

Participatory Learning is Needed to Increase Family Independence in Handling Post-stroke Patients at Home

Ali Hamzah^{1*}, Ihat Hatimah², Asep Saepudin³, Joni Rahmat Pramudia⁴,
Khemaradee Masingboon⁵

¹Poltekkes Kemenkes Bandung, Indonesia
^{2,3,4,5}Universitas Pendidikan Indonesia, Indonesia
*Email: ali.hamzah@staff.poltekkesbandung.ac.id

Submitted: 2023-09-15. Revised: 2023-10-11. Accepted: 2023-11-19.

ABSTRACT

Post-stroke patients often experience dependency and disability due to paralysis, and this requires their family's support to continue treatment at home. Currently, to carry out post-stroke treatment, they use homecare services because the family is less able to carry out post-stroke care independently at home. This research aims to identify an educational model that allows families to actively participate in learning to be independent in treating post-stroke patients at home. The mixed method used involves 56 families of post-stroke patients selected by purposive sampling technique for quantitative data. Two family members and two healthcare providers for qualitative data used in-depth interviews. The quantitative data were analyzed using the percentage formula presented as a frequency distribution table. Meanwhile, qualitative data were processed by data reduction, presentation, and conclusions. The results showed that most of the families of stroke patients did not receive and utilize homecare services for various reasons, including ignorance, inability, and unpreparedness, as well as inability to pay the costs. It is necessary to conduct research using the research and development (R & D) method with topics related to developing homecare service models for post-stroke patients at home based on participatory learning. The novelty of this research is the production of a model design that can answer the needs of families to increase independence in treating post-stroke patients at home.

Keywords: Family Independence, Participatory Learning, Post Stroke Patient

How to Cite:

Hamzah, A., Hatimah, I., Saepudin, A., Pramudia, J. R., & Masingboon, K. (2024). Participatory Learning is Needed to Increase Family Independence in Handling Post-stroke Patients at Home. *Journal of Nonformal Education*, 10(2), 49–61. <https://doi.org/https://doi.org/10.15294/jone.v10i1.1410>

INTRODUCTION

The World Health Organization (WHO) 2016 released data showing that in 2015, stroke was the second-highest death rate in the world (Permatasari, 2020). Furthermore, the American Heart Association (AHA) in 2017 RI (2018) stated that every 2 seconds, 1 out of 6 people in the world has a stroke. The World Stroke Organization in Data and Information Centered Ministry of Health of the Republic of Indonesia shows an additional 13.7 million new stroke patients with a case fatality rate due to stroke in the world, reaching 5.5 million (Kemenkes RI, 2018). The prevalence of stroke in Indonesia, according to the results of the 2018 Riset Kesehatan Dasar (Riskesdas), showed an increase compared to 2013, namely from 7% to 10.9%, in the age group ≥ 15 years as well as in the province of West Java, the prevalence increased by 11.4 % from 2013 (Kemenkes RI, 2018).

Stroke is a disease that can broadly impact patients and cause loss of productivity in carrying out their roles, physical and social crises, immense change in personality aspect, and reduction in quality of life (QOL).

Then this will further impact the economic life of patients and their families (Alshahrani, 2020). Even at the same time, the patient and family require money, considering that the process of repairing a stroke patient takes a long time and is gradual, so it requires a post-hospital follow-up program (Lucas-Noll et al., 2023) (Movahed et al., 2021) and (Cha, 2018). To continue the management of post-hospital stroke patients is generally carried out by the family, so the family has a vital role and bears a great responsibility (Stiexs & Chayati, 2021) (Roberts et al., 2021).

Family is the smallest cornerstone of societies, consisting of a mother, father, and children. In the term universal, family is based on an emotional foundation; the family has a shaping characteristic, family is limited in scope, family is a nucleus in social structure, social rules surround the family, the family has a permanent and at the same time a temporary (Arslan, 2023). The family is believed to have the will and ability to overcome its problems. If they are taught how to care for the patients or continue rehabilitation care at home, they may do better than without knowledge (Sheha et al., 2020). Involving family caregivers in discharge preparations is an effort to reduce the risk of complications and readmission of stroke sufferers and improve caregivers' quality of life. The participation of family nurses in patient care enables their participation at home based on adequate knowledge and skills in a joint effort to improve the quality of treatment of post-stroke patients (Tang & Chen, 2002).

The involvement of the patient's family in treating post-stroke patients at home is an effort to empower families to overcome problems that arise, which in turn will encourage family independence, and this is part of community education activities through providing education and assistance to families. They use homecare services to conduct follow-up programs for post-stroke treatment at family hospitals. The research results (2019) stated that post-stroke patients needed a homecare service program by a homecare agency because the family could not carry out post-stroke care and rehabilitation independently at home due to time constraints.

Unfortunately, homecare services also require a significant quantity of money, even though, at the same time, the family is experiencing a financial crisis. In these conditions, the family finds it increasingly difficult to pay for follow-up care, and as a result, many patients are not treated and cared for correctly. In this regard, data is needed that describes the current condition of home care services for the families of post-stroke patients as a starting material for developing appropriate, comprehensive interventions involving the family's active participation. This study aims to identify the current condition of home care services for the families of post-stroke patients in order that a model can be developed that is appropriate to the needs of a family of stroke patients.

