Research Article

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Factors Associated Caregiver Burdens among Family Living with Stroke Patient: A Systematic Review

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Abstract

Introduction: *Stroke is a life-changing event that impacts not only people with disabilities, but also their families which is a source of high demands for long-term care, potentially causing a burden on caregivers. This study aims to analyse the factors associated caregiver burdens among family of stroke patients.*

Method: *The method used was a systematic review sourced from journals searched through the Scopus, Science of Direct, WOS and Spinger Link databases published in less than the last 5 years (2018-2023). Keywords adjusted to Medical Subject Heading (Mesh) phrases, namely "Caregiver OR Family AND Burden OR Care OR Caring AND Stroke OR ((haemorrhagic stroke)) OR Stroke OR Disease". Analysis of the results of this study using the PEOS method (Population, Exposure, Outcomes, and Study Design).*

Results: *Study showed that 12 studies according to the specified inclusion criteria. All articles have a design cross-sectional study. The majority of respondents informal caregivers from various countries. The results of the review showed that factors related to caregiver burden in families of stroke patients are patient's condition, time of treatment, education level, income, length of treatment, patient complications, family support.*

Conclusion: *Based on the results found, there are several factors that can affect caregiver burden so that one of the nursing interventions that can be provided is the provision of education related to patient care and the importance of family support in caring for patient with stroke so that it is expected to reduce the burden on caregivers.*

Keywords: Caregivers Burden; Family; Stroke Patients

Introduction

Stroke, or cerebrovascular disease (CVD), is a disease that manifests with blockage or bleeding in the blood vessels that feed the brain. CVD is the second most common cause of death and the leading debilitating disease in advanced societies [1]. Stroke is a life-changing event that impacts not only people with disabilities but also their families and caregivers. Patients and their families may experience various physical, psychological, social, economic, and spiritual. Negative objective and subjective consequences such as psychological problems, physical health problems, economic and social problems, disrupted family affairs, and the and the feeling of having no control over problems arising from all services Such care is defined as the "burden of care. Björk dahl et al., 2007 in Kumar et al. [2]. The patient's transition from hospital to home is critical to maintaining consistent good health care for stroke sufferer [3]. During the rehabilitation period, a training and solving process is carried out problems that aim to reduce the number of patient disabilities by focusing on the condition. Meanwhile, patients with disabilities receive internal medical assistance process focus, nurses who care for patients play a role in the process and very much affected by this process. Moreover, the continuous transition from institutional care to community care makes the impact of delivery stroke care is becoming bigger than before, Han B, H et al., 2011in Kumar et al. [2]. Current epidemiological data shows that 16.9 million people suffer a stroke every year, which represents a global incidence of 258/100,000/year, with striking differences between income countries high and low, and the age-based incidence is 1.5 times higher. in men compared to women [4]. The World Health Organization (WHO) predicted that deaths from stroke would increase with mortality due to heart disease and cancer, from approximately 6 million in 2010 to 8 million in 2030 (American Heart Association, 2010). Ministry of Health of the Republic of Indonesia (2018) stated that non-communicable diseases (NCDs) in Indonesia are experiencing an increase compared to 2013, the prevalence of stroke increased from 7% to 10.9%.

Caregiver burden is a multidimensional concept that includes several aspects such as individual physical and psychosocial aspects and requires balance between variables such as exact timing, economic resources, psychological status (physical and social), role change, and the identification of new roles for care. Morais HCC, Soares AMG, Oliveira ARS, et al. (2012) in Çelik & Kara [1]. The impact of burdens that affect the caregiver's health condition include fatigue, sleep disorders, lack of appetite, headaches, high blood pressure, ulcers. Burden Caregivers also influence emotional conditions including stress, anxiety and worry with the patient's condition [5].

