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The Relationship between Burden and Quality of Life for Caring for Stroke Patients

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Abstract: This study aims to determine the relationship between burden and quality of life of stroke caregivers at the Bukittinggi National Stroke Hospital Polyclinic. This type of research is analytic research with a *cross sectional approach.* The analysis used in this study uses univariate analysis and bivariate analysis. The results of the study are 1. Less than half of the caregivers have a moderate burden in caring for stroke patients. 2. More than half of caregivers have a poor quality of life. 3. There is a relationship between the burden and the quality of life of stroke caregivers.

Keyword: Burden Relationship, Quality of Life, Stroke Patients.

INTRODUCTION

Stroke is still a major health problem and is the 3rd leading cause of death in developed countries after cardiovascular disease and cancer. Stroke is a condition when there is ischemia (inadequate blood flow) to a part of the brain or bleeding in the brain which results in brain cell death (Lewis, 2011). Stroke is caused by a change in the normal blood supply to the brain (Workman, 2009). Stroke is also called a brain attack, due to brain circulation disorders that occur suddenly in one or more blood vessels that supply the brain. WHO predicts that deaths from stroke will increase along with deaths from heart disease and cancer, which is approximately 6 million in 2010 to 8 million in 2030. Data in the United States shows that a new stroke is recorded for almost every 45 seconds a stroke occurs. and every 4 seconds a death from a stroke occurs (WHO, 2011).

After treatment at the hospital, most stroke survivors return home (Jeong et al., 2015). Home care is especially beneficial in the transition period after a client returns home from treatment at a rehabilitation hospital. Most post-stroke patients will experience sequelae that vary widely, which can be in the form of impaired mobility or motor disturbances, visual disturbances, speech disorders, swallowing disorders, emotional changes, and other symptoms (Junaidi, 2011). According to Joan et al., (2014), half of people who make it through a stroke are in a state of permanent disability and experience recurrence within weeks, months and years. This situation causes stroke sufferers to need help from caregivers or *caregivers* in carrying out their daily activities.

Nurses are divided into informal caregivers and formal caregivers. Informal caregivers are individuals (family members, friends or neighbors) who provide care without being paid, part time or all the time, live with or separately from the person being treated, while formal caregivers are caregivers who are part of the service system. , both paid and volunteers (Sukmarini, 2009). In general, the role of caregivers is carried out by informal caregivers (spouse, children, close friends) whose role is to provide care to stroke sufferers (Ogunlana et al., 2014).

Nurses who care for stroke sufferers experience psychological stress such as stress and worry, fatigue and experience limited interaction with the outside environment because they have to accompany and care for their families who have suffered a stroke. Strokes occur suddenly and cannot be predicted which results in the unpreparedness of caregivers (Ogunlana et al., 2014). This unpreparedness resulted in many caregivers being unable to anticipate problems in carrying out their roles and impacting physical, psychological, social and environmental conditions which are part of a person's quality of life. Quality of life is an individual's perception of their position in life in the context of the culture and values in which they live and in relation to life goals, expectations, standards and concerns. It is a broad concept that affects a person's physical health, psychological state, level of dependency, social relationships, personal beliefs and their relation to future desires for their environment (WHO, 2004).

Quality of life is multidimensional which includes the dimensions of physical health, psychological health, social relationships and relationships with the environment. Aspects assessed in physical health include energy and fatigue, pain and discomfort, sleep and rest, movement, daily activities, dependence on drug substances and medical assistance and ability to work. Carers for stroke sufferers experience an impact on physical health such as feeling tired, lack of rest. Aspects assessed in psychological health include self-image and appearance, negative feelings, positive feelings, self-concept, thinking, learning, memory and concentration, spirituality, religion and personal beliefs. Carers for stroke sufferers experience an impact on psychological health such as feeling anxious and worried and feeling pressured between caring for stroke sufferers and doing work. Aspects assessed in social relationships include personal relationships, social support and sexual activity. Carers for stroke sufferers experience an impact on social relations such as reduced quality of social relations. Aspects assessed in the environment include financial resources, freedom, safety and security, health and social care, ease of access and quality, health environment, opportunities to acquire information and skills, participation in recreational and leisure opportunities and the physical environment (pollution, noise, traffic, weather and transportation). Carers for stroke sufferers experience an impact on the environment such as financial problems in caring for stroke sufferers (Hung et al., 2012).

