for various daily activities. The scoping review showed the complexity of psychological challenges faced by caregivers, including anxiety, depression, and workload. Increased understanding of these psychological impacts may help improve the well-being of caregivers and stroke patients.

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