METHOD

This research uses descriptive analytical methods with a mixed-method approach. The design used in this mixed method approach is convergent parallel mixed methods. The number of respondents willing to become subjects and fill out the quantitative data instrument was 56 family members of post-stroke patients. In comparison, qualitative data was obtained from 2 homecare staff and two patient family members. Data was collected at two hospital homecare service units: Al Islam Hospital Bandung and Al Ihsan Hospital, West Java Province. The instrument consists of 3 questionnaires: knowledge, attitudes, and skills. The researcher created the instrument based on the literature and was first tested for validity and reliability. The validity test results for the knowledge instrument are 0.893 - 0.914, and the reliability is 0.907, while the validity test results for the attitude instrument are 0.878 - 0.900, and the reliability is 0.892, then the validity test results for the skills instrument are 0.885 - 0.903, and the reliability is 0.898. Qualitative data instruments were developed based on themes in the quantitative data results. The data collection process was carried out in the homes of post-stroke patients' families when health care was carried out during home visits. In contrast, qualitative data from homecare officers was collected using in-depth interviews. After the quantitative data is collected, it is checked for completeness, cleaned, entered, processed, and analyzed using the frequency distribution percentage formula. The qualitative data processing process is done through data reduction, data presentation, drawing conclusions, and data verification.

RESULTS AND DISCUSSION

This research aims to find a homecare service model that is more appropriate to the needs of families of post-stroke patients so that it is easier for them to understand the material being taught, hence that their knowledge, attitudes, and skills increase. Ultimately, they have independence in treating post-stroke patients through community education interventions.

Related to this research's aim, the results will explain and describe the actual conditions of existing home care services as a basis for designing a home care service model. The data will be presented quantitatively and then validated with qualitative data so that the model will be designed according to the needs of the families of post-stroke patients. This section will also provide a discussion of research findings to strengthen the process of designing the model to be created.

Description of Respondent Characteristics

The characteristics of the respondents in this study included age, education, occupation, relationship with patients, and experience taking care of stroke patients. The results can be seen in Table 1.

Table 1. Description of Respondent Characteristics

No	Respondent Characteristics	Frequency	Percentage
1.	Age:		
	• 18-30 years old	7	12.5
	• 31-45 years old	13	23.2
	• 46-59 years old	24	42.9
	• > 60 years old	12	21.4
	Amount	56	100
2.	Education:		
	• Basic Education (graduated from elementary and or junior high school)	8	14.3
	• Senior high school (graduated from MA/ SMA/SMK)	12	21.4
	• Higher education (Graduated from Diploma, bachelor/ Magister/ Doktor)	36	64.3
	Amount	56	100
3.	Occupation:		
	• Official government	9	16.0
	• Entrepreneur	24	42.9
	• Labor	8	14.3
	• No worker (homemakers/retired)	15	26.8
	Amount	56	100
4.	Relationship with the Patient:		
	• Spouse	11	19.6
	• Parent	30	53.6
	• Children	3	5.4
	• Sister/Brother	4	7.1
	• No relationship as the family	8	14.3
	Amount	56	100
5.	Experienced taking care of patients:		
	• < 1 tahun	20	35.7
	• 1-3 tahun	21	37.5
	• > 3 tahun	15	26.8
	Amount	56	100

Table 1. shows the characteristics of the 56 respondents who participated in this research, showing that almost half (42.9%) were in the age range 46 – 59 years, the majority (64.3%) of them had a higher education and a small portion had a secondary education (21.4%) and graduated from primary education (12.5%) and almost half work as entrepreneurs (42.9%) and a small number as housewives (26.8%). Then more than half (53.6%) of them have a family relationship with the patient as parents and a small number are partners (19.6%), and almost half of them have experience handling/caring for stroke patients at home for 1 - 3 years (37.5%) and less than one year (35.7%).

Description of the Initial Conditions of Homecare Services for Treating Post-Stroke Patients in Bandung City and Regency

An overview of the initial conditions of home care services in treating post-stroke patients in the city and district of Bandung can be seen in Table 2.

Table 2. Description of the initial conditions of home care services in treating post-stroke patients in the city and district of Bandung.

No	Question Aspect	Answer				Amount	
		Yes		No		f	%
		f	%	f	%		
1.	Knowledge of the existence of homecare services for post-stroke patients at home	45	80.4	11	19.6	56	100
2.	The benefits and importance of homecare services provided so far.	43	76.8	13	23.2	56	100
3.	There are still many families who have not provided homecare services for post-stroke patients due to lack of knowledge, inability, and unpreparedness to handle post-stroke patients at home	55	98.2	1	1.8	56	100
4.	There are still many stroke patients who have not received homecare services due to family limitations in financing the services of homecare staff.	54	96.4	2	3.6	56	100
5.	The family's readiness to pay additional costs if they use homecare services	28	50	28	50	56	100
6.	The need and importance of providing homecare services for post-stroke patients.	56	100	0	0	56	100

Based on table 2 shows the current condition of homecare services in Bandung City, namely that the majority of respondents already know about the existence of homecare services (80.4%), the benefits and importance of homecare services (76.8%), almost all (98.2%) Respondents felt that there were still many families who had not provided homecare services for post-stroke patients due to lack of knowledge, inability and unpreparedness to handle post-stroke patients at home and because of family limitations in financing the services of homecare staff (96.4%). Some respondents (50%) said they were ready, but others said they were not ready to pay additional costs if they used homecare services. However, all (100%) respondents agreed that they felt the need for and considered it essential to have homecare services for post-stroke patients.

Data about there are still families of stroke patients who have not used homecare services have similar opinion as two of the patient's families who explained that: as far as I know, up to now, not everyone has been served by homecare, and I do not even know what is a homecare service. This finding also was confirmed by the person in charge of homecare at Al Ihsan and Al Islam Hospitals who stated that the number of stroke patients who were taken to the Neurology Polyclinic was quite large, around 50 to 60 per month and only 1/3 of them used homecare services from the hospital.