Several factors are thought to influence caregiver burden, including characteristics socio-demographics of the caregiver, level of relationship with the patient, duration of caregiving, shared residency with the patient, responsibilities outside the caregiver role, distractions work. social activities and family routines, detachment from life professional, and financial consequences of the disease Balhara YPS, Verma R, Sharm S, et al. (2012) in Çelik & Kara [1]. These factors and term care length of time in stroke sufferers has a negative impact on the burden on caregivers and quality of life of caregivers Chen Y, Lu J, Wong KS et al. (2010) in Kukreti et al. [6]. Research conducted by Fang et al., it has been reported that 68.4 % of caregiver of stroke patients in China have moderate burden and above burden, which show that the burden of care is serious problem for caregivers [7]. Based on the background above, the author is interested in conducting a systematic review about “factors associated caregiver burdens among family living with stroke patients”.

Research Methods

The method applied in this study is a systematic review. Search process using research from the last 5 years 2018-2023 with 4 data bases, namely Scopus, Science Direct, Web of Science and Spinger Links, writing search results and selecting articles follow protocols and rules with Preferred Reporting Items for Systematic Reviews (PRISMA). Article search using keywords and Boolean system operators (AND OR NOT). Keywords in a systematic review adjusted to Medical Subject Heading (Mesh) phrases, namely “Caregiver OR Family AND Burden OR Care OR Caring AND Stroke OR ((haemorrhagic stroke)) OR Stroke OR Disease”. This research used the population, exposure, outcomes, and studies (PEOS) framework to determine the criteria.

Table 1. PEOS Framework

PEOS	Inclusion Criteria	Exclusion Criteria
Population	Informal unpaid caregivers (family member aged ≥ 18, man and women, have the main responsibility for patient care, and to be living with the patient)	Formal caregiver (Nurse, paid caregivers)
Exposure	Stroke patients	Uninvolved studies stroke patient
Outcomes	To find out the factors associated caregiver burdens among family living with stroke patients	Not discussing about load-causing factors caregivers’ burden
Study Design	Cross-Sectional	Review and analysis: literature review, systematic review, meta-analysis, except cross-sectional study
Publication Years	2018-2023	Under 2018 and above 2023
Language	English	Other international Language

The inclusion criteria in this systematic review were articles retrieved within 5 years lastly, using the cross-sectional method, the population was informal caregivers of stroke patients. The aim of this systematic review is to determine the factors that contribute the caregiver’s burden among family living with stroke patients. Article selection is carried out with screening based on language, year, open access, full text, duplicates (Mendeley), word key, title, abstract to search for articles that meet the requirements

