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THE EFFECTIVENESS OF POST-STROKE PATIENT CARE EDUCATION INTERVENTION IN STROKE CAREGIVERS: LITERATURE REVIEW Rumiati Rumiati1, I Made Kariasa2 Agung Waluyo3 1 A student of Nursing Master, Faculty of Nursing, University of Indonesia 2, 3 Lecturers of Faculty of Nursing, University of Indonesia Email : rumicute83@gmail.com Abstrak Background: The post-stroke recovery process does not only focus on the patient but also involves the caregiver who cares for him (the family). Caregivers have an important role in carrying out daily care for the post-stroke patients. Post-stroke patient care education interventions are urgently needed by the caregiver. A caregiver without being provided with education will certainly not be able to provide proper care and this will be a burden, both physically and psychologicaly. Objective: To analyze daily care educational interventions for post-stroke patients in stroke caregivers. Methods: Analyzing online databases from ProQuest, ScienceDirect, Springer Link, Wiley and Google Scholar. The article criteria: Has a Randomized Controlled Trial (RCT) and Quasi experimental design, published from 2015-2020, in English, full text, open access. Seven articles were obtained and the results are presented. Result: Educational intervention can be carried out by several methods, including direct education at the patient's bedside, lectures followed by questions and answers, then provision of booklets, home visits or by telephone follow-up. Educational interventions can improve caregiver knowledge and skills in providing daily care for post-stroke patients, reduce burdens, reduce anxiety and improve the caregiver guality of life. Educational interventions also have a positive impact on post-stroke patients, including improving functional abilities, increasing the ability to do daily activities (ADL), reducing cognitive impairment, anxiety, and depression and improving the quality of life of the post-stroke patients. Conclusion: Daily care education interventions for post-stroke patients can reduce the <u>burden on the</u> caregiver, both <u>physical and psychological</u> burdens. Keywords: education effect, intervention education, post stroke patients, stroke caregiver, stroke caregiver education, INTRODUCTION Stroke is a clinical manifestation from focal and global cerebral dysfunction that lasts very quickly, more than 24 hours. (Kuncoro, 2017). In general, stroke is divided into two, namely obstruction stroke (ischemic) with an incidence of 83% and bleeding stroke (hemorrhagic) by 17%. (Black & Hawks, 2014). Stroke is the main reason of mortality and the main reason of disability and dependence in daily life activities across the globe. (Deyhoul et al., 2020). Stroke is a matchless prominent reason of chronic disability all over the world. Approximately 5.5 million beings pass away annually from strokes and 44 million beings spend their life years adapted for disabilities. (Ali et al., 2020). In the United States, based on predictions a person has a stroke every 40 seconds averagely, and that someone dies from a stroke every 4 minutes. (Yu et al., 2019). The prevalence of stroke in Indonesia according to the diagnosis from the health workers is 7.0 per mile. (RISKESDAS, 2013). According to the Basic Health Research (RISKESDAS) (2018), the occurence of stroke in Indonesia based on a health diagnosis is 10.9 per mile. Thus there is an increase of 3.9 per mile in the occurence of stroke happens in Indonesia. The impact of both ischemic and hemorrhagic strokes is the emergence of disabilities that require long-term care. In carrying out post-stroke care, the stroke patients are very dependent on their families. The family (informal caregiver) has a very important role in providing daily care for post-stroke patients. According to Friedman, the main role of the caregiver (the family) is to provide care to family members who are sick and to keep and maintain health for the family members who suffer from a disease. (Hartiningsih, 2018). According to Zhu & Jiang (2018), 25-54% of caregivers reported a burden in delivering care for patients after stroke for the first six months. (Deyhoul et al., 2020). The impact of post- stroke patient care for the caregiver is a burden on the caregiver. The caregiver is not a load- free zone. The caregiver burden increases because they have to take full responsibility for

the care of the post-stroke patients while they do not have sufficient knowledge plus skills to treat for the home-based post-stroke patients. (Dharma et al., 2018; Pesantes et al., 2017). The caregiver's burden can be in the form of physical or psychological burdens. Physical burdens may include the emergence of fatigue (carrying the patient, moving the patient) due to excessive pressure and demands, while psychological burdens may cover anxiety, stress, emotions, and depression that will have an impact on the post-stroke patient care and decrease the quality of life of the caregiver. (Hekmatpou et al., 2019; Pesantes et al., 2017). Education is very important for the caregivers in providing care for the post-stroke patients. The education can provide support to caregivers by providing appropriate and correct understanding, knowledge and skills about the daily care of