The reasons why families do not use hospital homecare services are because they do not have the enough money to pay health workers, are not ready to treat patients at home and are worried about carrying out the wrong action so that it will endanger the patient. Besides this because they have their helpers who can be assigned to help after the patient back home and also because due to the distance and access to the Hospital which is quite far from the patient's home, making it difficult for patients and their families as well as health workers to serve them.

As a result, many post-stroke patients experience complications such as: decubitus, muscle atrophy, joint contractures, their bodies look dirty and smelly when they are taken to the hospital for control because the family does not know and is unable how to handle post-stroke patients at home. In fact, a small number of families stated that they did not want to treat patients at home because they were busy working, did not have enough time to care for patients at home and did not have helpers. But most families are willing and ready to participate actively in treating patients at home, as long as they are given sufficient information or knowledge and are trained in how to carry out several skills for handling patients at home.

The family also agree and realize the importance of they involvement in treating post-stroke patients at home so that the patient feels loved, cared for and considered important by the family, so this will motivate the patient to recover quickly. On the other hand, if the family does not want to be involved in treating the patient, it will cause the patient to become depressed and the quality of life will decrease and the patient's improvement process will take longer.

The importance of active family participation in continuing to treat post-stroke patients at home was conveyed by health workers because the family's participation would reduce their workload in treating patients and ensure that the patient will be handled well by the family. They also believe that active family participation will prevent complications, provide emotional support and enthusiasm for life in post-stroke patients.

The results of the study in Table 2 above show that most respondents already have good knowledge about the existence of homecare services and the benefits and importance of homecare services, and all believe that homecare services are essential to be carried out in post-stroke patients. This is inseparable from several supporting characteristics, namely factors of educational background, age, and respondents' experience, as shown in Table 1. Table 1 shows that most respondents have a higher education background, and almost some are between 46 and 59 years old and experienced in handling/treating patients for 1 to 3 years. Based on the characteristics of respondents who mostly have a college graduation education background, this is likely to significantly influence respondents' knowledge about stroke and homecare services. Respondents with a higher education background generally have broader insight, understanding, and ability to digest the information received. Diaz-Quijano et al. (2018) state that the factor that has the most significant influence on knowledge is education because people with higher education can give a more rational response to the information received and will think to what extent the advantage one gives to the development of others in achieving specific goals.

The results of this study show that there is conformity with the study of Diaz-Quijano et al. (2018), which concludes that there is a significant relationship between the level of education and the level of knowledge, where the higher the level of education, the higher the level of knowledge possessed, and vice versa. Good knowledge from respondents is also inseparable from age factors and experience in handling and caring for post-stroke patients at home. Almost half of the respondents (42.9%) are in the age range of 46-59 years, which, in general, in that age range, someone is already at a level of maturity and has enough life experience to understand various things he has experienced. In addition, most of the respondents (64.3%) have experience dealing with post-stroke patients for more than one year. Researchers believe that for 1-3 years of handling/ caring for patients at home, families have received much information related to stroke from the health team and authentic experience in handling patients. This will undoubtedly enrich the knowledge and insights of respondents who answer researchers' questions on the questionnaire.

A study by Bayerlein (2020) found that one of the sources of knowledge is prior experience concerning the opinion of empiricists. In the opinion of empiricists, experience is the only source of knowledge that can be accepted because it results from observing and processing the five senses. The more people gain experience, the more knowledge they will increase and the better they will behave. This means that respondents' experiences seen, heard, felt, and experienced while handling post-stroke patients become a source of knowledge for respondents. It adds to their better knowledge about stroke and home care services.

The results of this study are in line with the findings of studies conducted by Zhang et al. (2023), which identify a correlation Between Family Functioning and Health Beliefs in Patients with Stroke in Beijing, China, which concludes the level of family functioning in patients with stroke was positively correlated with health beliefs ($r = 0.364$, $P < 0.01$). The results of this study are almost the same as the finding from Ishak, Yueniwati,

and Kapti (2020), who discovered the data there is a relationship between the factors of knowledge ($p = 0.01$), awareness ($p = 0.03$) and behavior ($p = 0.00$) with family delays in bringing stroke patients to the emergency room. The results of this study are also in line with the findings of Deepradit et al. (2023), which state that the present family-based program improved family function in family caregivers and family members and decreased caregiver burden and stress in family caregivers. The program also improved functional status and reduced depression in post-stroke patients.

Furthermore, Table 2 above shows that although almost all respondents already know well about homecare services, almost all respondents feel that there are still many families who have not done homecare services to post-stroke patients because of a lack of knowledge, inability, and unpreparedness to handle post-stroke patients at home. This result also has something to do with the characteristics of respondents; only a tiny part of them have the same educational background or below primary education, and almost half have experienced treating stroke patients at home for less than one year. As explained earlier, knowledge is greatly influenced by education and experience, so low education and lack of experience cause many respondents who do not know to be unable and unwilling to carry out homecare services. As a result, many post-stroke patients do not get homecare services from their families.

