



## ORIGINAL ARTICLE

# PRIMARY FAMILY CAREGIVER PSYCHOLOGICAL STRESS OF STROKE SURVIVORS AT RSUD DR. H. SLAMET MARTODIRJDO PAMEKASAN

*Stres Psikologis Primary Family Caregiver Penderita Stroke di RSUD Dr. H. Slamet Martodirdjo Pamekasan*

Itsnatur Rizkiyah Apriliyanti<sup>1</sup>, Santi Martini<sup>2</sup>, Muhammad Aziz Rahman<sup>3</sup>, Ronnel D. Dela Rosa<sup>4</sup>

<sup>1</sup>Magister of Epidemiology, Faculty of Public Health, Universitas Airlangga, Surabaya, Indonesia, 60115, [itsnaturra23@gmail.com](mailto:itsnaturra23@gmail.com)

<sup>2</sup>Department of Epidemiology, Biostatistic, Population Studies and Promotion of Health, Faculty of Public Health, Universitas Airlangga, Surabaya, Indonesia, 60115, [santi-m@fkm.unair.ac.id](mailto:santi-m@fkm.unair.ac.id)

<sup>3</sup>Department of Public Health, Institute of Health and Wellbeing, Federation University, Australia, 3350, [ma.rahman@federation.edu.au](mailto:ma.rahman@federation.edu.au)

<sup>4</sup>Bataan Peninsula State University, College of Nursing and Midwifery, Bataan, Philippines, 2100, [rddelarosa@bpsu.edu.ph](mailto:rddelarosa@bpsu.edu.ph)

Corresponding Author: Santi Martini, [santi-m@fkm.unair.ac.id](mailto:santi-m@fkm.unair.ac.id), Department of Epidemiology, Biostatistic, Population Studies and Promotion of Health, Faculty of Public Health, Universitas Airlangga, Surabaya, 60115, Indonesia

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### ABSTRACT

**Background:** Primary Family Caregiver (PFC) has a vital role in providing care for stroke survivors and meeting their needs during a long-term recovery period. However, the PFC of stroke survivors experienced stress from a low level to a very high level. **Purpose:** Research to analyze the PFC psychological stress of stroke survivors has been conducted in Pamekasan. **Methods:** This type of research is a quantitative, analytic survey, and cross-sectional approach. The research subjects were 103 PFC ischemic stroke survivors who were outpatients at RSUD Dr. H. Slamet Martodirdjo Pamekasan. The sampling technique in this study was simple random sampling. The Depression Anxiety Stress Scale (DASS) questionnaire has been used to measure PFC stress levels. **Results:** Spearman-Rho analysis between education and stress level showed a correlation coefficient 0.22 with  $p = 0.02$  ( $p < 0.05$ ). This result means that there is a positive relationship between the two variables. However, age, gender, occupation, income, and kinship relationships did not have a significant relationship with the PFC psychological stress of stroke survivors. **Conclusion:** There is a positive relationship between education and stress levels. Health workers can form the PFC communities to help increase knowledge, skills, and coping strategies.

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## ABSTRAK

**Latar Belakang:** Primary Family Caregiver (PFC) memiliki peran penting dalam memberikan perawatan kepada penderita stroke dan pemenuhan kebutuhan pada masa pemulihan jangka panjang. Namun PFC penderita stroke mengalami stres mulai dari level rendah hingga level yang sangat tinggi. **Tujuan:** Penelitian dilakukan untuk menganalisis stres psikologis PFC penderita stroke dilakukan di Pamekasan. **Metode:** Jenis penelitian adalah kuantitatif, bersifat survei analitik, dan pendekatan cross sectional. Subjek penelitian yaitu 103 PFC penderita stroke iskemik yang rawat jalan di RSUD Dr. H. Slamet Martodirdjo Pamekasan. Teknik sampling dalam penelitian ini adalah simple random sampling. Kuesioner Depression Anxiety Stress Scale (DASS) digunakan untuk mengukur tingkat stres PFC. **Hasil:** Analisis Spearman-Rho antara pendidikan dengan tingkat stres menunjukkan nilai koefisien korelasi sebesar 0,22 dengan nilai  $p = 0,02$  ( $p < 0,05$ ). Hasil ini mengartikan bahwa terdapat hubungan positif antara kedua variabel tersebut. Namun usia, jenis kelamin, pekerjaan, pendapatan, dan hubungan kekerabatan tidak memiliki hubungan yang signifikan dengan stres psikologis PFC penderita stroke. **Simpulan:** Terdapat hubungan positif antara pendidikan dengan tingkat stres sehingga petugas kesehatan dapat membentuk komunitas PFC untuk membantu meningkatkan pengetahuan, keterampilan, dan strategi coping.