post-stroke patients. Caregivers who lack information or knowledge and skills in providing care to post-stroke patients may not be successful in providing support in the treatment, and may even endanger both the patient and the caregiver, this will subsequently affect their quality of life. Edukasi sangatlah penting bagi caregiver dalam memberikan perawatan pada pasien pasca stroke. (Dalvandi, 2018). METHODOLOGY The method used is literature review. The search was conducted by searching for research results published in the online database namely Proquest, ScienceDirect, Spinger Link, Wiley, and Google Scholar using the keywords of education effect, intervention education, stroke caregiver, stroke family, stroke caregiver education, post stroke patients. "AND" and "OR" were used to combine the keyword searches. The criteria for the article include having a Randomized Controlled Trial (RCT) and experimental Quasi design, published between 2015-2020, in English, full text, and open access. Based on the searches on the online database by entering the keywords, a total of 22,341 articles were obtained. After filtering by determining the publication period (2015-2020), the title, language and population, 576 articles obtained. The findings in accordance with the inclusion criteria sorted in 44 articles and finally there were 7 articles that met the requirements for review. The inclusion criteria include: articles published between 2015- 2020, full text, open access, research design included quasiexperimenta, and RCT, topics regarding post-stroke care education interventions for stroke caregivers (family), while the exclusion criteria were studies published before the year of 2015, the article was only an abstract, did not have a complete article structure, cross sectional design, the article is a literature review and systematic review. The flowchart of the article selection process is shown in Figure 1. Identification Search results for articles in the online database using keywords (n = 22,341) a. Proquest (n = 22.230) b. ScienceDirect (n = 60) c. Spinger Link (n = 15) d. Wiley (n = 5) The focus of the Screening Elligibility e.SeGleocotgedleaSrctihcolelasrb(anse=d o3n1) intervention was on inclusion criteria (n = 44) nurse, the type of study was qualitative and the Articles are filtered by title, Aorutitccleosmtehawtacsonuoldt innoltinbee year of publication (2015-

acwciethsstehdeaonbdjedcitdivneost(mne=et 2020), language and population the inclusio3n7c)riteria (n = 532) (n = 576) Included Qualified number of articles to be reviewed (n = 7) Figure 1. The Process of Article Searching The analysis of the 7 articles selected by the researcher according to table 1 is as follows: Tabel 1. Review Artikel Title <u>Increase in the functional capacity and</u> <u>quality of life among stroke patients by family caregiver empowerment program</u> <u>based on adaptation model</u> Author <u>(Dharma</u> et al., 2018). Method Quasiexperimental research with a pre- and post-test control group design. The total number of participants who completed the study was 80 participants. 40 participants in the intervention group with CEP-BEM and 40 participants in the control group with Community Health Nursing (CHN) integrated with the program at the health center. Result Education and training through the method of Caregiver Empowerment Program Based on the Adaptation Model (CEP-BAM) was shown to significantly improve the functional capacity and quality of life of post-stroke patients in the intervention group at the sixth month after the intervention. Effect of family education program on cognitive impairment, anxiety, and depression in persons who have had a stroke: A randomized, controlled study (Yu et al., 2019) Randomized Controlled Study allocated to either the FMEP group or the control group (1:1 ratio). Respondents came from the Second Affiliated Hospital of Harbin Medical University between April 2014 and March 2016 with the number of 144 respondents, 72 respondents in Education with the Family Member Education Program (FMEP) model significantly reduced cognitive impairment, anxiety and depression levels in the intervention group compared to the control group after the evaluation of 12 Conclusion <u>CEP-BAM</u> was a program which aims to increase the stroke patients functional abilities and life quality so that this will reduce the burden on the caregivers in providing care for the post- stroke patients. CEP-BAM effectively improved the functional capacity and quality of life of the post-stroke patients at the sixth month after the intervention. CEP-BAM effectively empowered families in assisting or facilitating patients with mild to moderate disabilities after stroke. However, the effectiveness of these interventions has not been proven in empowering families caring for patients with complex stroke conditions or severe disabilities. Caregivers play an important role in patient recovery and prevention of post-stroke physical and mental disorders. Caregiver education to care for stroke patients is considered a good way to increase their understanding of disease management, relevant physiological management, and Nursing Home Care Intervention Post Stroke (SHARE) 1 year effect on the burden of family caregivers for older adults in Brazil: A randomized