The logical consequence of ignorance, inability, and unwillingness of the family will have an impact on their unreadiness to treat post-stroke patients at home. As a result, patients are treated soberly and only based on instinct. Eventually, many of the post-stroke patients experience complications such as muscle wasting, joint stiffness, and injury to the buttocks area. In addition, table 2 also shows that almost all respondents have not received homecare services because of family limitations to pay for homecare staff services, and some of the respondents also stated that they were not ready if they had to pay fees if they used homecare services. This is also inseparable from the characteristics of stroke itself, which is a disease that requires a long time for the healing process, so it will burden the family economy. Ishak, Yueniwati, and Kapti (2020) found that there is a relationship between economic capabilities ($p = 0.00$) and decision-making ($p = 0.00$) with the family delays in bringing stroke patients to the emergency room at Labuha Hospital.

The inability and unreadiness to pay the cost of home care services to health workers was also triggered by the characteristics of respondents who almost half worked as self-employed and a small part did not work or only as ordinary housewives. As self-employed workers, respondents generally work in the informal sector that does not have a fixed income/income, in contrast to those who work in the formal sector, such as civil servants, TNI/POLRI, and workers in BUMN who have a fixed income, and settle every month.

On the other hand, the relationship between respondents and patients also affects the readiness to finance post-stroke care at home. In this study, most respondents have a relationship with patients as parents (father or mother), meaning that respondents themselves, as children, have a family and are responsible for supporting their family. So, the presence of patients at the respondent's home will increase their living costs, and at some point, the respondent expressed his unpreparedness to use the services of homecare officers.

Related to the research results above, increasing family knowledge is very important because it will impact family attitudes and behaviors in handling post-stroke patients at home. Study results (2022) indicated two kinds of needs for family members. The first is related to information on stroke and stroke rehabilitation, such as the need to be aware of stroke, complications, and disability caused by stroke and the approaches to managing disabilities following a stroke at home. Stroke education was their topmost need. The second was psychological support. The caregivers expressed that they need this support to mentally equip them to support the caregivers without being emotionally distressed. This was to meet the demanding needs of the stroke survivors.

Likewise, the findings of Lu et al. (2019) state that educational provision and support for family caregivers of post-patient patients with stroke can reduce tension between family and patient and improve their quality of life. (2021) indicated that the caregiver's social support and the care recipient's functional status significantly contributed to explaining the caregiver's health promotion behaviors. For this reason, it is necessary to carry out education that involves the family's active participation in the educational process, from the learning planning stage to the evaluation stage, or by applying participatory learning models under the umbrella of adult learning approaches.

The study found by Askari et al. (2018) suggests implementing participatory education based on homecare services, citing the cost-effectiveness of this approach, its potential to improve family members' active involvement in post-stroke patient care, and its potential to lower the risk of complications from prolonged bed rest in stroke patients. Participatory learning is thought to increase family involvement and participation because it designs the learning based on the findings of identifying their needs, making it more efficient and meeting expectations from the family. Families of stroke victims will be more driven to learn a variety of skills, particularly those about taking care of their members' basic needs, as this will reduce the costs that the family must bear and remove the family's reliance on medical professionals. The results of Allaham et al. (2022) demonstrated that the context-specific, affordable participatory learning approach improves health outcomes.

Research indicates that health education plays a significant role in raising the level of knowledge that patients and their families have about stroke, psychological support, readiness for care at home, and the risk of recurrence. It also helps them understand patients' difficulties when dependent on their families. (Deyhoul et al., 2018). The results of this study are in line with the findings from a study conducted by Ishak, Yueniwati, and Kapti (2020), which concluded that there was a relationship between knowledge and behavior with family delays in bringing stroke patients to the emergency room.

The results of this study are in line with previous research from Septianingrum et al. (2023) that showed a significant correlation between family support and self-efficacy ($p = 0,000$) with medium relationship strength ($r = 0,58$)—then concluded that the higher the family support, the higher the self-efficacy of stroke patients. The results of this study also support and strengthen the study by Vidyanti et al. (2022), which concluded that caregivers are crucial to keeping patients' physical and mental health in check and facilitating their interactions with medical professionals and other family members.

Description of Family Reasons to Participate Actively on Homecare Services

An overview description of family reasons to participate actively in homecare services can be seen in Table 3:

Table 3. Description of family reasons to participate actively in homecare services

No	Question Aspect	Answer				Amount	
		Yes		No		f	%
		f	%	f	%		
1.	Families can and are willing to participate actively in treating stroke patients at home.	36	64.3	20	35.7	56	100
2.	The presence of a stroke patient at home will affect the family's condition so that the family is believed to have participated actively in dealing with the problem if given the opportunity and directed by health workers.	56	100	0	0	56	100
3.	Homecare services based on participatory learning are needed to encourage families to be involved in treating post-stroke patients.	56	100	0	0	56	100
4.	The importance of the role of family support in treating post-stroke patients.	56	100	0	0	56	100
5.	Active involvement of the family in treating post-stroke patients at home	56	100	0	0	56	100
6.	Homecare services that involve family participation in treating post-stroke patients at home are believed to be able to generate enthusiasm, interest, and active family participation in taking part in educational activities.	56	100	0	0	56	100

Table 3 shows that most respondents (64.3 %) believe that Families can and are willing to participate actively in treating stroke patients at home. All of the respondents (100%) the family is believe that families participating actively in dealing with the problem of stroke patients will allow them to help Dan solve it and also encourage families to be involved in treating post-stroke patients. Then, all of the respondents (100%) agreed that the family has to participate actively. Active family involvement will make the patient feel happy and encourage the patient's enthusiasm for life to recover from his illness.

This data is in line with the opinion of the family members who explained that the stroke patients need a long time to recover, so patients often experience stress and depression and feel ostracized by their families. The presence of the family will motivate the patient to be enthusiastic about recovering because they are there to pay attention and support. Moreover, the presence of the family will support and motivate the patient to be enthusiastic about recovering and will create trust from the patient, and the patient will feel safe and comfortable.

