



UNIVERSITAS NAHDLATUL ULAMA SURABAYA

LEMBAGA PENELITIAN DAN PENGABDIAN KEPADA MASYARAKAT

Kampus A Wonokromo : Jl. SMEA No.57 Tlp. 031-8291920, 8284508 Fax. 031-8298582 – Surabaya 60243

Kampus B RSIJemursari : Jl. Jemursari NO.51-57 Tlp. 031-8479070 Fax. 031-8433670 – Surabaya 60237

Website : unusa.ac.id Email: info@unusa.ac.id

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Penulis : Yurike Septianingrum^{1,2} · Ah Yusuf¹ · Ika Yuni Widyawati¹ ·
Ratna Yunita Sari² · Erika Martining Wardani² · Naadiyah
Roebbi Musfrah² · Eni Puji Lestari³

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Ketua LPPM,

Achmad Syafiuddin, Ph.D.

NPP. 20071300

LPPM Universitas Nahdlatul Ulama Surabaya

Website : lppm.unusa.ac.id

Email : lppm@unusa.ac.id

Hotline : 0838.5706.3867

Stroke

by Ratna Yunita

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Research

Factors associated with family caregiver readiness to care for post-stroke patients after hospital discharge

Yurike Septianingrum^{1,2} · Ah Yusuf¹ · Ika Yuni Widyawati¹ · Ratna Yunita Sari² · Erika Martining Wardani² · Naadiyah Roebbi Musfirah² · Eni Puji Lestari³

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Abstract

Background Post-stroke patients often need support from their family caregivers to continue their care after hospital discharge. Family caregiver readiness in caring for stroke patients is needed to improve the patient's quality of life. This study aimed to analyze factors affecting family caregivers' readiness for post-stroke patient care after hospital discharge.

Methods A cross-sectional study of family members of stroke patients admitted to the neurology inpatient unit from February to April 2023, and they were selected through purposive sampling. The general demographic questionnaire, the stroke knowledge questionnaire, and the Family Readiness for Hospital Discharge Scale (FAM-RHDS) were used to gather the data. Data analysis was performed with IBM SPSS 26 software. Data were examined through the descriptive, Pearson correlation, and multiple linear regression tests.

Results Fifty-nine respondents completed the questionnaires. Factors that were significantly related to family readiness to care for stroke patients were age ($p = 0.000$), gender ($p = 0.000$), income ($p = 0.000$), occupation ($p = 0.000$), marital status ($p = 0.000$), and knowledge ($p = 0.000$). Education level was the one that didn't correlate with family readiness ($p = 0.452$). Gender is the most dominant factor affecting the readiness of family caregivers to care for stroke patients (coefficient $B = 10.847$).

Conclusion Male family caregivers should be given special attention to improve their readiness to care for post-stroke patients. Assessment of family caregivers' readiness for discharge should be part of discharge planning and those who are unprepared may be provided with additional interventions prior to discharge.

Keywords Family · Patient discharge · Non-communicable disease · Quality of life · Stroke

1 Introduction

An ischemic stroke occurs when a blood vessel supplying the brain with oxygen and nutrients is obstructed, and it causes around 87% of all strokes [1]. Ischemic stroke is caused by blocked blood vessels due to diseases such as atherosclerosis, arteries, thrombus, and embolus [2]. Many stroke patients experience permanent physical, cognitive, and emotional disorders. In the Southeast Asian region, according to data from the Southeast Asian Medical

✉ Yurike Septianingrum, yurike.septianingrum-2021@fkip.unair.ac.id; Ah Yusuf, ah-yusuf@fkip.unair.ac.id; Ika Yuni Widyawati, ika-y-w@fkip.unair.ac.id; Ratna Yunita Sari, ratna@unusa.ac.id; Erika Martining Wardani, erika@unusa.ac.id; Naadiyah Roebbi Musfirah, naadiyahroebbi042.ns19@student.unusa.ac.id; Eni Puji Lestari, eni.puji.lestari-2022@fkip.unair.ac.id | ¹Doctoral of Nursing, Faculty of Nursing, Universitas Airlangga, Surabaya, Indonesia. ²Department of Nursing, Faculty of Nursing and Midwifery, Universitas Nahdlatul Ulama Surabaya, Surabaya, Indonesia. ³Inpatient Department, Universitas Airlangga Hospital, Surabaya, Indonesia.



