

## The Influence of Family Centered Care Against Quality Life of Stroke Patient at Home in Tomohon City Indonesia

Vione Deisi Oktavina Sumakul<sup>1\*</sup>, Brigita Maria Karouw<sup>2</sup>, Henny Pongantung<sup>3</sup>,  
Ake Royke Calvin Langingi<sup>4</sup>

Gunung Maria Tomohon College of Health Sciences

**Corresponding Author:** Vione Deisi Oktavina Sumakul [vionesumakul@gmail.com](mailto:vionesumakul@gmail.com)

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### ABSTRACT

Stroke is a neurological condition that can lead to death, physical and mental impairment, and even premature death. It is important to understand the changes that occur in the early stages of a stroke as they contribute to cell damage at the time of the stroke. It is vital to undertake self-intervention that is expected to improve healing, quality of life, hospitalization time, and stroke mortality.. The aim of this study was to analyze the influence of family centered care against quality life of stroke patient at home in Tomohon City, Indonesia. The method used was pre-experimental with a pre-post test design with a sample of 150 patients stroke using the Wilcoxon test. The sampling technique uses non-probability. The instruments were used questionnaire about family care centered for patient stroke. The research results obtained a value of  $p = 0.001 < \alpha = 0.05$ , stating that there was an influence of family centered care on stroke patient care at home in Tomohon City. The conclusion in this study is that level of family centered care on stroke patient care must be increase at home in Tomohon City to reducing level of stress. It is because family centered care on stroke patient increase quality of life patient stroke.

## **INTRODUCTION**

The World Health Organization (WHO) describes stroke as a symptom that occurs suddenly and causes brain dysfunction that lasts for 24 hours or more. Stroke can occur due to a broken or blocked cerebral blood vessel, which stops a part of the brain from getting the blood supply that carries the necessary oxygen, causing cell death or cell damage (Basuni et al., 2023). Stroke is a neurological condition that can lead to death, physical and mental impairment, and even premature death. It is important to understand the changes that occur in the early stages of a stroke as they contribute to cell damage at the time of the stroke. It is vital to undertake self-intervention that is expected to improve healing, quality of life, hospitalization time, and stroke mortality (Bakri et al., 2020).

According to the latest estimates of the Global Burden of Disease (GBD) in 2019, stroke remains the second leading cause of death and the third leading reason for disability worldwide when combined with years of life lost due to disability. (disability-adjusted life-years, or DALYs). More than \$891 billion (1,12% of global GDP) is estimated to be spending stroke costs worldwide (Feigin et al., 2022). In the world, strokes are a significant public health problem. About 5.5 million people die from strokes every year, and 44 million people suffer from disabilities. Data analysis from the 2019 GBD study showed an increase in the total stroke incidence of 70.0 from 1990 to 2019, while a decrease in the incidence rate of age-adjusted ischemic stroke by 10% and a decline in the number of intracerebral bleeding by 29.0 over the same period (Utama & Nainggolan, 2022); (Benjamin et al., 2019). In addition to the impact on stroke victims, the related defects also pose significant challenges for nurses (Hu et al., 2016).

Data on stroke patients in Indonesia according to Basic Health Research (RISKESDAS) data in 2018 reached 713,783 patients (10.9%) of the total Indonesian population. The patients mentioned are of all age categories, i.e. over 15 years. Stroke is commonly found in people between middle-aged adults and the elderly (Kementerian Kesehatan RI, 2019). Although stroke is the number one disability and number two cause of death in the world after heart disease, about 90% of stroke cases can be prevented by controlling risk factors such as hypertension, smoking, unbalanced diet, lack of physical activity, diabetes, and atrial fibrillation (Direktorat Jenderal Pelayanan Kesehatan Kemenkes RI, 2023).

In 2021, the third highest number of strokes in Indonesia will be in North Sulawesi Province. In solving this problem, the public must better understand the risk factors of strokes that can be modified and non-modified (Warouw; & Wilar, 2023). In 2023 it will rise to the first national ranking according to the diagnosis of health workers with prevalence (10.8%), followed by Yogyakarta (10.3%), Bangka Belitung, and DKI Jakarta with 9.7 strokes per mile respectively. (Halinda et al., 2023).

For long-term effects of strokes often lead to increased stress in patients. Besides the patient, the family is also the caregiver for the stroke patient. One of the family health tasks is to take care of family members who have health

problems, including stroke patients. These family duties and roles are called guardians. Being a caregiver if a family member has health problems is their responsibility (Rahmani et al., 2019). A person who provides assistance to someone who is disabled and needs help because of illness or limitation, such as a spouse, child, grandson, nephew, brother, neighbor, friend, or other family relationship, is called a caregiver (Pesantes et al., 2017).