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## INTRODUCTION

Primary Family Caregiver (PFC) is someone who provides care to another person who has a disability or limitations due to suffering from illness. They are children, spouses, in-laws, grandchildren, siblings, neighbors, friends, or someone with other related relationships (1). PFC plays a role in providing intensive care to sufferers who experience impaired bodily function due to chronic diseases such as stroke. Sufferers are very dependent on the presence of a PFC (2). An essential role of PFC for stroke sufferers is to provide care and meet their needs during the long-term recovery period (3–6). PFC helps stroke sufferers with activities like mobility, communication, and care for sufferers physically and psychologically (1).

Stroke is still a global and national health problem. The number of stroke sufferers in the world has increased from 2015 to 2019. The cases have increased by approximately 3 million in years (7). The prevalence of stroke disease in Indonesia was known to be 10.9 per mile in 2018. East Java is a province in Indonesia. The stroke prevalence in East Java was 12.4 per mile in 2018 (8). In 2022, the Ministry of Health's Directorate General of Health Services stated that one of the treatments for stroke sufferers is providing a rehabilitation

program that aims to restore the sufferer's abilities. However, often these rehabilitation programs are not carried out routinely because the costs are too high, and there are logistics, and psychological problems. Therefore, a home-based rehabilitation program is needed that involves family members of stroke sufferers as caregivers in providing care at home.

Based on information from Regional Public Hospital Dr. H. Slamet Martodirdjo Pamekasan, the number of stroke patients hospitalized was ranked in the top ten compared to other diseases during the last two years, namely in 2019 and 2020. Apart from that, the majority of stroke sufferers treated at Regional General Hospital Dr. H. Slamet Martodirdjo are elderly and suffered an ischemic stroke in 2019 and 2020.

Chronic conditions experienced by stroke sufferers cause a decrease in independence and require long-term care. Someone who suffered a stroke has difficulty carrying out their activities and needs help PFC (9,10). This condition causes the PFC to have a dual responsibility, namely caring for stroke patients and adapting to their lifestyle. The higher the patient's disability, the higher the dependency on the PFC, resulting in a higher psychological burden experienced by the PFC (1,11). Research showed that 78% of PFC have experienced stress from low levels to very high

levels (12). The PFC stresses have an impact on care for stroke sufferers (13). Other research also showed that the psychological stress felt by the PFC is caused by several factors, namely the characteristics of the PFC such as age, gender, education, work, income, and kinship relationships (11,14).

Based on several things that were explained, this research aimed to analyze the psychological stress of Primary Family Caregivers (PFC) of ischemic stroke sufferers at RSUD Dr. H. Slamet Martodirdjo Pamekasan.

## METHODS

This research used an analytical survey and a cross-sectional approach. The research was conducted in Pamekasan Regency from May to October 2021. The population in this study were stroke sufferers who were outpatients at RSUD Dr. H. Slamet Martodirdjo Pamekasan from 2019 to March 2021, with 1012 stroke survivors. The inclusion criteria were ischemic stroke sufferers, elderly (46-65 years), and domiciled in Pamekasan Regency. The exclusion criteria are stroke sufferers who experience difficulty in communicating (aphasia). Four hundred stroke survivors were eligible as a sample population in this study based on the inclusion criteria. The research subjects were Primary Family Caregivers (PFC) of the eligible stroke sufferers.