Information Center, Indonesia ranks first with the highest death rate due to stroke [3, 4]. A stroke that is not handled correctly will cause various impacts on patients, including a self-care deficit or dependence on other people, so they will need assistance to improve their abilities in daily life [5, 6]. Therefore, patients need help from the family to carry out activities such as eating, dressing, bathing, toileting, decorating, controlling elimination, moving, and mobilizing independently [7]. Meeting the basic needs of stroke patients is provided by family members who are 'non-professional' caregivers with limited training. In contrast, the family still has an important role in decision-making in the continued care of stroke patients [8]. Despite this, families still have a low rate of involvement in care planning, resulting in a wide range of unmet needs (e.g., lack of information about the recovery process and strategies for meeting the patients' needs) [9]. The low involvement of families leads to their unreadiness to care for their family members who have suffered a stroke. Nonetheless, caregivers often lack a clear understanding of the role they are committed to, and this affects caring for their family member with stroke [10].

The family's ability to provide instrumental, emotional, and daily activity support affects the outcome of stroke patients [11]. Family members play a crucial role in providing care and are required to assist patients with their rehabilitation programs, but they frequently feel unreadiness about their new responsibilities [12] because they are typically not trained [13]. Family caregivers' unreadiness can have a negative impact on their own lives, such as increased stress, anxiety, decreased health status, mood problems, low quality of life, fewer social contacts, and decreased well-being [14]. Additionally, the family's unreadiness also has an impact on the patient, such as the occurrence of adverse events, readmission to the hospital, and increased treatment costs [15, 16]. Assessing the caregiver's readiness for the caregiving role is crucial to tailor a plan of care to address any gaps in readiness [10].

Family unreadiness is influenced by several factors, such as age, gender, marital status, education level, income, and employment status [7, 13, 17]. Older family caregivers experienced caregiving more positively than younger caregivers, but they also experienced higher levels of depression, memory loss, and anxiety [18, 19]. Despite experiencing more negative experiences than men, women felt more prepared for caregiving [20]. Higher self-confidence in the care provided by individuals with higher education [21, 22]. Family caregivers who have a lower level of education were able to receive more support from community nurses [7]. Income and occupation play an important role in family unreadiness. Lower-income and poor job type have been associated with stress-related problems while caring for a stroke family member [23].

The literature indicates that family caregivers' characteristics influence the caregiving experience. The more prepared the family is in caring for stroke patients, the better the patient's outcome will be [24]. Families who feel unprepared may commit more errors in care, duplicate services, and provide inappropriate treatment for stroke survivors, even increase the risk of stroke patients' re-admission to the hospital [25]. Many studies have examined the role and support of the family in stroke patients [26–28], but rarely have examined family readiness in caring for stroke patients which is examined in this paper. This study aims to analyze the factors that influence family readiness in caring for post-stroke patients after hospital discharge. In previous research, family knowledge factors were associated with potential complications in stroke patients [29]. However, its relationship with the readiness of the patient's family to care for stroke patients has not been studied. Therefore, we analyzed whether knowledge factors influenced family readiness in caring for family members after stroke.

2 Materials and methods

2.1 Materials

A cross-sectional study of fifty-nine family caregivers who care for ischemic stroke patients in the neurology inpatient ward of Universitas Airlangga Hospital Indonesia from February to April 2023. The sample size was calculated using Slovin's formula, while the sample was selected through purposive sampling. The inclusion criteria in this study were adults, who could read and write, and living with patients. Family members of stroke patients with cognitive impairment were excluded from the study. The inclusion and exclusion criteria were determined by neurologists using medical data.