Tables 3 show that all of the respondents agree that Homecare services based on participatory learning are needed to encourage families to be involved in treating post-stroke patients, and they believe that involving family participation in treating post-stroke patients at home generates enthusiasm, interest, and active family participation in taking part in educational activities. This result also has something to do with the characteristics of the respondents, some of whom have a role as a laborer (14.3 %) and no worker (26.8 %). Because of this condition, some need to educate themselves to treat the patient without dependence on homecare services.

In this regard, breakthroughs need to be made to overcome this problem, including the involvement of Community Education. Community education is the type of education needed to ensure self-confidence, self-respect, and personal independence, as well as to safeguard human rights and achieve social equality. Community education is essential in stimulating community members to participate actively in social activities, find or generate employment, increase their incomes, and improve their quality of life. (Rahma et al., 2019).

Community Education conceptually has the function of helping people to help themselves and educating people to educate themselves, meaning that Community Education exists to help people to be able to help themselves and educate people to be able to educate themselves. Regarding the function of Community Education, the health problems experienced by the families of post-stroke patients are one of the targets of the Community Education service, namely helping the families of post-stroke patients to help themselves.

One of the efforts that Community Education can make is to empower families through educational activities so that families who receive education can utilize the results of their education in treating post-stroke patients at home. This effort can be carried out jointly with health scientific disciplines, especially with the nursing profession, which both have duties and responsibilities to serve patients from when they are treated in the hospital until the patient returns home.

The education process of families of post-stroke patients using a participatory learning model is carried out to increase family knowledge, attitudes, and skills in carrying out follow-up treatment of patients at home so that families will have sufficient knowledge, attitudes, and skills, and abilities in handling post-stroke patients at home. Participatory learning models involving families in dealing with post-stroke patients are a form of implementation of informal education or informal learning.

Informal education is the process of learning through all the everyday interactions that people have with their surroundings over a lifetime, anywhere, at any time, and without the individual in question even realizing that he has taught or learned anything. A person has changed due to this interaction, whether deliberate or accidental, conscious or unconscious, and in insight, understanding, attitude, values, and behavior. (Aspects of informal education and its characteristics, 2022).

Regarding the idea of informal education, Freire states that it takes the form of a dialogical (or conversational) approach rather than a curriculum. Moreover, "dialogue involves respect" (Jones & Brady, 2022). In other words, informal learning is both a human instinct and a primitive stage of human learning. As a result, formal education has grown in importance as a means of instruction (Zhou, 2023).

Applying participatory learning to educate family patient's stroke in order to improve family knowledge, attitude, and skill in treating post-stroke patients to the recommendations of the study results Sheha et al., (2020), which confirms that healthcare professionals should support and enhance family caregivers' knowledge and abilities in caring for stroke survivors. They should also follow up with them regarding their condition and offer ongoing home support, which is essential for a full recovery. Arbarini et al. (2018) provided insight into the phenomenon of family caregivers providing informal care for stroke survivors, which is defined as compassionate care given despite multiple challenges. A proper system of referral to a social worker and the

provision of a family caregiver education program prior to the stroke survivor's discharge from the hospital are suggested in an attempt to minimize such difficulties.

This is also in line with the recommendations of (2021). Their study recommended further developing a specific program designed to provide caregivers with preparedness for delivering stroke patient care. In addition, such programs should consider assisting caregivers with social support, stress-relieving activities, and activities to improve the relationship between caregivers and patients.

The family must have good knowledge and the ability to care for it. Therefore, nurses must support families through health education and ongoing mentoring. The nurse must also follow up regularly to ensure the patient's condition improves. Nursing education could support the development of family monitoring for senior stroke patients, particularly regarding stressor identification, coping resource assessment, and coping mechanism development (Yusrini et al., 2019). Involving the family in the education process should start the day the patient is discharged from the hospital by providing discharge planning. Then, as soon as the patient returns home, the family should be contacted by health professionals to coordinate long-term care during the patient's post-stroke recovery, monitor the patient's activity, and provide education once a week (Farahani et al., 2021).

Related to the research results above, increasing family knowledge is very important because it will impact the attitudes and behavior of families in dealing with post-stroke patients at home. For this reason, it is necessary to carry out education that involves the active participation of the family in the educational process, starting from the learning planning stage to the evaluation stage, using an adult learning approach (andragogy), one of which is the application of a participatory learning model.

Participatory learning models are a series of events in the learning process involving the learners contributing actively to learning activities, from planning, implementation, and assessment. The learners' role in participatory learning is realized as very dominant activeness and participation of learners in participatory learning (Arbarini et al., 2018). The advantages of the participatory learning model include the fact that families need the material delivered as learners/learning citizens. Families can directly participate in the educational process from the start of the learning preparation stage to the evaluation stage so that through these stages, the family will be involved from the start, accelerating family independence.

Several previous researchers have applied a participatory learning approach (PLA) in any setting. Arbarini et al. (2018) found that by utilizing a participatory learning approach, the goal of empowering the rural community was achieved by accelerating the literacy process by involving the learners in functional literacy education.

Faizah et al. (2023) identify how classroom action research (CAR) uses the Participatory Action Research (PAR) approach to find workable solutions to teacher problems. Theoretical, cognitive, and technical pre-training mastery of SDN 1 Sukomulyo teachers increased by 62% in the "less positive" category to 73% in the "positive" category following training, with an additional 31% increase in the medium category, according to the results of the training utilized by PAR. Additionally, 98% of teachers gave positive feedback on introducing CAR training. Arbarini et al. (2020) stated that PLA encourages participants in the Keluarga Harapan Program to act responsibly, lead fulfilling lives, and make the most use of their knowledge in health and education.