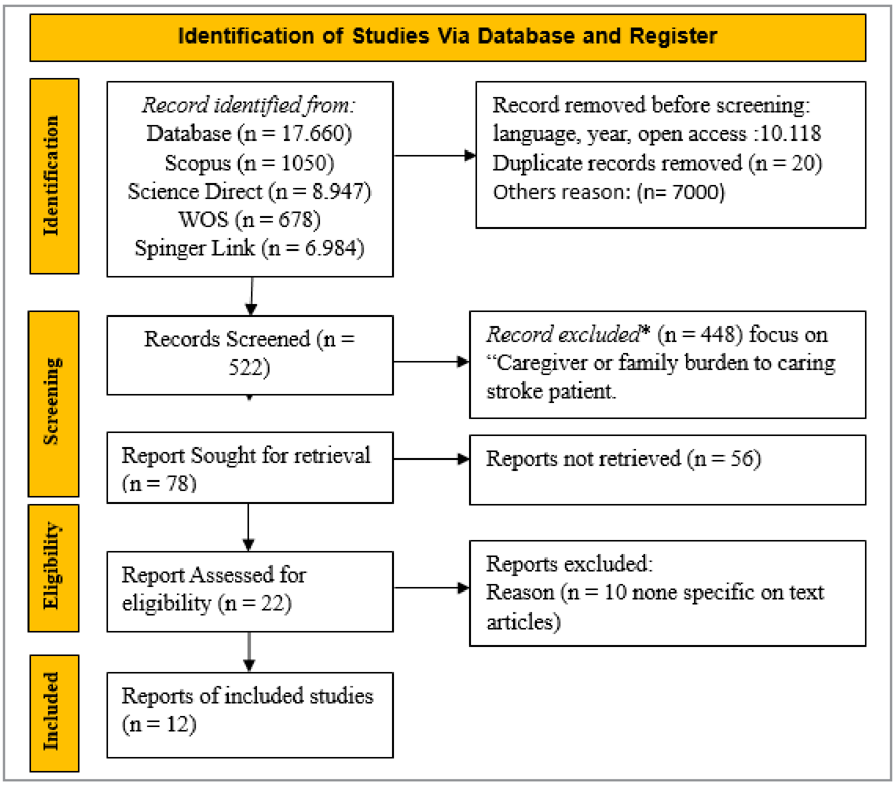

Figure 1 PRISMA Flow or Article Selection Process.

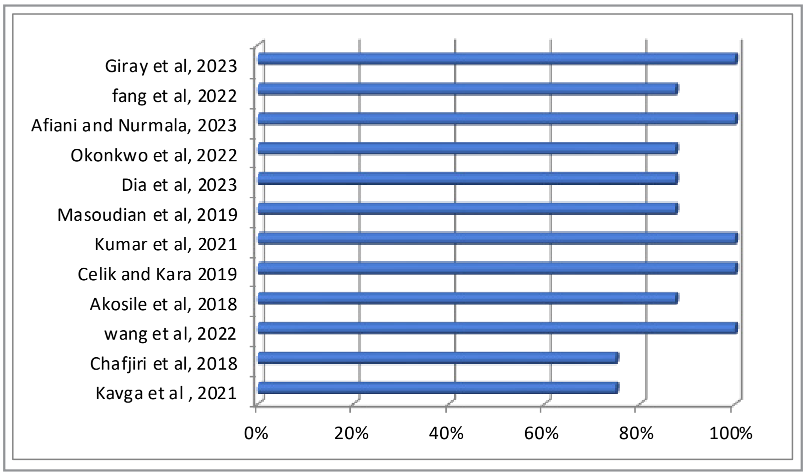

Figure 1 Risk of Bias

Figure 1: Displays the overall risk of assessment bias. Most studies that have been risk analysed typically use JBI with a Cross-Sectional design and have been met the criteria of more than 70 % so that 12 articles are suitable for use.

Table 1. PEOS Framework

S.no	Title and Author	Method: Design, Sample, Variable, Instrument, Analysis	Result
1.	The effects of patients' and caregivers' characteristics on the burden of families caring for stroke survivors, [8]	D: Cross- Sectional Study and correlational S: 109 patients and caregivers V: Characteristics Patients and caregivers, family burden I: Questionnaire and scale A: Analysis was performed using IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY, USA: IBM Corp	Caregiving burden is associated with patient and caregiver characteristics. The patient's education level, the number of family members living at home, the presence of equipment and facilities in the house, and the length of treatment associated with greater perceived burden. Based on caregiver characteristics, those in good health had a significantly lower perceived burden. Higher PRQ 20 00 scores were significantly associated with higher BCOS scores (less burden), and higher CES -D scores were significantly associated with lower BCOS scores (more burden)