controlled trial (Day et al., 2020) intervention groups with FMEP and 72 respondents in control groups with conventional treatment. The inclusion criteria were as follows: (1) patients with symptoms of early ischemic stroke. amplified by tomography of the brain or other resonance images of the brain, (2) patients ≥ 18 years of age, (3) patients are <u>able to</u> meet <u>the cognitive</u>, anxiety, and depression assessments within 7 days after stroke, have a permanent caregiver in the family, the caregiver has no cognitive impairment and (4) the patient has suffered from stroke> 12 months. A randomized clinical trial. The number of respondents was 48 stroke caregivers which divided into the intervention group of 24 respondents and the control group of 24 respondents. The intervention group would accept SHARE and conventional methods while the control group would accept conventional methods only. The sample selection was carried out at the Stroke Special Care Unit (SCU-Stroke) in a Brazilian hospital from May 2016 to September 2017. months after the intervention. The results showed a reduction in the level of burden of the stroke caregiver in providing care for the elderly after stroke. Effect of a Planned Health Teaching on Improving Knowledge and Competence of Home Care Practice of Post (Ali et al., 2020) A quasi-experimental study two group pre and post-test. The number of samples was 59 respondents, 25 respondents were in

intervention groups and 25 respondents were in There was a significant increase in the caregiver's knowledge in caring for the stroke patients, and there was an increase in the psychological support skills that will enable them to provide better care for their family members who have suffered a stroke. FMEP is recommended because it supports the caregivers of patients who have had a stroke to improve communication with family members and reduces mental disorders, thereby reducing cognitive impairment, anxiety, and depression. The SHARE intervention has a statistically significant effect on the burden of the caregivers in providing care for the elderly after stroke in the Isolation domain. This is innovative and is justified by the high prevalence of stroke worldwide, with few interventions proposed at home with this specific population. This study highlights the importance of developing technical intervention treatments for adaptation to conditions found in the home, offering emotional support and for finding alternative solutions to problems identified in relation to treatment. Planned health education is important to increase the knowledge and skills of the stroke caregivers about patient care practices at home which can result in an increase in the Stroke Patient Among Caregivers' Achievement Effect of Informational Support on Anxiety in Family Caregivers of Patients with Hemiplegic Stroke The effect of family-centered empowerment program on the family caregiver burden and the activities of daily living of Iranian patients with stroke: a randomized controlled trial study (Azizi et al., 2020) (Deyhoul et al., 2020) control groups. Data were collected from the university hospital at El Fayoum city Egypt from 1 March 2019 to 31 August 2019. Quasi-experimental study using a pretest-posttest design with a control group. The number of samples was 78 respondents recruited from the Neurology Department of Farshchian Hospital in Hamadan, Iran, 40 respondents were in intervention groups and 38 respondents were in control groups. Data were collected from April to November 2016. The intervention group will receive informational support from the caregiver in four sessions, while the control group will receive daily routine care Randomized controlled trial study. The number of samples was 90 divided into 45 respondents in intervention groups and 45 respondent in control groups. The intervention group received the Family-Centered Empowerment Model (FCEM) with 4 stages with one hour for each stage while the control group did not get FCEM. functional ability of stroke patients. There was a significant positive correlation between the caregiver practice and functional ability of the patients in the intervention group. The two groups were similar in terms of demographic variation. In addition, there was no significant difference between the two groups regarding the average level of condition and the nature of anxiety before the intervention. However, after the intervention, the average level of condition and anxiety in the intervention group showed a significant decrease compared to the control group. The ability of the stroke patients in the intervention group to carry out activities of daily life significantly increased 2 months after the intervention compared to the control group. Two weeks and two months after the intervention, the caregiver burden significantly decreased in the intervention group compared to the control group. functional ability of the stroke patients. Informational support or providing information is effective in reducing the condition and nature of anxiety in stroke patient caregivers. Therefore, it is recommended that nurses consider informational support as an important nursing intervention in caring for stroke patients. Family- centered education is the right model in helping stroke patients and

