KONSELOR

The relationship between stress levels in informal caregivers and quality of life of stroke patients in RSUD Kota Depok period 2019

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Abstract
One of the main problems faced by stroke patients is the ability of the family to provide assistance and meet their needs, to enhance their quality of life. Furthermore, the stress on caregivers is an important factor to consider, as it influences their ability to provide care. This study aimed to determine the relation of informal caregiver stress levels to the quality of life of stroke patients in RSUD Kota Depok period 2019. The method involved an analytical study with a cross sectional design, and a sample totaling 36 outpatients at the Neurology Polyclinic, taken by purposive sampling technique. This study was analyzed using Gamma and Somers'd test, and the results showed that there was a relation between the informal caregiver's stress level (p = 0.001; r: -0.475) with quality of life stroke patients. Therefore, it was concluded that the stress levels of informal caregivers significantly influence the quality of life in stroke patients.

Keywords: Informal caregiver, quality of life, stress, stroke

Introduction

According to the American Heart Association (AHA) / American Stroke Association (ASA), stroke is a disease characterized as an in fraction of the central nervous system, which may be ischemic or silent, intracerebral hemorrhage and subarachnoid hemorrhage. In the central nervous system, infarction is the death of retinal cells, brain, and spinal cord caused by ischemia. This can be detected through neuropathological, radiological examination, other objective evidence, and symptoms persisting for more than 24 hours (Sacco et al., 2013). Stroke is the main cause of death in the world (Reiche et al., 2019). Furthermore, Indonesia is the fourth most populous country, with a population of around 250 million people (Hussain, Al Mamun, Peters, Woodward, & Huxley, 2016). Data from 2013 to 2018 showed that there has been an increase in the prevalence of stroke from 7% to 10.9% per mil (Kementerian Kesehatan, 2018). This is one of the biggest causes of death in the Asian continent, causing significant lifestyle changes in patients regarding mobility, emotional patterns, behavior, and communication skills (Chin, Sakinah, Aryati, & Hassan, 2018). Additionally, stroke causes a decrease in independence during daily life activities, changes in emotional and psychological status, as well as deteriorating social communication that affect the quality of life in patients (Kim, Kim, & Kim, 2014).

The quality of life refers to an individual's perception of the life they live in accordance with the culture and values of their environment. This is in comparison with the goals, expectations, and standards fixed by the individual (Muhammad, Syafrita, & Susanti, 2019).

The main problem in stroke patients involves how the family, the environment and medical personnel successfully provide and meet their care needs. Assistance is also required to improve their abilities, in order to enhance their quality of life (Karim & Lubis, 2017).

According to the National Alliance For Caregivers, a caregiver is someone responsible for providing the daily needs of others in need.9 Caregivers are divided into two groups, namely informal and formal. An informal caregiver is someone that provides assistance to other people which have familial or close

relationships with them, such as family, friends, and neighbors. This group of caregivers are not usually paid, work part-time or full-time, and live together or separately from the person being cared for (Thoits, 2011). Meanwhile, stroke sufferers need care at home which is usually provided by family members, but long-term and ongoing commitments are often associated with financial and psychological burdens (Jeong, Jeong, Kim, & Kim, 2015).

Many factors affect the ability of caregivers to manage the needs of stroke patients after hospitalization. Maintaining physical endurance and the mental health of caregivers is important, to provide proper care for stroke patients at home. The stress on caregivers is an important factor to consider, because there may be an impact on caregivers as well as stroke patients (McLennon, Bakas, Jessup, Habermann, & Weaver, 2014). A study showed that high levels of emotional stress in caregivers were associated with high depressive symptoms in patients treated (Ejem, Drentea, & Clay, 2015). Furthermore, according to the US Level of Health & Social Care Digital Resources, emotional factors significantly influence an individual's quality of life. Studies on the relation between caregiver stress and stroke patients' quality life is rare in Indonesia. Therefore, due to the differences in culture between the Indonesian people and foreigners, it became necessary to carry out a research on the correlation between caregiver stress levels, and the quality of life of stroke patients.

RSUD Kota Depok is a type B hospital located in West Java Province, which has the highest number of stroke cases in Indonesia. Stroke is among the 10 highest diagnoses in Depok City Hospital with 2,018 cases. Given the importance of the quality of life of patients and the role of caregivers, researchers were interested in conducting studies on the relation of informal caregiver stress levels to the quality of life of stroke patients in RSUD Kota Depok period 2019.

Method

The research method made use of observational analysis with cross-sectional design. The samples included all patients in Depok City Hospital that had been diagnosed with stroke before and fulfilled the research's inclusion criteria. These respondents totaled 36, and the sampling method was non-probability (purposive sampling). The number of samples were calculated from the formula of correlative analysis.