Families of stroke sufferers believe that stroke treatment is focused only on their illness problems, although the needs of the stroke sufferer vary widely. A basic human need is a need to be met by a stroke patient, but most families don't understand it. One of the basic human needs is to maintain life and health; the inability to fulfil this self-care physically leads to new diseases (Oktovin et al., 2020). Quality of life is the judgment of a person's life. In the acute phase after a stroke, patients with poor functional status tend to have poor quality of life (Novera et al., 2019).

Proper treatment is needed during the advanced treatment phase as it can lead to complications. Patients who have had a stroke often return to the hospital with advanced symptoms, such as loss of motor skills (hemiplegial or hemiparesis), total bedrest, loss of communication or speaking difficulties (halting), perception disorders, cognitive dysfunction, and psychological effects, which interfere with daily life activities (ADL) to meet basic human needs (Sadia, 2020).

Health problems of stroke patients or their unwillingness to return home may be affected by their family's ignorance or inability to treat at home (Al-Mahdi et al., 2022). Stroke sufferers and family members have historically found themselves treated in healthcare systems driven by biomedical or disease-oriented care models. (perawatan tradisional yang pasif). Even today, health care is often based on scientific empiricism, is reductive, reactive, and disease-centred. Patients treated in this type of care model have little or no contribution or responsibility (Creasy et al., 2016). The stress levels of the post-test and pre-test patients are very different, always showing the rate of decrease after intervention (Fiana, 2023).

Previous research by I. Fouad et al., (2022), his findings show that patients and caregivers tested experienced significant changes in the self-efficiency category before and after empowerment. Although all nurses experience severe levels of weight before being trained, two-thirds of them experience low to moderate levels of load after training. This research shows that by implementing a family-based empowerment model regularly and consistently, levels of self-efficiency, self-esteem, perceived threats, and the burden borne by the caregiver can be increased. This will facilitate the path to healthy aging and staying healthy during this period. According to this study, empowerment initiatives should be made to provide individuals and their guardians with the tools they need to engage in activities, especially at the beginning.

The same is true of the study by Adhitya et al., (2020) where the results of his literature review show that implementation of discharge planning for stroke patients in Indonesia, especially patients and their families, has positive

effects, such as improved quality of life, muscle strength, and reduced patient dependence on others. In addition, they are able to improve knowledge, attitude, service, readiness, and support on how to treat stroke patients at home. Therefore, researchers can use these findings as a basis for further research on how to apply discharge planning well to stroke patients and patients' families at home, thereby improving the quality of nursing care in Indonesia

A study by Lutfi S & Mintarsih (2021) found that improving the quality of life of stroke patients was also determined by family knowledge. Research with the method of research using the quantitative research method with the cross sectional approach with the number of samples in this study that is as many as 105 people, using the statistic rank spearman test. This research states that the importance of family support systems in the treatment of stroke patients in improving the quality and functional capacity of the stroke patient body.

The study analyses the impact of home-centric stroke care on family care. Furthermore, the study explores the scientific validity of the use of family-based care interventions to look at the quality and spirit of life of stroke patients and offers methodological insights for related studies. Family-centric stroke patient care interventions have proven to be effective interventions in boosting the spirit, self-motivation for life. Effectiveness development of these interventions can be used as models as well as useful guidelines to improve the quality of life of stroke patients at home.

## **THEORETICAL REVIEW**

### ***Understanding Stroke and Its Impact on Quality of Life***

Stroke is a major health issue that can lead to significant physical, cognitive, and emotional impairments, profoundly affecting a patient's quality of life. The aftermath of a stroke often includes challenges such as mobility limitations, speech difficulties, and emotional distress, which can severely impact the patient's ability to perform daily activities and maintain social relationships. Quality of life (QoL) for stroke patients is multidimensional, encompassing physical health, psychological well-being, social relationships, and environmental factors. According to the World Health Organization (WHO), quality of life is defined as an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns.

### ***Family-Centered Care (FCC) Conceptual Framework***

Family-Centered Care (FCC) is an approach to healthcare that recognizes the vital role of the family in the patient's recovery and well-being. FCC is grounded in the understanding that the family is the constant in a patient's life, whereas healthcare providers may change. The core principles of FCC include respect for the patient and family's preferences, providing comprehensive information, involving family members in care decisions, and offering emotional support. FCC is particularly relevant in the management of chronic conditions like stroke, where long-term care and support are necessary.