The sample size used in this research was determined using the proportion estimation formula, with an estimate of 103 respondents to be included in this study. The study used a simple random sampling technique to select the study sample. The dependent variable in this study was PFC stress level. Stress level is a person's mental condition that causes physiological and psychological reactions. The independent variables in this study were age (length of life calculated from birth to the time the research was conducted, in years), gender (genital characteristics from birth), education (highest formal education level status), employment (activities carried out every day for earning a living to meet life's needs), income (results obtained after doing a job in rupiah received every day/week/month), and kinship relationships (relationship status between PFC and stroke sufferers). Depression Anxiety Stress Scale (DASS) is a questionnaire designed to measure the stress level of Primary Family Caregivers (PFC) of stroke sufferers through 14 questions about stress.

The data analysis technique used the Spearman-Rho correlation test.

This study has received ethical permission with No.70/053/432.603/KEPK/2021.

## RESULTS

Table 1 shows that the number of Primary Family Caregivers (PFC) of stroke sufferers aged >40 years (70.9%) dominates compared to Primary Family Caregivers (PFC) aged ≤40 years (29.1%).

**Table 1**  
Respondent Characteristics

Variables	n	%
<b>Age</b>		
≤40 Years	30	29.10
>40 Years	73	70.90
<b>Gender</b>		
Male	20	19.40
Female	83	80.60
<b>Education</b>		
Low	42	40.80
High	61	59.20
<b>Employment</b>		
Work	55	53.40
Doesn't Work	48	46.60
<b>Income</b>		
<Minimum Wage	80	77.70
≥Minimum Wage	23	22.30
<b>Kinship Relationships</b>		
Not a Partner	44	42.70
Partner	59	57.30
<b>Stress Level</b>		
Experiencing Stress	13	12.60
Not Experiencing Stress	90	87.40

Table 1 shows that the number of Primary Family Caregivers (PFC) of stroke sufferers aged >40 years (70.9%) dominates compared to Primary Family Caregivers (PFC) aged ≤40 years (29.1%). The results of the gender variable analysis showed that the majority of PFC are women. The percentage of female Primary Family Caregivers (PFC) is 80.60%.

Based on PFC, the level of education is included in the higher education category (59.20%), while 40.80% of others fall into the low education category. Education that is classified category as low includes not attending school (2.90%), elementary school (33%), and junior high school (4.90%). Education classified as high is senior high school (30.10%) and bachelor (29.10%).

PFC of stroke sufferers who are known to work are 53.4%. Primary Family Caregiver (PFC) job types are farmers (13.60%), laborers (12.60%), self-employed (11.70%), honorary (7.80%), civil servants/police (5.80%), and fishermen (1.90%).

Apart from that, as many as 77.7% of PFC are known to have income below the Pamekasan Regency Minimum Wage. PFC who are partners of stroke sufferers (57.30%) dominate compared to PFC who are not partners of stroke sufferers. Kinship relationships between PFC and stroke sufferers include wives or husbands (57.30%), parents of stroke sufferers (1.9%), siblings (4.90%), children of stroke sufferers (30.1%), and other relatives (5.80%). The table also shows that the majority of PFC of stroke sufferers are known not to experience stress (87.40%) when compared to PFC of stroke sufferers who experience stress (12.60%).

PFC sometimes have difficulty relaxing or relaxing (36.90%), sometimes get annoyed easily (31.10%), often spend a lot of energy because they are anxious (43.70%), sometimes quickly become impatient (21.40%), sometimes have difficulty resting (31.10%), sometimes get angry too easy (25.20%), sometimes have difficulty calming down after something disturbs them (36.90%), and periodically get easily agitated (35%).