caregivers to improve quality of life, self- efficiency, and self- esteem. This model has a design that is simple, easy to understand, and inexpensive. This model can be applied by nurse managers in nursing, nursing education planners, and other health care providers to empower the caregivers. This study is focused on caregivers who have good physical and mental status so that they are able to transfer the knowledge they learn. The effect of patient care education on burden of care and the quality of life of caregivers of stroke patients (Hekmatpou et al., 2019) A randomized clinical trial. The number of samples was 100 stroke caregivers. 50 samples in the intervention group and 50 samples in the control group. Sampling was conducted at Al- Zahra educational hospital, Isfahan, Iran in 2017. The sampling technique was purposive sampling. The randomization technique used was the random block technique, which is four blocks. The intervention group received face-to-face training interventions in addition to routine training for two 1.5 hour sessions at the hospital and were given training booklets and evaluations by telephone and home visits. The control group received regular training. The results showed that there was a significant difference in the mean quality of life and care burden in the stroke caregiver in the post- intervention group compared to the control group. The care burden on the caregiver was significantly associated with health status, economic status, marital status, number of children, hours of care, days of care, and the relationship between the caregiver and the patient. In addition, quality of life has a significant relationship with health status. Patient care education reduces the burden of care and improves the quality of life for stroke patient caregivers. Thus, to reduce complications in the care of the stroke patients, family education should be a priority for nursing and discharge procedures. RESULT A total of seven articles found were all discussing post-stroke care education interventions for stroke caregivers. Research conducted by Hekmatpou et al (2019), states that in their research which focuses on the effect of post-stroke patient care education on reducing the burden of care and improving the quality of life of stroke caregivers. The intervention was given through two sessions. The first session of 1.5 hours in the hospital and a training booklet containing 30 pages, written in easy and practical language, were given to stroke caregivers. The second session after the patient and stroke patient caregiver went home. The intervention was given through telephone consultations at intervals of 3 days followed by two home visit sessions as well as practical home training for 1 week after the second telephone counseling. The researchers become the caregiver trainers. The trainer responded to all questions regarding nursing interventions and the caregiver performed some practices on the patient under the supervision of the trainer. Educational interventions can significantly reduce the burden of care and improve the quality of life of stroke patient caregivers. The care burden of stroke patients is significantly related to economic health, marital status, number of children, hours of care, days of care, and the relationship between the caregiver and patients, while quality of life has a significant relationship with health status. In another study conducted by Azizi et al (2020), which focuses more on the effectiveness of informational support on the level of anxiety in the caregiver for hemiplegic stroke patients. The intervention was given through four sessions every two days until the ninth day in the inpatient ward. Two support sessions were conducted at the bedside of the patient, followed by a training session with a lecture method and a question and answer session. Each

session lasted one hour. The caregiver was also given a booklet and given the researcher's telephone number so that they can ask questions while being treated in the hospital. The intervention found that the caregiver anxiety level of stroke patients significantly decreased. Two other studies, namely Yu et al (2019) and Dayhoul et al (2020), about post-stroke patient care educational interventions for stroke caregivers have the same focus namely family (caregiver) empowerment, however the effects investigated are different. Yu et al (2019), looked at the Family Member Education Program (FMEP) intervention on cognitive impairment, anxiety, and depression in post-stroke patients, while Dayhoul et al (2020), saw the Family-Centered Empowerment Model (FCEM) Intervention on increasing ability of post-stroke patients to carry out activities of daily life (ADL) and reducing the burden of the caregivers in providing care for the post-stroke patients. The caregiver received five educational sessions for the first 2 weeks of the FMEP intervention. The educational topics include stroke, the impact of stroke, physical care, and mental health care and general problems. The caregiver received five educational sessions for the first 2 weeks of the FMEP intervention. The educational topics include stroke, the impact of stroke, physical care, and mental health care and general problems. The next 3 to 8 weeks, the caregivers were invited to take part in weekly