The quality of life of caregivers is strongly influenced by the burden factor of caregivers (Nir et al., 2009). Stroke creates a burden on the people around them, in general the burden is felt by the main caregiver (Caplan, 2009). Stuart (2013) also revealed that the experience of caregivers in caring for sick clients will cause a burden.

Data from RSSN Bukittinggi in 2016 found that outpatient stroke patients at the Polyclinic RSSN Bukittinggi in 2014 were 1,478 people and increased in 2015 to 1,570 people. The data shows an increase in visits of stroke sufferers at the RSSN Bukittinggi Polyclinic (Medical Records RSSN Bukittinggi). This proves the number of stroke survivors who are cared for by caregivers at home.

Based on a preliminary study at the RSSN Bukitinggi Polyclinic on April 22 2016, researchers interviewed 10 caregivers , 4 out of 10 caregivers complained of problems in caring for clients such as financial problems, namely costs for treatment accommodation, 4 out of 10 caregivers felt pressured to think about caring for sufferers stroke by doing work, 5 out of 10 caregivers are worried about the condition of stroke sufferers and 6 out of 10 caregivers often complain of being tired and running out of time in caring for their sick family and the quality of social relations is reduced. This situation certainly has an impact on the physical, psychological, social and environmental which will affect the quality of life of stroke caregivers.

Attention to caregivers is very important because the success of treatment and care for stroke patients cannot be separated from the help and support provided by caregivers who accompany them for almost 24 hours in providing care and providing emotional support. Caregivers also play a role in preventing stroke complications and recurrent strokes. If caregivers experience problems such as health problems, this will affect stroke sufferers because stroke sufferers depend on caregivers. Based on this description, the authors are interested in conducting research on the relationship between burden and quality of life for stroke survivors at the Bukittinggi National Stroke Hospital Polyclinic.

METHOD

This type of research is analytic research with a *cross sectional approach. The cross sectional* approach is a study to study the dynamics of the correlation between risk factors and effects, by way of approach, observation or data collection at one time (*point time approach*). This means that each research subject was only observed once and measurements were made of the character status or subject variables at the time of examination (Notoadmodjo, 2010). The design of this study aims to study the relationship between the independent variables and the dependent variable, namely the burden of caregivers and the quality of life of caregivers of stroke sufferers, by collecting data at the same time or using a one-time approach.

Univariate analysis is all the variables that will be used in research, analyzed and tabulated. Univariate analysis in this study describes the frequency and percentage of all the variables studied, namely the characteristics of the respondents (age, gender, education, occupation, relationship with stroke survivors and length of care for stroke survivors), burden and quality of life of caregivers.

Bivariate analysis is used to see the relationship between the independent variables and the dependent variable. The test used to evaluate the frequency being investigated or to analyze the results of observations or research to find out whether there is a significant relationship in studies using categorical data is the *chi square test* with a degree of confidence of 95% ($p <0.05$). If the p value < 0.05 means there is a relationship between the independent variables and the dependent variable and if $p > 0.05$ it means there is no significant relationship between the independent variables and the dependent variable.

RESULTS AND DISCUSSION

Burden of Actors Caring for Stroke Patients

The results of the 2016 study on the burden of caretakers for stroke sufferers at the Bukittinggi RSSN Polyclinic showed that out of 76 caretakers for stroke sufferers, less than half (46.1%) of nurses felt the burden of caring for stroke sufferers at a moderate level, this number was more than the caregivers. who feel no burden, light burden and heavy burden. Caregivers' burden are all terms that describe the physical, emotional and financial responses of caregivers to change and the role of providing assistance to someone with physical or mental limitations (Jeong et al., 2015). According to Gbiri et al., (2015), the burden on caregivers is a multidimensional concept which includes physical, social, psychological and financial factors. Moderate burden is the level of experience of caregivers that is affected by most of the burden affecting caregivers in providing care to stroke patients.