Several previous researchers have also studied the application of participatory learning in overcoming health problems. Allaham et al. (2022) found that the context-specific and economical PLA model has demonstrated improved health outcomes. Seal et al. (2023) studied using a modified participatory learning and action cycle to improve immunization awareness and uptake among internally displaced people living in camps. The study's findings indicated that the PLA approach can significantly alter public health practices and knowledge in humanitarian settings when implemented in collaboration with indigenous social groups.

The result of this study, by a previous study by Chakraborty et al. (2020), was implementing a community-based intervention that used participatory learning and action to stop violence against women and girls in Mumbai's informal settlements. According to the findings, community members and support services in vulnerable urban informal settlements can benefit from participatory approaches that help create

relationships and networks. They can also produce nuanced understandings of gender inequality, violence, and potential mechanisms and barriers that can help interventions.

A beneficial effect of research on using participatory learning methods interventions during the COVID-19 pandemic was increased student health literacy (Cahyanti et al., 2024). A study by Putri et al. (2020) concludes that a participatory learning model can be developed and implemented to raise family awareness of the importance of parenting during the first thousand days of life to prevent stunting. The forms of family participation in health promotion vary widely, with the lack of participatory practices being a significant challenge. Family participation is a valuable approach in shaping health promotion and should be further developed so that families will be equipped to care for post-stroke patients at home (Kuchler et al., 2022).

Consequently, to improve their knowledge, attitudes, and abilities, nurses must teach their families about the importance of treating stroke patients at home Sheha et al., (2020) and to improve their comprehension of the dangers of having another stroke and the difficulties associated with patients' dependence on their families (Deyhoul et al., 2018). According to a study, Sun et al. (2023) concluded that telerehabilitation can effectively reduce the caregiver burden and improve stroke caregivers' knowledge and competence. (2020) indicated that using smartphone-enabled education can effectively meet the needs of family stroke survivors. Furthermore, to involve and promote family givers in treating poststroke patients, community training programs and support groups need to be established (Kuchler et al., 2022).

CONCLUSION

This study concluded that up to now, not all families of stroke patients receive and utilize homecare services for various reasons, including ignorance, inability, and unpreparedness, as well as inability to pay the costs. It is necessary to conduct research using the research and development (R & D) method with topics related to developing homecare service models for post-stroke patients at home based on participatory learning to improve the ability and independence of families in continuing the management of post-stroke patients at home. Therefore, the novelty of this research is the production of a model design that can answer the needs of families to increase independence in treating post-stroke patients at home as well as reduce family dependency on homecare agencies so that it can reduce the costs of treating patients at home.

REFERENCES

- Allaham, S., Kumar, A., Morriss, F., Lakhanpaul, M., Wilson, E., Sikorski, C., Martin, J., Costello, A., Manikam, L., & Heys, M. (2022). Participatory learning and action (PLA) to improve health outcomes in high-income settings: A systematic review protocol. *BMJ Open*, *12*(2), 1–6. <https://doi.org/10.1136/bmjopen-2021-050784>
- Alshahrani, A. M. (2020). Quality of life and social support: Perspectives of Saudi Arabian stroke survivors. *Science Progress*. <https://doi.org/10.1177/0036850420947603>
- Arbarini, M., Jutmini, S., Joyoatmojo, S., & Sutarno. (2018). Effect of Participatory Learning Model on Functional Literacy Education. *Journal of Nonformal Education*, *4*(1), 13–24.
- Arslan, A. (2023). Characteristics, types, and functions of family concept. *African Educational Research Journal*, *11*(1), 45–48. <https://doi.org/10.30918/aerj.111.23.001>
- Askari, H., Yaghoubinia, F., Keykhah, A., & Karimi, F. (2018). Investigating the Effect of Home-Based Training for Family Caregivers on the Incidence of Bedsore in Patients with Stroke in Ali Ebne Abitaleb Hospital, Zahedan, Iran: A Clinical Trial Study. *Medical-Surgical Nursing Journal, In Press*(In Press). <https://doi.org/10.5812/msnj.87325>
- Aspects of informal education and its characteristics*. (2022). <https://doi.org/10.15651/2437-1882.22.3.033>.DESCRIPTION
- Bayerlein, L. (2020). The impact of prior work experience on student learning outcomes in simulated internships. *Journal of University Teaching and Learning Practice*, *17*(4), 1–19.