workshops that provide counseling, communication, and assistance to solve any problems they faced. Furthermore, the stroke and rehabilitation specialist nurse would conduct home visits as needed and provided further support. Between 3 and 12 months, a monthly telephone evaluation was conducted to check the condition of the caregiver and patient. During this period the nurse may make visits to the patient and caregiver if necessary and the caregiver may continue to attend weekly workshops at any time. FMEP has been shown to be effective in reducing cognitive impairment, levels of anxiety and depression in post-stroke patients. FCEM intervention was carried out in four stages, namely 1). determining the perception of threats through the method of discussion, 2). self-efficacy through problem solving methods, 3). increasing self-esteem through educational participation methods and 4), processing and evaluation of results. Each stage was carried out for 1 hour. The first, second and third stages were carried out in the hospital, namely in the inpatient room through direct presentations / lectures / slides, questions and answers, counseling, face-to-face discussions and the distribution of booklets to the stroke caregivers. The fourth stage related to data collection through questionnaires which were carried out through three stages: before the intervention, after 2 weeks in the hospital neurology ward, and 2 months after the intervention at home, then the questionnaire was returned by mail. To ensure the continuity of the respondents in the research and filling out the questionnaire until the last stage, weekly telephone counseling was carried out to the caregivers and their questions would be answered by the researcher. FCEM has been shown to significantly increase the ability of post-stroke patients to carry out daily life activities (ADL) and reduce the burden on caregivers in providing care for post-stroke patients. Three other studies, namely Ali et al (2020), evaluated the effectiveness of planned education on caregiver knowledge and skills in caring for post-stroke patients at home and improving the functional ability of post-stroke patients. The intervention was carried out for four weeks. Implementation was done both individually and in groups. At the end of the caregiver program, a booklet was given. The educational interventions significantly increase the knowledge and

skills of the caregivers in providing care for the post-stroke patients as well as in improving the functional abilities of the post-stroke patients. Dharma et al (2018), studied the effect of the CEP-BAM program on the functional capacity and quality of life of post-stroke patients. . CEP- BAM was carried out for 6 months and was divided into three phases, namely pre-education, intervention, and monitoring / evaluation. The CEP-BEM intervention effectively improved the functional capacity and quality of life of post-stroke patients at the sixth month after the intervention. Day et al (2020), in their study, looked at the effect of educational interventions on reducing the burden on caregivers in providing care for post-stroke patients. The educational interventions given to the stroke caregivers are called Nursing Home Care Intervention Post Stroke (SHARE) interventions. SHARE Intervention Intervention was carried out for one month in five stages, namely 1) guiding the caregiver to help stroke sufferers in their daily life at home and in using health services, 2) teaching the caregiver about feeding by mouth or nasoenteric, personal hygiene, bathing, changing diapers, dressing and undressing, transfering, positioning, medical treatment, handling of tools, such as vesicles and ostomy, if necessary, 3) providing orientation related to stroke, causes and consequences of disease, how to prevent new strokes, what resources are offered by health care facilities, and how to access them, 4) providing emotional support to the caregivers and stroke patients and 5) providing health education materials. SHARE has been shown to significantly reduce the burden on caregivers in providing care for post-stroke patients, especially the elderly. DISCUSSION Stroke is the most common cause of permanent disability worldwide and has a variety of serious negative effects both for the patients and caregivers who provide care for the post-stroke patients. There are four important points from the summary of the results of the literature review, namely: Education interventions increase the knowledge and skills of the stroke caregiver (the family) in providing care for the post-stroke patients, especially daily care at home Sufficient knowledge and skills can reduce the burden on caregivers in caring for stroke patients. According to Azizi et al (2020), one of the effects of stroke for the caregivers is that anxiety in providing care for the post-stroke patients. Post-stroke patient care often causes anxiety to the stroke caregiver, this is because the incident occurs suddenly and unexpectedly, and also because of the caregiver's lack of knowledge and skills in providing care for the post-stroke patients. Apart from anxiety, another impact in providing care for post-stroke patients is that it is quite a burden for the stroke caregiver. Caring for stroke patients at home is a very complex and