### ***The Role of Family-Centered Care in Stroke Recovery***

In the context of stroke recovery, FCC focuses on involving family members in the care process, ensuring they are well-informed about the patient's condition, treatment options, and rehabilitation strategies. By empowering the family with knowledge and skills, FCC aims to improve the overall care environment at home, which can positively impact the patient's recovery and quality of life. The supportive role of family members can help alleviate the psychological burden of the patient, reduce feelings of isolation, and enhance adherence to rehabilitation programs. Studies have shown that when family members are actively involved in care, patients are more likely to experience better functional outcomes, greater satisfaction with care, and improved quality of life.

### ***Mechanisms Through Which FCC Improves Quality of Life***

FCC enhances quality of life for stroke patients through several mechanisms:

1. **Emotional Support:** The presence of supportive family members can reduce anxiety and depression, common psychological issues following a stroke. Emotional support from the family is crucial for boosting the patient's morale and motivation to engage in rehabilitation.
2. **Practical Assistance:** Family members can assist with daily activities, transportation to medical appointments, and adherence to medication regimens, which are vital for the patient's recovery and well-being.
3. **Continuity of Care:** By involving family in care planning and decision-making, FCC ensures that the care provided at home is consistent with the patient's needs and preferences, leading to a more personalized and effective care experience.
4. **Empowerment and Education:** FCC emphasizes educating family members about stroke and its management, enabling them to better support the patient and improve the home care environment.

### ***Empirical Evidence Supporting FCC in Stroke Care***

Research has demonstrated that FCC can significantly improve the quality of life in patients with chronic conditions, including stroke. Studies have found that patients receiving FCC report higher satisfaction with care, better emotional well-being, and improved physical function. For example, a study by Bakas et al. (2006) found that stroke patients whose families were involved in their care experienced better outcomes in terms of functional independence and quality of life compared to those who did not receive FCC. Another study by Greenwood et al. (2009) emphasized the importance of involving family members in the rehabilitation process, as it contributes to more favorable recovery outcomes.

### ***Application of FCC in Tomohon City, Indonesia***

In the context of Tomohon City, Indonesia, implementing FCC for stroke patients can be particularly beneficial given the cultural emphasis on family support and communal living. The integration of FCC into home care practices can help bridge gaps in healthcare access and support services, ensuring that stroke patients receive continuous and holistic care in a familiar environment. The local healthcare system can benefit from adopting FCC principles by providing training and resources to families, thereby enhancing the overall quality of life for stroke patients in the community.

## **METHODOLOGY**

### ***General Overview of Patients Stroke Data Methods.***

A pre-experimental approach with a sample of 150 stroke patients' families is one of the assessment methodologies frequently used in evaluating the effectiveness of imaging therapy. Because of abnormal data (Sig.  $0.040 < \alpha 0.05$ ), the Wilcoxon test is used to test for normality. The Colmogorov Sminornov test was used because there were more than 50 respondents in the information. Pre and post-stroke tests are techniques for assessing stroke treatment of patients with family-centric care interventions.

This research focuses on the following important aspects:

1. Patient Stroke Treatment Data Before Intervention. This study offers a new approach to measuring stroke treatment of patients with family-centric care interventions.
2. Post-intervention Stroke Treatment Data. After providing family-centric care intervention, give an overview of the effectiveness of this intervention in improving the quality of life of the patient.
3. Assessment of Changes in Care of Stroke Patients After Intervention. According to statistical analysis, family-centric care can improve the quality of life of patients. It offers stronger support for clinical management choices in relation to the successful execution of stroke patients.
4. Useful implementation in clinical situations at home. In the city of Tomohon, Indonesia, the study also highlights the importance of providing family-centric care at home. It practically helps in improving the service of stroke patients.

Thanks to these advances, research not only improves the body of literature but also provides modelling that can be used to more successfully build a family-centric stroke patient care enforcement.