**Table 2**  
Test of Normality

Variable	Kolmogorov-Smirnov	Significance
Age	0.44	0.00
Gender	0.49	0.00
Education	0.38	0.00
Employment	0.35	0.00
Income	0.48	0.00
Kinship Relationships	0.37	0.00
Psychological Stress	0.52	0.00

Based on the normality test on Table 2, it is known that the variables age, gender, education, employment, income, kinship relationships, and psychological stress have a significance value of 0.00 ( $p < 0.05$ ). This means that these variables are not normally distributed. This condition is the basis for determining the use of the non-parametric test for analysis, namely Spearman-Rho.

Based on bivariate tests using the Spearman-Rho test on Table 3, it is known that education has a significant relationship with the psychological

stress of PFC because the significance value is 0.02 ( $p < 0.05$ ). The correlation coefficient for these two variables is 0.22. The correlation coefficient for these two variables means that the correlation between the two is very weak. A positive value in the correlation coefficient indicates that the relationship between the two variables is unidirectional, meaning that lower education impacts the higher psychological stress level of the Primary Family Caregiver (PFC). Meanwhile, age, gender, occupation, income, and kinship relationship did not have a significant relationship with the psychological stress of Primary Family Caregivers (PFC). The significance value of the relationship between age, gender, occupation, income, and kinship with psychological stress is  $> 0.05$ .

**Table 3**  
Test of Spearman-Rho

Variable	Correlation coefficient	Significance
Age with Stress	0.01	0.89
Gender with Stress	-0.11	0.25
Education with Stress	0.22	0.02
Jobs with Stress	0.00	0.97
Income with Stress	0.06	0.52
Kinship Relationships with Stress	0.09	0.35
Kinship Relationships with Stress	0.09	0.35

Based on bivariate tests using the Spearman-Rho test on Table 3, it is known that education has a significant relationship with the psychological stress of PFC because the significance value is 0.02 ( $p < 0.05$ ). The correlation coefficient for these two variables is 0.22. The correlation coefficient for these two variables means that the correlation between the two is very weak. A positive value in the correlation coefficient indicates that the relationship between the two variables is unidirectional, meaning that lower education impacts the higher psychological stress level of the Primary Family Caregiver (PFC). Meanwhile, age, gender, occupation, income, and kinship relationship did not have a significant relationship with the psychological stress of Primary Family Caregivers (PFC). The significance value of the relationship between age, gender, occupation, income, and kinship with psychological stress is  $> 0.05$ .

## DISCUSSION

The large number of PFC aged >40 years compared to the number of PFC aged ≤40 years is because all respondents in this study were elderly stroke sufferers. As many as 55.30% of elderly stroke sufferers are partners of PFC. The ages of stroke sufferers and their partners do not differ much, so most of the PFC in this study were >40 years old. Apart from that, elderly stroke sufferers are also cared for by PFC, who are parents (1.90%), siblings (4.90%), children (5.80%), and other relatives (2.90%). They are known to be >40 years old. Different research results show that more than 78% of stroke sufferers are aged ≥ 55 years (15). Other research results indicate that the majority of PFC of stroke sufferers are elderly (16).

Most PFC are women. The results of this research are similar to those of other studies (14,17). According to different research results, it is known that 66.70% of PFC of stroke sufferers are women (14). The results of similar research state that as many as 68.80% of PFC of stroke sufferers are women (17). Other research states that most PFC are women (71.10%) (18). Most stroke cases are experienced by men (57.30%). Most stroke sufferers are cared for by PFC who are their partners (57.30%). Therefore, in this study, women dominate as PFC. Apart from that, the large number of female PFC is due to the culture in society that women take care of the household at home, including caring for sick family members or becoming PFC (17).