The criteria for this research were outpatients diagnosed with stroke without paying attention to the NIHSS score and were willing to be respondents. For informal caregivers, they must have been active with stroke patients for at least 6 months, including family members, friends, neighbors, and were willing to be respondents in this study. Furthermore, the research data collection was in form of primary and secondary data. Primary data were obtained through interviews using questionnaires directly with stroke patients and informal caregivers. The secondary data used was taken through a medical record sheet obtained at RSUD Kota Depok, where the researcher retrieved the list of patients (totaling 36) that met the inclusion criteria. Medical records were observed to obtain diagnostic data from patients, and interviews were conducted, where patients filled SSQOL questionnaires for stroke patients and KCSS questionnaires for informal caregivers. In addition, KCSS was validated (r count 0.444), and the results showed that the questionnaire was valid. The reliability test of the KCSS questionnaire (r alpha value 0.926) also showed that it was reliable.

Results and Discussion

From the table 1, most male stroke patients were found between 56-65 years, and totaled 17 people (47.2%). The average age of patient respondents this study was 58.3. The highest number was found in females, totaling 19 people (52.8%). Furthermore, the most recent education of respondents was in the elementary school group, namely 13 people (36.1%).

From the table 2, most informal caregiver respondents were in the 46-55 age group, or the elderly group, totaling 14 people (38.9%). The average age for this category was 46.8 years old. Most of the respondents were female, totaling 24 people (66.7%). Furthermore, the most recent education of respondents was found in the high school group, totaling 14 people (38.9%). For most, the work status of respondents was unemployed, as much as 58.3%. The highest relationship status among respondents, specifically wife and children, was equal to 12 people (33.3%).

Table 1. Distribution of Characteristics of Stroke Patients at RSUD Kota Depok

Age	N	%
36-45	2	5.6%
46-55	12	33.3%
56-65	17	47.2%
>65	5	13.9%
Gender		
Female	19	52.8%
Male	17	47.2%
Level of education		
Elementary School	13	36.1%
Junior High School	7	19.4%
Senior High School	12	33.3%
Diploma	1	2.8%
Undergraduate program (S1)	3	8.3%
Total	**36**	**100%**

Distribution of Characteristics of Stroke Patients at RSUD Kota Depok (Putri I R, 2019)

Table 2. Distribution of Informal Caregiver Characteristics at RSUD Kota

Age	n	%
17-25	3	8.3%
26-35	5	13.9
36-45	5	13.9
46-55	14	38.9%
56-65	6	16.7%
>65	3	8.3%
Gender		
Female	24	66.7%
Male	12	33.3%
Level of Education		
Elementary School	5	13.9%
Junior High School	8	22.2%
Senior High School	14	38.9%
Diploma	1	2.8%
Undergraduate program (S1)	8	22.2%
Work Status		
Work	15	41.7%
Unemployment	21	58.3%
Family Status		
Husband	7	19.4%
Wife	12	33.3%
Children	12	33.3%
Son/Daughter-in-Law	2	5.6%
Mother	1	5.6%
Relative	2	2.8%
Total	**36**	**100%**

Distribution of Informal Caregiver Characteristics at RSUD Kota Depok (Putri I R, 2019)

From table 3 above, the stroke patients with a better quality of life have informal caregivers (14 respondents) with a mild stress level. Stroke patients with less quality of life have informal caregivers (12 respondents) with higher stress levels. Furthermore, statistical test results using Gamma and Somers'd obtained p value <0.05, which was 0.001. This showed that there was a significant correlation between the level of informal caregiver stress and the quality of life of stroke patients in Depok City Hospital in 2019. The value of correlation strength (r) was equal to -0.475.

Table 3. The Relation Between Informal Caregiver Stress levels and Quality Of Life of Stroke Patients

Quality of Life	Level of Stress		Total	r	p
	Moderate	**Mild**			
Well	8	14	22		
Less	12	2	14	-0.475	0.001
Total	**20**	**16**	**36**		

The Relation Between Informal Caregivers' Stress Towards Quality of Life Stroke Patients

The results are also in line with previous research which stated that the incidence of stroke increases with age, especially beginning from 50 years. Stroke rarely occurs below 50 years of age, but the risk doubles after (Prok, Gessal, & Angliadi, 2016). Physiologically, this is due to the degenerative process, especially in the extracellular matrix where the elastic blood vessels become more rigid. Additionally, changes in extracellular matrix protein and blood vessel walls activate the formation of atherosclerosis in the blood vessels of the brain which hinder its blood supply, causing brain infarction (Palombo & Kozakova, 2015).

The incidence of stroke in this study occurred more in women. This agrees with the study of Benjamin et al, where women had a higher risk of stroke than men. This was due to a case incidence of 1:5 in women aged 55-75 years, while in men, 1:6 within same range (Benjamin et al., 2018). Furthermore, increased risk factors for stroke are proportional to increasing age. In the middle age, the risk factors for stroke are higher in men, but during the menopause transition the risk factors in women increase, especially the ones which have experienced menopause for 10 years (Lisabeth & Bushnell, 2012).