2.	The relationship between the spiritual attitude of the family caregivers of older patients with stroke and their burden, [9]	D: Descriptive cross - sectional S: 407 caregivers V: Spiritual attitude, nurturing family I: Questionnaire and scale A: Data was analysed using SPSS 18.0. software (SPSS, Inc., Chicago, IL, USA)	The research results showed that 88.9% of caregivers were women. The mean age of participants was 38.3±8.8 years. The duration of care was 0.5 years in 84.4% of participants, while the mean was 4.2 ± 2.5 years. The mean spiritual attitude score was 108.77 ± 6.20. The majority of participants (49.3%) had moderate and relatively good spiritual attitudes (score 72 –120), 27.8% had high or good spiritual attitudes; 8.7% had a light burden, 54.4% had a moderate burden, and 37% had a good burden. Average score - The average load was 28 ± 12.75. A statistically significant positive relationship was observed in this study between the mean score of spiritual attitudes and the total score of burden in all its dimensions, namely time dependence, as well as developmental, physical, social and emotional
3.	Resilience and caregiving ability among caregivers of people with stroke: The mediating role of uncertainty in illness, [10]	D: Study cross - sectional S:320 patient and caregiver V: Resilience and caregiver abilities I: Questionnaire A: SEM-PLS, Pearson correlation, t test, one-way ANOVA.	A total of 306 couples were involved in this study. The tested model 2 fits the data well (ÿ = 118.2, def. = 64, RMSEA = 0.053, CFI = 0.946, TLI = 0.923). A statistically significant path linked caregiver resilience status to illness uncertainty (ÿ = ÿ0.558, SE = 0.022, P < 0.01), caregiver resilience to caring ability status (ÿ = ÿ0.269, SE = 0.013, P < 0.01) and nurse uncertainty about illness to caring ability (ÿ = 0.687, SE = 0.051, P < 0.01). We also found that caregiver uncertainty in illness mediated the relationship between caregiver resilience and caring ability (ÿ = ÿ0.384, SE = 0.061, P < 0.01
4.	Informal caregiving burden and perceived social support in an acute stroke care facility, [11]	D: Cross-sectional survey S: 56 informal caregivers V: Caregiver burden and social support I: Questionnaire and scale A: Using Statistical Package for the Social Sciences (SPSS) version 20	The prevalence of caregiving burden among caregivers was 96.7% with a high level of strain while 17.9% perceived social support as a low level. No significant association was found between caregiver burden and caregiver or survivor-related socio-demographics other than primary level education. Only the family domain of the Multidimensional Scale of Perceived Social Support was significantly correlated with burden (r = ÿ 0.295).
5.	The relationship between the stroke survivors' functional status and their informal caregivers' burden and quality of life, [1]	D: Cross- sectional study S: 100 patients with their caregivers V: Functional status of stroke survivors I: Form and scale A: SPSS 15.0 package program. used in evaluation and statistical analysis of data. Data were evaluated using descriptive statistics, Kolmogorov-Smirnov test, and t test parametric and non-parametric.	The mean FIM and BI values of patients were 61.0 ± 30.0 and 42.6 ± 28.3, respectively. The mean caregiver score on the SF36- QLS general health perception subscale was 51.7 ± 22.7; Their mean CBS score was 39.2 ± 13.8. Caregiver quality of life was found to be moderate to high in the domains of physical functioning, social functioning, mental health, bodily pain, and general health, but low in the domains of physical role functioning, emotional and burden of informal caregivers functioning, and vitality
6.	Quality of Life in Recent Stroke Patients and Burden on Caregivers in Gujarat state of Western India, [2]	D: Cross sectional study. S: 30 patients and 30 caregivers V: Quality of life and caregiver burden I: Questionnaire A: Data was analyzed using SPSS software.	This research shows that there is a negative correlation between the burden of providing care on nurses and the quality of life of stroke patients. The correlation between ZBI score and quality of life was statistically significant (r= -0.558 and p= 0.001). Both QOL and ZBI scores were related to MMSE scores.There is a positive correlation between the MMSE score and the quality of life of stroke patients and there is a negative correlation with the burden of care on caregivers. Variables such as patient age, patient gender, post-stroke duration, type of stroke, treatment undertaken, and their impact on quality of life have no correlation with the burden of providing care.
7.	Burden of Care and Quality of Life in Home Caregivers of Patients With Stroke in Iran, [12]	D: Study Cross- Sectionals S: 62 house sitters V: Burden of care and quality of life I: Questionnaire and scale A: Data were analyzed using SPSS 22. Descriptive statistics (e.g. mean, standard deviation, and percentage)	Showing that the increasing burden of care on informal home caregivers reduces quality of life in all areas. Thus, the results of this study indicate that increasing the burden of care on caregivers reduces their quality of life in all aspects; in particular, caregivers who provide care to their partners face a greater burden. Therefore, these caregivers should be at the center of attention when planning to reduce the burden of care.
8.	Depression status and functional outcome of patients with ischemic stroke and the impact on caregivers living in Chengdu: a cross-sectional study, [13]	D: study cross- sectional S: 966 patients and caregivers V: Depression status and functional outcome, caregiver impact I: Scale A: Multivariable logistic regression analysis, linear regression model multiple.	In total, 966 IS survivors and caregiver partners were included in the study. Among IS survivors, 35.51% (343/966) experienced depression. Age [adjusted odds ratio (aOR), 1.02; 95% confidence interval (CI), 1.00–1.04; p = 0.036], National score Institutes of Health Stroke Scale (NIHSS) (aOR, 1.57; 95% CI, 1.47–1.68; p < 0.001), and PSSS score (aOR, 0.86; 95% CI, 0.84– 0.89; p < 0.001) was associated with increased risk depression. NIHSS score (b = 2.57, p < 0.001), patient depression status (b = 2.54, p < 0.001), duration care (b = 0.359, p = 0.006), and social support from caregivers (b = ÿ0.894, p = 0.038) is significantly related to the ZBI score. The PSSS score is the main risk factor for depression in IS sufferers, and the patient's depression status and severe functional deficits have a negative impact on theZBI score of the primary caregiver. Social support can reduce ZBI scores.