2.2 Data collection procedures

After obtaining permits from universities and hospitals, two students were trained by the principal investigator (YS) as research assistants (RA). They were trained in all research procedures, including respondent recruitment (based on inclusion and exclusion criteria), administration of informed consent, and questionnaire-filling techniques. Two days before discharge, the head of the room and the nurse identified the eligibility of family caregivers. Then, the RA screened and confirmed the eligibility of family caregivers based on medical records, explained the purpose and procedures of the study, and obtained informed consent. Within 4 h before discharge, the RA distributed demographic, knowledge, and family caregiver readiness questionnaires through Google Forms. If the respondents had difficulty filling in, they could ask the RA. The demographic questionnaire includes age, gender, income, education level, occupation, and marital status. The original English version of the knowledge questionnaire and the family caregiver readiness questionnaire were translated into Bahasa (Indonesian version) by two nursing experts who were proficient in English. We tested the validity and reliability of the knowledge questionnaire and family caregiver readiness questionnaire on thirty family caregivers of stroke patients. Pearson Product Moment is used in the validity test to determine the validity or suitability of the instruments used by researchers to measure and obtain research data from respondents [30]. If the Pearson correlation value is positive and supported by a significance value of less than 0.05, then the test item is declared valid. The reliability test of this research questionnaire used IBM SPSS 26 software to determine Cronbach's Alpha value [31]. The results of the reliability test with an alpha coefficient value > 0.7 are declared reliable [32].

The demographic data of family caregivers included age in years, gender, marital status (married, single, divorced, or widowed), and occupation (working or not working). Based on the Indonesia Ministry of Education, Culture, Research, and Technology, education levels consist of primary (elementary and junior high school), secondary (senior high school), and high education (college). Income is categorized based on the minimum wage of employees in the East Java region of 4.5 million rupiah [33].

The knowledge questionnaire was modified from the Stroke Knowledge Test (SKT) [34], consisting of 14 items that were used to evaluate stroke risk factors (question number 1, 2, 4, 8, 10), signs and symptoms of recurrent stroke (question number 3, 5, 6, 11), stroke treatment and rehabilitation (question number 7, 8, 12, 13, 14). A total of 14 questions are arranged in the format of right and wrong answer choices. Correct answers are marked with 1 (one), and wrong answers are marked with no (0). Total scores range from 0 to 14. The higher the score, the better the knowledge. All items in this questionnaire were declared valid and reliable, with Cronbach's alpha 0.785.

The family caregiver's readiness instrument used the Family Readiness for Hospital Discharge Scale (Fam-RHDS) questionnaire, which includes 22 question items, which are questions number 1–7, consisting of two parts (a and b). Those measures the patient's perception of readiness to go home from the hospital, including personal status (question number 1–7), knowledge (question number 8–14), coping skills (question number 15–17), and support (question number 18–22). All 27 items in this questionnaire were declared valid (r count > 0.361), except numbers 2a and 2b because they were invalid (r count < 0.361). So, we decided to exclude these two items due to their invalidity and lack of substance in this study. The Fam-RHDS is a self-reported summated rating scale with items scored on an 11-point scale (0–10) with anchor words (e.g., not at all, totally) to cue the subject of the meaning of the numeric scale. The total score range is 0–270, the greater the score value, the higher score indicates greater readiness. All items in this questionnaire are reliable, with Cronbach's alpha 0.959. The scale was determined to be a reliable instrument that could be applied to Indonesian society.