The results of this study also agree with the research which stated that there is a relationship between age and the quality of life of stroke patients (Rahman, Dewi, & Setyopranoto, 2017). This is because low education will result in low knowledge. Individuals with higher educational backgrounds are more mature and adapt easily to the changes that occur, allowing patients readily accept positive influences and health information (Notoatmodjo, 2010).

In this study, the data obtained from 36 respondents based on gender characteristics showed that the informal caregivers with the most moderate stress levels were women. Meanwhile, in the category of mild stress, women also had the largest portion. That's because women spend six times more time than men in daily activities, caring for the sick, the elderly, and children at home (Aslan, Sanisoglu, Akyol, & Yetkin, 2009). This is consistent with the study of Unver et al which showed that most caregivers are female (Unver, Basak, Tosun, Aslan, & Akbayrak, 2016). According to other studies, 23.4% of women were more vulnerable to stress and depression than men (Amilia Brillianita, 2013).

From the analysis, the most informal caregivers which experience stress in the moderate category were found in the age range 46-55 years. The occurrence at age ≥45 years than 17-45 years showed that the increase in age was in line with increasing stress levels. This agrees with Rafiyah & Sutharangsee that the age factor is positively related to the level of stress caused by older caregivers which have more anxiety than younger caregivers (Rafiyah, 2011; Rohmatin, Limantara, & Arifin, 2016).

The highest number of informal caregivers with moderate stress levels based on the characteristics of work status, were the unemployed. In the mild category, the ratio of work status between caregivers working caregivers or not were the same ratio. This result is in accordance with previous research that family caregivers without a job or source of income will create a burden for themselves and the family. Furthermore, around 63.3% of families with an income below the provincial minimum wage are more prone to experience depression and stress (Rohmatin et al., 2016).

In this study, the number of informal caregiver with moderate stress had the most recent high school education while the respondents with the least stress mostly had undergraduate education. This agrees with Evans's research which stated that caregivers with low levels of education have higher levels of stress than the ones with higher education (Alamdani & Nuraini, 2016).

Based on the characteristics of the most informal caregivers, their relationship status were respondents in a relationship, either as a child and wife. This is in line with Vani et al which stated that most caregivers were wives (Widianti & Prawesti, 2018). These results also agree with a study by Octavia which showed that most informal caregivers were children of the patients (Octavia, 2018).

Furthermore, the results are in line with research conducted by Ejem et al, that there are caregivers which experience emotional stress which in turn affect the mental health of the patients they care for. This is evident in the symptoms of depression felt by patients. 13 Previous studies also stated that poor life satisfaction and the symptoms of depression in caregivers may affect the health and welfare of care recipients (Grant et al., 2013). According to the AS Level of Health & Social Care Digital Resources, emotional factors affect an individual's quality of life (AS Level Health & Social Care Digital Resources, 2019). The correlation strength value (r) of -0.475, signified that the correlation power was moderate with negative correlation direction or opposite direction. Alternatively, the greater the value of one variable, the smaller the value of other variables. The higher the level of informal caregiver stress, the lower the quality of life in stroke patients. High stress levels and inadequate support for caregivers may lead to various bad manifestations such as chronic changes in health conditions, deterioration of personal relationships, physical complaints, depressive symptoms, feelings of decreased competence, decreased quality of life, and inflammation (Carroll, Chippior, Karmali, Sriram, & Ysseldyk, 2019). Furthermore, caregivers with high levels of stress often experience loneliness, isolation, and lack of appreciation which is aggravated by the inability to receive care (Bevans & Sternberg, 2012). According to Priharmanto's research, there is a significant relationship between family caregiver stress levels and the quality of care provided (Priharmanto, 2017). The ability of caregivers to fulfill the needs of patients after stroke is influenced by many factors such as mental health and physical endurance. Stress is also an important factor in determining the ability of caregivers for stroke patients. The levels of stress on caregivers is an important factor to consider in the ability of caregivers to provide care for stroke patients at home. This is because there can be an impact on caregivers as well as stroke patients being treated (McLennon et al., 2014). Therefore, the theory put forward by Given also showed that the amount of responsibility, assignment, pressure, and stress experienced by the caregivers in providing care for patients may have adverse consequences. The level of stress experienced by the caregiver may hinder their role in treating patients (Rahmawati, Jodin, & Widianti, 2018). Caregivers with a low burden report that they get adequate support from social networks, friends, family and acquaintances, and have higher welfare (Reblin, Small, Jim, Weimer, & Sherwood, 2018).

Conclusion

There is a significant correlation between the stress levels of informal caregivers with the quality of life of stroke patients in Depok City Hospital 2019. This study encourages caregivers to overcome stress by getting adequate support from social, networks, friends, family. Overcoming the stress indirectly improves their ability to provide care for patients, thereby enhancing the quality of life in stroke patients.

Acknowledgment

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