The number of PFC who have education in the high category is greater than the number of PFC who have education in the low variety. The results of this research are in line with other studies which state that there are more PFC of stroke sufferers who have higher education compared to PFC of stroke sufferers who have low education (14,17). Research showed that as many as 63.90% of PFC have education in the high category (14). The same condition was found in other research results, which stated that more than 70% of PFC of stroke sufferers had higher education (17,19). Since 2012, the government in Indonesia has implemented a 12-year compulsory education program known as Universal Secondary Education. Universal secondary education is regulated by the Minister of Education and Culture Regulation 80 of 2013. The government provides opportunities for people to continue their education from junior high to higher secondary school. A similar policy exists in the Pamekasan district: the government has declared

compulsory education for 12 years. This policy is contained in Pamekasan Regency Regional Regulation 8 of 2014 concerning the Education Delivery System and Pamekasan Regency Regional Regulation 14 of 2015 concerning Child-Friendly Districts. This policy provides opportunities for people to pursue education from lower to higher levels.

The number of PFC who work dominates compared to PFC who do not work. The results of this research align with those of other studies (17,20). Further analysis showed that 47.9% of PFC of stroke sufferers work (17). As many as 60.7% of PFC of stroke sufferers work (20). The majority of PFC of stroke sufferers in this study were of productive age (92.20%). Productive age is when people work to produce something for themselves and others (21). Apart from that, the large number of PFC of stroke sufferers who work is because PFC have the responsibility to support their families in meeting their daily needs and the need for health services such as paying for sick family members (20).

Most PFC have <Pamekasan Regency Minimum Wage> income. The results of this research are similar to those of the previous study. Other research stated that as many as 68.70% had incomes below the Regional Drinking Wage (17). The large number of PFC of stroke sufferers who have incomes below the Pamekasan Regency Regional Minimum Wage is because the number of PFC who do not work and work as farmers and laborers dominates.

The majority of PFC who care for stroke sufferers are partners (husband or wife) of stroke sufferers. The results of this study are similar to the results of other research, which states that the majority of PFC of stroke sufferers are partners of stroke sufferers (52.70%) (14). PFC as partners of stroke sufferers dominate in this study because all stroke sufferers are elderly.

Based on the results of interviews with several respondents in this study, it was found that one of the causes of stress felt by PFC of stroke sufferers was the COVID-19 pandemic. The research results show that the number of PFC who do not experience stress dominates when compared to PFC who experience stress. The results of this study are similar to the results of previous research, which stated that the majority of PFC of stroke sufferers experienced normal stress (91.30%) (22). PFC who experienced stress in the normal category in this study dominated the numbers because when the data was collected, it was discovered that COVID-

19 cases were decreasing. They have begun to adapt to pandemic conditions, which has affected their coping abilities; however, based on the research results, it is known that several respondents are experiencing stress due to the COVID-19 pandemic. This condition impacts his health, work, and financial capabilities. In addition, most of the PFC of stroke sufferers in this study were >40 years old. PFC of stroke sufferers were found to have no difficulty accepting everything that happened, such as caring for stroke sufferers because at that age, the desire to care for and guide other people emerged (22).

Age does not have a significant correlation with psychological stress. Other research shows that age is related to a person's time to gain knowledge, including knowledge to care for stroke sufferers (23). Knowledge is closely related to the PFC education level. PFC of stroke sufferers who have education in the high category (59.20%) in this study are known to be more dominant when compared to PFC who have education in the low category (40.80%). A person's knowledge becomes a source of coping to deal with stress (24). Different conditions are known that age can influence stress in PFC. The research results show that PFC stress is more common at ages  $\geq 45$  years compared to 17-45 years because it is increasing (14).

Gender does not have a significant correlation with psychological stress. Other research shows that there is no influence between gender and PFC for stroke sufferers in providing care (23). PFC of stroke sufferers who are women (80.60%) in this study are known to be more dominant when compared to PFC who are man (19.40%). Based on this, it concluded that although women are more often found as PFC of stroke sufferers, it cannot be ensured that they have better skills when caring for sufferers. Different conditions are known that PFC with the highest levels of stress in the mild and moderate categories are women (14).

Education can influence stress in PFC. A person's level of education affects his emotional intelligence. Good emotional intelligence will influence good coping skills, too. Someone with a higher level of education will be able to control their emotions well so that stress can be controlled (25). This condition is caused because the knowledge a person possesses becomes a source of coping to deal with stress (24). Other research results show that PFC with the lowest stress levels are mainly in the undergraduate or high-level education category (14).