<https://doi.org/10.53761/1.17.4.4>

- Cahyanti, E. T., Lubis, S. M., Hidayah, S. N. R., Andhika, H. P., & Arifah, I. (2024). Efektifitas Metode Participatory Learning Terhadap Peningkatan Literasi Kesehatan pada Masa Pandemi COVID-19. *Perilaku Dan Promosi Kesehatan: Indonesian Journal of Health Promotion and Behavior*, 5(2), 62. <https://doi.org/10.47034/ppk.v5i2.6916>
- Cha, Y. J. (2018). The economic burden of stroke is based on South Korea's national health insurance claims database. *International Journal of Health Policy and Management*, 7(10), 904–909. <https://doi.org/10.15171/ijhpm.2018.42>
- Chakraborty, P., Daruwalla, N., Gupta, A. D., Machchhar, U., Kakad, B., Adelkar, S., & Osrin, D. (2020). Using Participatory Learning and Action in a Community-Based Intervention to Prevent Violence Against Women and Girls in Mumbai's Informal Settlements. *International Journal of Qualitative Methods*, 19, 1–14. <https://doi.org/10.1177/1609406920972234>
- Darmawan, D., Alamsyah, T. P., & Rosmilawati, I. (2020). Participatory Learning and Action untuk Menumbuhkan Quality of Life pada Kelompok Keluarga Harapan di Kota Serang. *Journal of Nonformal Education and Community Empowerment*, 4(2), 160–169. <https://doi.org/10.15294/pls.v4i2.41400>
- Deepradit, S., Powwattana, A., Lagampan, S., & Thiangtham, W. (2023). The effectiveness of a family-based program for post-stroke patients and families is a cluster randomized controlled trial. *International Journal of Nursing Sciences*, 10(4), 446–455. <https://doi.org/10.1016/j.ijnss.2023.09.020>
- Deyhoul, N., Vasli, P., Rohani, C., Shakeri, N., & Hosseini, M. (2018). The effect of educational intervention on family caregivers' perceived threat of the risk of dependence among patients with stroke: A randomized clinical trial. *Iranian Red Crescent Medical Journal*, 20(6). <https://doi.org/10.5812/ircmj.65467>
- Diaz-Quijano, F. A., Martínez-Vega, R. A., Rodriguez-Morales, A. J., Rojas-Calero, R. A., Luna-González, M. L., & Díaz-Quijano, R. G. (2018). Association between the level of education and knowledge, attitudes, and practices regarding dengue in the Caribbean region of Colombia. *BMC Public Health*, 18(1), 1–10. <https://doi.org/10.1186/s12889-018-5055-z>
- Faizah, S. N., Khairiyah, U., Alawiyin, M., & Maulidiyah, Y. N. (2023). Pemberdayaan Guru SD melalui Participatory Action Research dalam Mengoptimalkan Kompetensi Penelitian. *Amalee: Indonesian Journal of Community Research and Engagement*, 4(1), 135–146. <https://doi.org/10.37680/amalee.v4i1.2063>
- Farahani, M. A., Bahloli, S., & ... (2020). Investigating the needs of family caregivers of older stroke patients: a longitudinal study in Iran. In *BMC ... bmcgeriatr.biomedcentral.com*. <https://doi.org/10.1186/s12877-020-01670-0>
- Farahani, M. A., Ghezjeljeh, T. N., Haghani, S., & ... (2021). The effect of a supportive home care program on caregiver burden with stroke patients in Iran: an experimental study. In *BMC Health Services ... Springer*. <https://doi.org/10.1186/s12913-021-06340-4>
- Ishak, S. J., Yueniwati, Y., & Kapti, N. R. E. (2020). Factors Related to Family Delay Bring Stroke Patients to Emergency Departments of Labuha Hospital. *International Journal of Science and Society*, 2(4), 657–672. <https://doi.org/10.54783/ijssoc.v2i4.260>
- Jones, I. D., & Brady, G. (2022). Informal Education Pedagogy Transcendence from the 'Academy' to Society in the Current and Post-COVID Environment. *Education Sciences*, 12(1). <https://doi.org/10.3390/EDUCSCI12010037>
- Kemenkes RI. (2018). Hasil Riset Kesehatan Dasar Tahun 2018. *Kementrian Kesehatan RI*, 53(9), 1689–1699
- Kuchler, M., Rauscher, M., Rangnow, P., & Quilling, E. (2022). Participatory Approaches in Family Health Promotion as an Opportunity for Health Behavior Change—A Rapid Review. *International Journal of Environmental Research and Public Health*, 19(14). <https://doi.org/10.3390/ijerph19148680>
- Lu, Q., Mårtensson, J., Zhao, Y., & Johansson, L. (2019). Living on the edge: A qualitative study: Family caregivers' experiences caring for post-stroke family members in China. *International Journal of Nursing Studies*, 94(22), 1–8. <https://doi.org/10.1016/j.ijnurstu.2019.02.016>
- Lucas-Noll, J., Clua-Espuny, J. L., Lleixà-Fortuño, M., Gavaldà-Espelta, E., Queralt-Tomas, L., Panisello-