9.	The Burden and Quality of life of Caregivers of Stroke Survivors with Cognitive Impairment in Selected Healthcare Facilities in Anambra State, Nigeria, [14]	D: cross-sectional survey S: 109 pairs of patients and their caregivers V: Load and Quality of life nanny I: questionnaire A: Data were analyzed using the Statistical Package for Social Sciences (SPSS) version 27.	Physical health domain quality of life is moderate (53.29 ± 15.19), psychological health is low (46.33 ± 16.96), social relationships are moderate (51.16 ± 0.31), environmental health is moderate (51 .22±15.88), caregiver burden was high (6.35±1.29). The quality of life of caregivers of stroke sufferers with cognitive impairment is classified as moderate, and caregiver stress is classified as high in the population sample studied.
10.	Analysis of influencing factors of burden of caregiver among stroke patients at home, (Afiani & Nurmala, 2023)	D: Study Cross- Sectionals S; 120 caregivers V: caregiver burden and factors which influences it I: Questionnaire A: Multiple linear regression and t-test	Only the duration of daily treatment factors influences the burden of care, while the factors age, gender, family relationships, education, employment, length of treatment, health problems of home care providers, and stroke neurological deficits are not affected.
11.	Relationships between care burden, resilience, and depressive symptoms among the main family caregivers of stroke patients: A cross-sectional study, [7]	D: Study Cross- Sectionals S; 245 caregivers V: Maintenance burden, resilience and depression I: questionnaire A: Mediation analysis was performed using the PROCESS macro (Model 4) for SPSS, applying Bootstrap analysis with 5,000 samples and 95% confidence intervals	The results showed that with constant side hemiplegia, Index Barthel, education level, monthly income, care time per day, and living with the patient in the regression equation, resilience partially mediates the correlation between care burden and symptoms depression to mediation effect ratio. amounting to 26.32%. Resilience plays a mediating role in the correlation between care burden and depressive symptoms. Stroke is one of the leading causes of disability and death in adults globally Impact: These findings demonstrate the protective effect of resilience in reducing the negative influence of care burden on depressive symptoms, suggesting that resilience training interventions can be developed to reduce depressive symptoms of primary family caregivers of stroke patients.
12.	The caregiver burden of informal caregivers for stroke patients with and without dysphagia: A multi-center, cross-sectional study in Türkiye, [15]	D: multi-center, prospective, study and cross-sectional S: 120 stroke patients and their caregivers. V: Caregiver burden and Dysphagia I: Instruments and interview A: Descriptive analysis, t test, chi- square test, Test Mann-Whitney U	CB levels were higher in those caring for stroke patients with dysphagia than in those caring for stroke patients without dysphagia. Caregiver burden was found to be associated with patient swallowing-related quality of life and stroke- related quality of life. Significant predictors of high CB scores (F=2.55, R2=0.59; p=0.007) were caregivers who worked (B=17.48, p=0.003), caregivers who had a high school education (B=-19.6, p=0.03), and secondary school (B=-16.28, p=0.02) educational status, son, daughter (B=30.63, p=0.007) or other patient relatives (B=20.06, p=0.01), lower FOIS stage (B=-3.14 , p=0.011), SWQoL scores were lower (B=0.52, p=0.009) and SIS (B=-0.37, p=0.04) were lower.