Occupation does not significantly correlate with the psychological stress of PFC. The employment status of the PFC is due to the sense of responsibility when caring for sufferers to meet their daily needs and the need for health services such as paying for sick family members (20). Stroke in Indonesia is one of the diseases covered by the government through the Health Organizing Agency (26). This condition can reduce the financial burden that must be borne by PFC when caring for sick family members. Based on this, it can be concluded that employment status is not related to the psychological stress of PFC of stroke sufferers. Apart from that, the PFC job as a farmer is known to dominate the numbers in this research. Farmers and some other PFC work as fishermen and entrepreneurs. This job does not have specific time regulations, so even though PFC is included in the work category, the work time is more flexible so that it can reduce stress. Different conditions are known; the PFC who experience the most stress in the moderate category are those who do not work (14).

Income does not have a significant correlation with psychological stress. Stroke is a disease that requires long-term treatment and recovery, so it is expensive (27). This condition causes substantial costs to be borne by the PFC of stroke sufferers (28). Significant expenses, if accompanied by inadequate income, will have an impact on the difficulty of meeting the needs of stroke sufferers for treatment and recovery (29). Stroke is one of the diseases covered by the government through the Health Organizing Agency program (26). The existence of adequate health insurance has an impact on meeting the needs of stroke sufferers for treatment and recovery (29). This condition can help reduce the burden that must be borne by the PFC. However, different research results state that PFC who experience the most stress in the moderate category is those who do not work. PFC who do not work or have no income will become a burden, impacting stress (14).

Kinship relationships do not have a significant correlation with psychological stress. This condition is caused because most PFC are partners of stroke sufferers who have a close relationship with stroke sufferers. Still, they often have difficulty caring for stroke sufferers. Stroke sufferers often ignore PFC advice, such as avoiding unhealthy eating patterns, not smoking, and getting enough rest. Other research shows that PFC who are partners or non-partners of stroke sufferers often find it challenging to care for stroke sufferers

because sufferers often suddenly become angry, annoyed, cry because of the disease, refuse to take medication regularly, and refuse to avoid lousy eating patterns (30). However, other research states that the emotional support provided by PFC to stroke sufferers has a good impact on psychological aspects so that it can reduce the risk of psychological problems arising. The close relationship between the PFC and stroke sufferers can have an impact on reducing the psychological burden felt by the PFC (11).

### Research Limitations

It is essential to know that many factors cause PFC of stroke sufferers to experience stress at different levels. Previous research found that age, gender, education, occupation, income, and family relationships can influence the stress level of PFC of stroke sufferers. Meanwhile, the results of this study only found one factor that was related to the stress level of PFC of stroke sufferers. Differences in research design, sample criteria, time, and location can influence the results of this study. Further research is needed to determine other factors that influence the stress level of PFC, namely PFC and stroke sufferers. Factors in the PFC that can influence the stress level of the PFC are the length of time caring for the sufferer, knowledge, family social support, and coping strategies. Meanwhile, factors in stroke sufferers that can influence the stress level of PFC are the characteristics of stroke sufferers, type of stroke, and degree of severity of stroke sufferers.

### CONCLUSION

Based on bivariate tests using the Spearman-Rho test, it is known that education has a significant relationship with the psychological stress of PFC of stroke sufferers. However, age, gender, occupation, income, and family relationship do not have a significant relationship with the psychological stress of PFC of stroke sufferers. Based on these, it is recommended that health workers develop health programs with a home visit system that focuses on the sufferer and the PFC of stroke sufferers. Apart from that, health workers can form associations or communities for PFC to increase community knowledge, skills, and stress-coping strategies.

### CONFLICT OF INTEREST

There is no conflict of interest in this research.

### AUTHOR CONTRIBUTIONS

IRA: conceived the research concept, analyzed the data and drafted the article. SM: provides direction and revisions. MAR and RDDR: contributed to writing-reviewing and editing.

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