very strenuous activity. (Day et al., 2020; Deyhoul et al., 2020; Hekmatpou et al., 2019). According to Dharma et al (2018), the caregiver burden increases because the caregiver does not have sufficient knowledge and skills in providing care for the post-stroke patients. Therefore, with the education for the caregiver about the care of the stroke patients, the caregiver's knowledge and skills will increase thus they can provide proper care. The education redcan reduce ucing anxiety and in the end will be able to reduce the burden on stroke caregivers. Structured education can improve the caregiver's ability to care for the stroke patients Educational interventions are also the primary caregiver's need in providing care for post-stroke patients. (Zawawi et al., 2020). When a family member experiences a stroke, the caregiver has a big role, namely providing care for the family member who is sick. The role of the caregiver as part of the patient support system is very

important in improving the guality of life of the post- stroke patients. Caregivers must be empowered to care for and guide patients to adapt to life after stroke. Therefore, the caregiver's knowledge and skills in helping patients adapt to life after stroke must be improved. An increase in the caregiver's knowledge and skills in providing care for post-stroke patients will have a significant impact on the functional ability and guality of life of the patient. (Dharma et al., 2018). Education and training for the caregivers can reduce physical, psychological and social burdens in caring for the stroke patients The burden on the caregivers is not only physically but also psychologically and socially. (Hekmatpou et al., 2019). These burdens can be prevented, reduced or even limited if the stroke caregivers receive education intervention along with training about the care of the post-stroke patients. (Pesantes et al., 2017). One of the interventions that can be used to overcome this impact is educational intervention on the post-stroke patient care for the stroke caregivers. This education intervention does not only affect the stroke patient caregivers but also the stroke patients. According to Ali et al (2020), education has an effect on increasing the knowledge and skills of the stroke caregivers in providing care for the post-stroke patients, besides that it can also improve the patient's functional abilities. This is in line with a research conducted by Bakri et al (2020), which states that there is an effect of health education on stroke patient care at home on the level of family knowledge. In addition, educational interventions also have an effect on reducing the burden on the caregivers in providing care for the post-stroke patients hence this also has an impact on the <u>guality of life of the</u> caregiver. Hekmatpuou et al (2019). In line with this research, Masriani (2014), said that health education directly provided to families increases the family knowledge in caring for stroke sufferers at home so that it can improve the quality of life of the stroke patients and reduce the burden on the family itself. The caregiver plays an active role in the recovery process of the post-stroke patients Neurological recovery occurs after the onset of the stroke, whereas functional recovery continues to some extent in the first three months to 6 months after the stroke. (Yenni, 2011). One of the caregiver's active roles is to assist in functional recovery, especially post-stroke functional disorders. Functional impairment is a decrease in physical capacity to meet basic daily needs such as self-care, eating, drinking and decreased ability to interact with the environment in which the patient lives. (Nurramadany, 2014). This can be done correctly and appropriately by the caregiver, if the caregiver is provided with education. Education will increase the caregiver's knowledge and skills in providing care so that this will also have an impact on the patient. These impacts include an increase in the ability to carry out daily activities (ADL), the ability or functional capacity and the quality of life of stroke patients. Care giver plays an active role in the recovery process of post-stroke patients. (Deyhoul et al., 2020; Dharma et al., 2018). According to Yu et al (2019), educational interventions will have an effect on reducing cognitive impairment, anxiety and depression in post-stroke patients. CONCLUSION Poststroke patient care is a complex problem that requires collaboration with other health teams such as doctors, nurses, nutritionists, and the rehabilitation team. care education interventions for stroke patient caregivers have very positive impacts not only for the caregivers but also for the post-stroke patients. These impacts, among others, are that the caregiver can increase the caregiver's knowledge and skills in providing care for the post-stroke patients, reduce the

burden, reduce anxiety and improve the <u>quality of life of the</u> stroke <u>caregivers</u>. For the post <u>-stroke patients the</u> impacts are, among others, increasing the ability or functional capacity, increasing the ability to perform daily activities (ADL), reducing cognitive impairment, anxiety and depression and <u>improving</u> <u>the quality of life of the</u> post-stroke <u>patients</u>.