## **RESULTS**

The aim of this study was to analyze the interventions used to evaluate differences in the quality of life of stroke patients before and after the intervention. Here are the main findings of this study:

*Respondent Characteristics*

**Table 1. Frequency Distribution Of Respondents**

<b>Demographic Characteristics</b>	<b>n</b>	<b>(%)</b>
<b>Age</b>		
• 35-45 Years Old	4	2,7
• 46-55 Years Old	78	52
• 56-65 Years Old	45	30
• 66-75 Years Old	20	13,3
• >76 Years Old	3	2
<b>Sex</b>		
• Male	70	46,7
• Female	80	53,3
<b>Education</b>		
• Elementary School	0	0
• Junior High School	3	2
• Senior High School	140	93,3
• University	7	4,7
<b>Stroke Type</b>		
• SH	15	10
• SNH	135	90
<b>Causes of Disease</b>		
• Hypertension	67	44,7
• Obesity	54	36
• Alcoholic	29	19,3

*Univariat Analysis*

**Table 2. Quality Life of Stroke Patient at Home Pre Intervensi in Tomohon City Indonesia.**

<b>Items</b>		<b>Pre-test (n=150)</b>	
		<b>n</b>	<b>(%)</b>
<b>Problem Solving</b>	Low	146	97,3
	Moderate	3	2
	High	1	0,7
<b>Care in context of FCC</b>	Collaboration	10	6,7
	Flexibility	126	84
	Incorporation	14	9,3
<b>Autonomy</b>	Low	148	98,7
	Moderate	2	1,3
	High	0	0
<b>Seeking social support</b>	Low	149	99,3
	Moderate	1	0,7

	High	0	0
<b>Negotiation</b>	Make decisions together	140	93,4
	Empowering families	5	3,3
	Involvement of family	5	3,3

**Table 3. Quality Life of Stroke Patient at Home Post Intervensi in Tomohon City Indonesia.**

	Items	Post (n=150)	
		n	(%)
<b>Problem Solving</b>	Low	0	0
	Moderate	2	1,3
	High	148	98,7
<b>Care in context of FCC</b>	Collaboration	145	96,7
	Flexibility	5	3,3
	Incorporation	0	0
<b>Autonomy</b>	Low	0	0
	Moderate	3	2
	High	147	98
<b>Seeking social support</b>	Low	2	1,3
	Moderate	1	0,7
	High	147	98
<b>Negotiation</b>	Make decisions together	2	1,3
	Empowering families	2	1,3
	Involvement of family	146	97,4
		4	

*Bivariate Analysis*

**Table 4. Differences Quality Life of Stroke Patient at Home Before and After Family Centered Care in Tomohon City Indonesia (n=150)**

Items		Pre (n=150)		Post (n=150)		p
		n	(%)	n	(%)	
<b>Problem Solving</b>	Low	146	97,3	0	0	.001*
	Moderate	3	2	2	1,3	
	High	1	0,7	148	98,7	
<b>Care in context of FCC</b>	Collaboration	10	6,7	145	96,7	.001*
	Flexibility	126	84	5	3,3	
	Incorporation	14	9,3	0	0	
<b>Autonomy</b>	Low	148	98,7	0	0	.001*
	Moderate	2	1,3	3		
	High	0	0	147		
<b>Seeking social support</b>	Low	149	99,3	2	1,3	.000*
	Moderate	1	0,7	1	0,7	
	High	0	0	147	98	
<b>Negotiation</b>	Make decisions together	140	93,4	2	1,3	.001*
	Empowering families	5	3,3	2	1,3	
	Involvement of family	5	3,3	146	97,4	

**DISCUSSION**

This study examines pre-experimental methods, where the intervention of family centered care as an intervention to increase the quality life of stroke patient at home. The results of the study show that family centered care increase the quality life of stroke patient.

The results of this study are in line with Hiengkaew & Vongsirinavarat (2016) stating that one factor in improving the quality of life of post-stroke patients undergoing home treatment is through physical therapy for individuals. It's part of the problem solving in improving the quality of life of post-stroke patients. Study by Galvin et al. (2011) stated that there was no statistically significant improvement (P0.05), but this improvement lasted for three months of observation. During the follow-up, participants in the FAME community are more integrated into the community. Compared to the control group, family members in the FAME group significant levels of care stress on monitoring

(P0.01). Conclusion: This evidence-based FAME intervention can help maximize patient recovery and family involvement after acute stroke by using all available resources. It's part of the problem solving stroke patient care.

Salamung et al. (2021) suggest that families assume certain health-related duties. There are five aspects of health: the family's knowledge of each member's health issues; their ability to decide what steps to take when a family member becomes unwell; their ability to keep the home's atmosphere intact; and their capacity to utilize the health facilities that are available. A happy household is one in which members are able to communicate their thoughts, feelings, and disagreements in an honest, transparent, and spontaneous manner; they can also recognize and value each other's emotions; encourage each other's independence; take responsibility for their actions; and behave in a close, loving, and supportive manner.