Discussion

Stroke is one of the most severe neurological disorders that results from decreased cerebral blood flow in certain parts of the brain due to blood vessel injury [16]. Stroke is a long-lasting and debilitating condition, which has a profound negative impact not only on the sufferer, but also on their family [17]. Disability because stroke causes dependence on others in activity life daily living (ADL), and the need for long-term care, often provided by informal caregivers who do not have professional care skills or knowledge [15]. Research conducted by Jaracz et al., reported that stroke will now continue to be a major public health concern, which is a source of high demands for long-term care, and the potential to cause caregiver burden for patients' families and other informal caregivers [18]. According to Rombough et al., Due to the sudden and unpredictable onset of stroke, stroke survivors and their caregivers often face issues that impact daily life [19]. After a stroke, family support increases, and providing chronic care for a family member can be burdensome. Caregiving for stroke patients is associated with higher levels of caregiver burden [20].

Caregiver burden can be defined as the strain experienced by someone caring for a chronically ill, disabled, or elderly family member [21]. An informal caregiver is an unpaid person (for example, a relative or spouse) who is responsible for caring for someone with a chronic illness or disability [22]. Burden of care is used to describe the side effects of existing care. Not surprisingly, caregiver stress is common and is caused by the continuous emotional and physical strain of caregiving [23]. Situational acceptance and recognition strategies are highly problematic for patients and their families. It is a multidimensional response to the physical, psychological, emotional, social and financial stress associated with the caregiving experience [24]. Research by Ugur & Erci, reported that caregivers of stroke patients have various problems such as depression, anxiety, fatigue, hopelessness, easy fatigue, decreased physical health, social isolation, and others [25].

The 12 articles that have been obtained that the most relevant factors associated with caregiver burden were patient's condition, time of treatment, education level, income, length of treatment, patient complications, family support [17]. Research conducted by Ariska et al., reported that the factors that influence caregiver burden are: age, gender, education, employment, income status, family relationships and family support [26-27].

Conclusion

Based on the results, found there are several factors that can affect caregiver burden so that one of the nursing interventions that can be provided is the provision of education related to client care and the importance of family support in caring for clients with stroke so that it is expected to reduce caregiver burdens.

Suggestion

Further research is needed on the solution of factors related to the burden of caregivers on families living with stroke patients so that caregivers can be mentally, physically and emotionally prepared in caring for stroke patients so as to help reduce caregiver burden.

Limitation

This systematic review is only mentioning factors related to caregiver burden but does not discuss solutions to overcome those factors. Only 12 articles were reviewed so there may be other factors that have not been mentioned in this review.

Declaration of Conflict of Interest

In writing this systematic review the author states that there is no conflict of interest.

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