2.3 Data analysis

Data were analyzed using descriptive tests, Pearson correlation tests, and multiple linear regression. The descriptive test of family caregiver's characteristics was presented as mean and standard deviation or percentage. Pearson correlation test with a significance of $\alpha = 0.05$ was used to analyze a linear correlation between two continuous variables, and the multiple linear regression test was used to predict the values of a response (dependent) variable from a collection of predictors (independent) variables (significance $\alpha = 0.05$). In the multiple linear regression test, we need to test whether there is a correlation between the independent variables in the regression model using the variance inflation factor (VIF) in the multivariable models. Then we also test the normality of the data using the Kolmogorov–Smirnov test to determine whether the residuals are normally distributed or not. In addition, we also checked homoscedasticity using the Glejser test [17]. We reported the multiple linear regression results in the form of unstandardized and standardized regression coefficients, standard errors, t-value, and p-value.

Table 1 Characteristics of respondents (n = 59)

Characteristics	Frequency (f)	Percentage (%)
Age, (Mean ± SD)	47.36 ± 10.527	
Gender		
Male	42	71.2
Female	17	28.8
Income		
Less than the regional minimum wage	46	78
Regional minimum wage or more	13	22
Education level		
Primary	7	11.9
Secondary	41	69.5
High	11	18.6
Occupation		
Working	31	52.5
Not working	28	47.5
Marital status		
Married	46	78
Single/divorced/widowed	13	22
Knowledge, (Mean ± SD)	4.68 ± 3.05	
Readiness, (Mean ± SD)	117 ± 23.91	

Table 2 Bivariate correlation analysis of predictive factors to family caregivers' readiness (n = 59)

Characteristics	Pearson r	p	R ²
Age	0.916	0.000*	0.896
Gender	0.78	0.000*	
Income	0.547	0.000*	
Education level	0.016	0.452	
Occupation	0.591	0.000*	
Marital status	0.5	0.000*	
Knowledge	0.7	0.000*	

*Significant, with $p < 0.05$

3 Results

No data is missing in this study, and a total of 59 family caregivers of stroke patients participated in this study. Table 1 showed that most of the respondents were aged 47.36 ± 10.527 , male (71.2%), had income less than regional minimum wage (78%), had secondary education (81.4%), working (52.5%), married (78%), and mean of knowledge 4.68 ± 3.05 , which indicated poor knowledge, and the mean of family caregivers' readiness was 117 ± 23.91 , which indicated they were not ready to care their family member with stroke. The results of the bivariate test between variables using the Pearson correlation test are shown in Table 2. The Pearson correlation test showed that factors that correlated with family readiness were age, gender, income, occupation, marital status, and knowledge (each has a p-value of 0.000). Education level was the one that didn't correlate with family readiness ($p = 0.452$). All these factors influence the readiness of family caregivers by 89.6% ($R^2 = 0.896$).

In general, all respondents showed moderate readiness, as well as in all four subscales (Table 3). Based on the RHDS subscales, the highest level of readiness was reported in coping ability, while the lowest level was in the knowledge subscale. The results of the multiple linear regression test are summarized in Table 4. This shows that age, gender, marital status, and knowledge were correlated with readiness to have a family ($p < 0.05$). Gender is the most dominant factor affecting the readiness of family caregivers to care for post-stroke patients (coefficient B = 10.847).

Table 3 The subscales of family readiness for hospital discharge (n = 59)

Subscales	Number of items*	Scale mean (SD)	Item mean (SD)	Range (Min–Max)	Cronbach's Alpha
Personal status	12	53.23 (1.61)	4.47 (1.48)	28–65	0.902
Knowledge	7	29.8 (8.08)	4.26 (1.12)	15–45	0.935
Coping ability	3	13.23 (3.83)	4.4 (1.19)	9–22	0.899
Expected support	5	21.37 (5.4)	4.34 (1.13)	12–38	0.904
Total scale	27	117.97 (27.05)	4.37 (1.48)	72–181	0.967

*All items scored on a 1–10 scale

Table 4 The multiple linear regression analysis of family caregivers' readiness (n = 59)