The same is true of Kasornsunt (2016) where in his research states that factor care in context of family centered care (FCC) is a transitional matter. This is because the treatment of stroke patients at home is usually flexible. Besides, there are collaborative treatments, but they cost a lot because they involve multidisciplinary treatment. Incorporation or unification factors are also needed in the treatment of stroke patients at home. Similarly, a study by Kurniati et al. (2022) stated that care requires a collaborative bond between nurses, patients and post-hospitalization families, with the aim of preparing the victim's physical, psychological, social, family independence, knowledge, care skills and sustainable reference systems.

Study by I. Fouad et al. (2022) also involved families in stroke treatment to improve the quality of life of the victims. As part of family centered care especially for negotiating factors, care also requires family involvement. Besides, patients also need to make joint decisions so that the treatment process goes as expected. According to Phinyo et al. (2015) the treatment of stroke patients at home is not exempt from social support. If the patient does not get the support of the community then the patient will lose hope and spirit for life.

The results of Focus Group Discussion (FGD) and observations are qualitative sources of data. Instead, quantitative data is obtained through the dissemination of FCC questionnaires, evaluation of the status of ingestion of stroke patients, and analysis of observations using descriptive statistical tests. In the treatment of stroke patients with dysphagia disorder, this research has developed the FCC Model, which is a reference in medicine. It has a positive impact on improving skills, ability to practice swallowing, and evaluation of swallows ability in the therapy of strokes patients with disphagia disturbance. Furthermore, the development of the Model FCC at the Center enables nurses to apply FCC values when treating stroke patient with a dysphagic disorder (Al-Mahdi et al., 2022).

The study by Husna & Hidayati (2020) results showed that self-care stroke patients who received empowerment therapy experienced a significant improvement compared to the group that did not receive intervention. To enhance self-care of stroke patients, empowerment therapy is recommended. Kosasih et al. (2018) on them study findings show that health education

contributes to increased knowledge of patients and their families about stroke, preparedness, the role of the family in treating patients who have suffered strokes, psychological support, and preparation for home care of patients who suffer from stroke. However, health education does not affect the level of readiness of stroke patients to receive the transition. Recommendation: Health education is not sufficient to improve the preparedness of patients who suffer the stroke to receive transitions.

Based on the results of this study, the researchers argue that the improvement in the quality of life of stroke patients at home is determined by the family centered care (FCC) which includes the family as problem solving, as a careful family in the context, as autonomy, seeking social support, and as a negotiator.

## **CONCLUSIONS AND RECOMMENDATIONS**

In conclusion, there was an improvement in the quality of life of stroke patients during home care using family-centric care interventions. Although this approach is judged correct, it still has shortcomings. These interventions are not reliable enough to measure the level of stress as well as the quality of stroke patients when treated at home. Therefore, the study suggests new approaches such as family as problem solving, as family caring in context (FCC), as autonomy, seeking social support, and as negotiators as well as providing training to families in providing care to stroke patients without using rigid and passive methods of care.

For further research, some recommendations can be given are as follows:

1. **Data and Method Development:** Conducting further research to develop the results of this research. Similarly, this is an appropriate method and more recommended to use modeling methods so that management of stroke patient care at home is more effective.
2. **Enhancing Index Methods:** Reducing subjectivity in weighing and selecting indicators in index methods by developing a more objective and family-based approach. Using more sophisticated analytical techniques can help improve the accuracy and validity of measurement results.
3. **Unidirectional research:** Conduct unidirectional studies to monitor the progress of stroke patient care at home. It provides a deeper insight into the factors that contribute to reducing stress levels and improving the quality of life of stroke patients during home treatment.
4. **Collaboration between Researchers and Institutions:** This encourages collaboration between researchers, academic institutions, to gather richer data and share best practices in measuring and developing treatment in patients suffering from retirement system disorders as well as family care.

It is hoped that through these recommendations, further research could become a family-centric stroke patient care solution and make a more significant contribution to reducing stress levels and improving the quality of life of stroke patients treated at home.

## FURTHER STUDY

Some limitations in this study need to be considered. First, the research team had to adapt to stroke patients at home because of high levels of stress and very low life expectancy. Second, the distance between the researchers and each respondent's home varied, some near and some far enough so that the monitoring of family care for the stroke patient was not optimal. Third, more samples are needed to maintain the validity of this study.

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