- Tafalla, A., & Carles-Lavila, M. (2023). The costs associated with stroke care continuum: a systematic review. *Health Economics Review*, 13(1), 1–18. <https://doi.org/10.1186/s13561-023-00439-6>
- Movahed, M. S., Barghazan, S. H., Adel, A., & Rezapour, A. (2021). Economic Burden of Stroke in Iran: A Population-Based Study. *Value in Health Regional Issues*, 24, 77–81. <https://doi.org/10.1016/j.vhri.2020.04.004>
- Permatasari, N. (2020). Perbandingan Stroke Non Hemoragik dengan Gangguan Motorik Pasien Memiliki Faktor Resiko Diabetes Melitus dan Hipertensi. *Jurnal Ilmiah Kesehatan Sandi Husada*, 11(1), 298–304. <https://doi.org/10.35816/jiskh.v11i1.273>
- Putri, D. K., Herawati, T., Alfiasari, A., Riany, Y. E., Latifah, M., Dwi, H., Jihan, I. R., & Indro, M. N. (2020). Edukasi Keluarga Pengasuhan 1000 HPK untuk Pencegahan Stunting di Desa Cibatok 2. *Jurnal Pusat Inovasi ...*, 2(1), 18–27. <https://jurnal.ipb.ac.id/index.php/pim/article/view/29557>
- Rahma, R. A., Zulkarnain, Desyanty, E. S., & Wahyuni, S. (2019). The Role of Community Learning Center (CLC) in Providing Nonformal Education Services Based on Entrepreneurship. *Journal of Nonformal Education*, 5(2), 109–116. <https://journal.unnes.ac.id/nju/index.php/jne>
- Roberts, M. K., Stewart, K. A., Tessore, N. M., San Roman, E., Harris, G., Goldenberg, F. D., & Prvu Bettger, J. (2021). Experiences of Family Caregivers After an Acute Neurological Event. *Neurocritical Care*, 34(1), 45–53. <https://doi.org/10.1007/s12028-020-00973-9>
- Seal, A. J., Mohamed, H. A., Stokes-Walter, R., Mohamed, S., Abdille, A. M., Yakowenko, E., Sheikh Omar, M., & Jelle, M. (2023). Use of an adapted participatory learning and action cycle to increase knowledge and uptake of child vaccination in internally displaced person camps (IVACS): A cluster-randomized controlled trial. *Vaccine*, 41(19), 3038–3046. <https://doi.org/10.1016/j.vaccine.2023.02.016>
- Septianingrum, Y., Yusuf, A., Widyawati, I. Y., Zrechva, T. F., Wijayanti, L., Hatmanti, N. M., & Fitriasari, A. (2023). Correlation between family support and self-efficacy in stroke survivors. *Bali Medical Journal*, 12(3), 2784–2787. <https://doi.org/10.15562/bmj.v12i3.4375>
- Sheha, E. A. A. E. M., Soultan, A. A. A., Malk, R. N., & Elsherbeny, E. M. M. (2020). Effect of a Planned Health Teaching on Improving Knowledge and Competence of Home Care Practice of Post Stroke Patient Among Caregivers' Achievement. *International Journal of Studies in Nursing*, 5(2), 51. <https://doi.org/10.20849/ijsn.v5i2.761>
- Sidek, N. N., Kamalakannan, S., Tengku Ismail, T. A., Musa, K. I., Ibrahim, K. A., Abdul Aziz, Z., & Papachristou Nadal, I. (2022). Experiences and needs of the caregivers of stroke survivors in Malaysia—A phenomenological exploration. *Frontiers in Neurology*, 13. <https://doi.org/10.3389/fneur.2022.996620>
- Stiexs, A., & Chayati, N. (2021). A systematic review of the family caregiver's physical, psychological, and spiritual impact in home-based stroke treatment. *Open Access Macedonian Journal of Medical Sciences*, 9(T4), 236–239. <https://doi.org/10.3889/oamjms.2021.5795>
- Sun, W. J., Song, Y. Y., Wang, C., Jiang, Y., Cui, W. Y., Liu, W. J., & Liu, Y. (2023). Telerehabilitation for Family Caregivers of Stroke Survivors: A Systematic Review and Meta-Analysis. *Journal of Nursing Management*, 2023. <https://doi.org/10.1155/2023/3450312>
- Taft, K., Laing, B., Wensley, C., Nielsen, L., & Slark, J. (2021). Health promotion interventions post-stroke for improving self-management: A systematic review. *JRSM Cardiovascular Disease*, 10, 204800402110044. <https://doi.org/10.1177/20480040211004416>
- Tang, Y. Y., & Chen, S. P. (2002). Health promotion behaviors in Chinese family caregivers of patients with stroke. *Health Promotion International*, 17(4), 329–339. <https://doi.org/10.1093/heapro/17.4.329>
- Ugur, H. G., & Erci, B. (2019). The effect of home care for stroke patients and education of caregivers on the caregiver burden and quality of life. *Acta Clinica Croatica*, 58(2), 321–332. <https://doi.org/10.20471/acc.2019.58.02.16>
- Utaiasang, A., Pearkao, C., Junsevg, K., Sangsaikaew, A., Boonkong, D., & Korcharoenyos, C. (2021). Family members' experiences in caring for stroke patients: A case study in the border provinces of the upper Northeast of Thailand. *Open Access Macedonian Journal of Medical Sciences*, 9, 172–179. <https://doi.org/10.3889/oamjms.2021.7125>
- Vidyanti, A. N., Muhrodji, P., Wicaksono, H. D. A., Satiti, S., Trisnantoro, L., & Setyopranoto, I. (2022).

- Roles and Problems of Stroke Caregivers: A Qualitative Study in Yogyakarta, Indonesia. *F1000Research*, 10, 1–24. <https://doi.org/10.12688/f1000research.52135.2>
- Wagachchige Muthucumarana, M., Samarasinghe, K., & Elgán, C. (2018). Caring for stroke survivors: experiences of family caregivers in Sri Lanka—a qualitative study. *Topics in Stroke Rehabilitation*, 25(6), 397–402. <https://doi.org/10.1080/10749357.2018.1481353>
- Yusrini, Susanti, H., Wardani, I. Y., & Fitriani, N. (2019). Family experience in providing support and achieving post-stroke late adulthood development. *Enfermeria Clinica*, 29, 900–904. <https://doi.org/10.1016/j.enfcli.2019.04.137>
- Zhang, L., Shu, Y., Han, C., & Liu, J. (2023). Correlation Between Family Functioning and Health Beliefs in Patients with Stroke in Beijing, China. *Journal of Multidisciplinary Healthcare*, 16(February), pp. 1067–1074. <https://doi.org/10.2147/JMDH.S394396>
- Zhou, S. (2023). *Formal, Nonformal, and Informal Education in China* (Issue Isemss). Atlantis Press SARL. https://doi.org/10.2991/978-2-38476-126-5_53