Variables	B	SE B	Standardize β	t-value	p-value
Age	1.431	0.194	0.630	7.385	0.000*
Gender	10.847	3.303	0.219	3.284	0.002*
Income	–2.697	3.486	–0.047	–0.774	0.443
Education level	0.678	2.003	0.016	0.339	0.736
Occupation	0.010	2.773	0.000	0.003	0.997
Marital status	7.666	3.131	0.134	2.449	0.018*
Knowledge	1.187	0.492	0.152	2.413	0.019*

*Significant, with $p < 0.05$

The bold values with asterisks (*) were the significant p-values, and the bold value in B/SE B/standardize beta was the most dominant factors influencing in family readiness

4 Discussion

The aim of this study was to evaluate the readiness of family caregivers and determine the associated factors, including demographic variables and knowledge. The findings are that age, gender, income, occupation, marital status, and knowledge are associated with family readiness to care for post-stroke patients. This is in line with Ariska et al. study [35], which shows that age, gender, employment status, income, marital status, family relationships, and family support are significantly related to the burden of caregivers in caring for stroke family members. Families who are not ready to care for family members with post-stroke are at risk of experiencing a crisis and feeling burdened [36]. Most of the respondents were aged 26–45 and had poor readiness. Young adults risk experiencing role tension when given the responsibility of caring for a sick family member [37]. Young adult caregivers experience the burden of caregiving because it hinders their education, career, and social relationships [38]. Young adult caregivers experience the pressure and demands of caring for their relatives with post-stroke while also looking for ways to continue their studies, start a career, and/or start a family because young adults are a productive age.

Our findings showed that gender was a dominant factor influencing family readiness. Informal care for family members with chronic medical conditions or disabilities is predominantly provided by women worldwide [39]. The finding that women were better readied than men is consistent with previous studies [17]. This finding is similar to Ariska et al. [35], who state that women more often care for sick family members. This is influenced by the norms and culture that apply in Indonesian society, where women's role is to take care of the household, such as cooking, washing, cleaning the house, serving their husbands, and caring for family members, while men's role is to earn a living. Female spouses faced a significant increase in total burden and burden in the areas of external support, caregivers' routine, patients' support, patients' behavior, and caregivers' coping strategies [39, 40]. The readiness of women caregivers was higher than that of men, and the same was true for caregivers who lived with a patient who was cared for [13]. This is supported by the fact that the number of caregivers was higher among women [41]. So far, the caring role has been more identical to women than men because women have motherly characteristics and are more patient and painstaking in caring for sick family members.

Income and occupation are also factors that influence readiness to care for post-stroke patients. According to studies, caregivers who have a lower socioeconomic status tend to experience increased depression, caregiving burden, and hours spent on caregiving, as well as decreased access to and use of formal services [42]. Stress during caring for a disabled family member is influenced by lower income, influencing their life satisfaction [23]. Employed caregivers are faced with the challenge of providing care while also meeting work demands and pursuing professional goals. In situations where the patient is unable to work or health insurance is not sufficient, the caregiver's income and employment are often used to meet family expenses [43].

Marital status is also a factor that is influencing family caregivers' readiness. If the caregiver is the patient's spouse, then they are better ready to care for the patient as they understand the patient's care needs. Our findings are also consistent with previous research showing that caregiving wives are more satisfied with their marriages when recipient husbands are more emotionally supportive [44]. On the other hand, other studies have shown that the well-being of single elderly caregivers is at a higher level than married elderly caregivers. The reason may be that they can provide care for other elderly (elderly spouses) and care for their spouse [45]. These two different findings are also based on differences in age and relationship status with the patient. If the caregiver is the patient's spouse, then they will be better prepared. Still, if they are not the patient's partner, then the responsibility for caring for the patient will interfere with the marital relationship with their spouse.

In this study, the only factor that did not correlate with family readiness was education level. The previous study found no correlation between family caregivers' education level and readiness [17]. The readiness for caregiving was not significantly influenced by other family caregivers' sociodemographic characteristics, such as residential area, educational level, and cohabitation with the older relative [46]. Surprisingly, caregivers with higher educational levels did not indicate better preparation for caregiving [13]. It's possible that this is the case because providing care requires knowledge, skills, and abilities that are not taught in a formal educational context.

Most respondents had poor knowledge about stroke based on mean and standard deviation, so this also caused them to be unprepared to care for post-stroke patients. Good knowledge of the patient influences a positive attitude and better treatment capabilities [47]. Family caregivers' knowledge of good sleep is positive for the patient's good quality of life as well [48]. Good knowledge and experience can increase the patient's family's self-efficacy so that care helps the family be better prepared to provide care after returning home [49]. Nurses can give the caregiver anticipatory guidance on what to expect. Caregivers' distress can be relieved by this type of information, which can address uncertainties about their ill family members' disease and treatment status, as well as the care they may need.

The findings of this study can be used as a basis for nurses' independent intervention during discharge planning. Adequate information and family-nurse engagement in the care process for post-stroke patients is needed to improve their quality of life (QoL). Furthermore, increasing the ability of male caregivers in the patient care process is necessary so that there is no gap between women and men regarding their abilities.

5 Strengths and limitations

The strength of this study was the use of the Fam-RHDS questionnaire as an instrument to measure family caregiver readiness to care for post-stroke patients, which has almost never been done before. Previous studies measured family knowledge and motivation to describe family readiness. Our finding showed that gender was the dominant factor affecting family caregiver readiness was interesting to discuss as it relates to gender stereotypes in Indonesian society.

This study had several limitations. Due to its cross-sectional nature, causal relationships cannot be inferred in this study. Limited sample size in this study because this study was in a single hospital and may not reflect the readiness of stroke family caregivers in other facilities and geographic locations. It is recommended that more sampling locations be conducted in other regions to generalize these findings to a larger population of stroke family caregivers in Indonesia. The Fam-RHDS instrument has never been published in Bahasa (Indonesian version), so we translated the questionnaire first, after which we tested the validity and reliability in order to get accurate and reliable results.

6 Conclusions

Family caregivers in this study had moderate readiness to provide care to their family members with stroke, and this is influenced by age, gender, income, occupation, marital status, and knowledge. Assessment of family caregivers' readiness for discharge should be part of discharge planning and those who are unprepared may be provided with additional interventions prior to discharge. Nurses play an important role in supporting family readiness regardless of the intensity of care. In addition, nurses should consider the gender vulnerabilities that exist in daily interactions with families and help overcome gender stereotypes. For example, male family caregivers who are single, divorced, or widowed have been shown to be less prepared and may require special attention in interventions to enhance family readiness.

Further research to explore more factors from the perspective of nurses or stroke patients and their influence on family caregiver readiness is warranted. Nurses play an important role in helping family caregivers become more confident and competent in the healthcare process by creating an extension program related to improving family readiness to care for stroke patients at home. In addition, longitudinal studies of changes in family caregiver readiness over time need to be integrated with the concept of transitional care to develop good transitional care programs to improve the quality of life of stroke patients and their family caregivers.

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Author contributions Conceptualization: YS, AY, IYW; methodology: YS, AY, IYW; methodology; formal analysis and investigation: NRM; writing—original draft preparation: YS, NRM; writing—review and editing: RYS, EMW; funding acquisition: AY; resources: EPL; supervision: IYW.

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Availability for publication The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate The study was authorized by the Universitas Airlangga Hospital Ethics Committee and registered with protocol number NA-02-23022 and number 027/KEP/2023. We explained the aims and procedures of this study before patients voluntarily signed informed consent. We respect their decision to participate or withdraw from this study. All procedures were executed in accordance with the relevant guidelines and regulations.

Consent for publication Not applicable.

Competing interests The authors declare that they have no competing interests.

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