According to Stuart (2013), the experience of caregivers in caring for sick clients will cause a burden. Stroke creates a burden on the people around them, in general the burden is felt by the main caregiver (Caplan, 2009). Burden refers to all the difficulties and challenges experienced by caregivers as a result of caring for stroke patients because a stroke occurs suddenly which will result in caregivers facing problems or difficulties in carrying out their roles.

The results showed that more than half of the caregivers often felt that stroke survivors were very dependent on themselves (52.6%), this was because stroke sufferers experienced limitations in carrying out their activities. According to Joan et al., (2014), half of people who make it through a stroke are in a state of permanent disability and experience recurrence within weeks, months and years. This situation results in the importance of the role of caregivers in caring for stroke patients. Less than half of caregivers said they were often worried about the future of stroke survivors and often felt their health was disturbed by taking care of stroke survivors. This is caused by fatigue and lack of rest because they have to care for and supervise stroke sufferers. This is in line with the opinion of Berg et al., (2005), that caregivers have a risk of experiencing health problems.

The results of the study showed that out of 76 caregivers, 6 caregivers felt a heavy burden when caring for stroke patients (7.8%). Based on filling out the questionnaire, 5 out of 6 caregivers always felt that stroke sufferers were expecting attention as if caregivers were the only people who could be expected, half of the caregivers always felt they had to do more for stroke sufferers and felt they had to be able to do their job. better care for stroke survivors. This shows that caregivers feel a burden in carrying out their roles.

Based on the length of care for stroke patients, more than half of the caregivers had cared for stroke patients for 6 to 12 months (69.7%). Less than half of the caregivers feel moderate burden (45.3%). The length of time caring for patients will cause feelings of pressure and depression on caregivers and will cause a burden on caregivers. This will change the interaction patterns, habits and lifestyle of caregivers which can cause stress and boredom for caregivers (Kumar et al., 2015). Research conducted by Pierce et al., (2008) regarding caretakers for stroke sufferers told that caregivers felt pressured and bored because they had to care for stroke sufferers for a long time.

Quality of Life of Performers Caring for Stroke Sufferers

The results of research on the quality of life of stroke caregivers at the 2016 RSSN Bukittinggi Polyclinic showed that more than half (52.6%) of stroke caregivers expressed a poor quality of life. Quality of life is an individual's perception of their position in life in the context of the culture and values in which they live and in relation to life goals, expectations, standards and concerns. This is a broad concept that affects a person's physical health, psychological state, level of dependency, social relationships, personal beliefs and their relation to future desires for their environment (WHO, 1994 in Skevington et al, 2004).

Stroke occurs suddenly and cannot be predicted which results in the unpreparedness of caregivers (Ogunlana et al, 2014). This unpreparedness resulted in many caregivers being unable to anticipate problems in carrying out their roles and impacting physical, psychological, social and environmental conditions which are part of a person's quality of life.

Research conducted by Cramn et al., (2011), found that caregivers for stroke sufferers have a poor quality of life because caregivers experience limitations in carrying out their roles as a result of caring for stroke sufferers. When caring for stroke patients, especially those with limitations or disabilities will affect the quality of life of caregivers (Hung et al, 2012).

WHOQOL BREF divides a person's quality of life into four domains, namely the physical, psychological, social and environmental domains. From the analysis of each of these quality of life domains, the average score for the physical domain was 11.47, the average score for the psychological domain was 11.9, the average score for the social domain was 11.5 and the average score for the environmental domain that is 11.59. The results showed that the physical domain had the lowest score and the psychological domain had the highest score.

Aspects assessed in physical health include energy and fatigue, pain and discomfort, sleep and rest, movement, daily activities, dependence on drug substances and medical assistance and ability to work. Based on the aspect of the physical domain, more than half (63.2%) of the caregivers had a poor physical domain, more than half of the caregivers said they were dissatisfied with sleep (56.6%) and ability to do work (57.9%). This is because they have to care for and supervise stroke sufferers.

Carers for stroke sufferers experience impacts such as feeling tired, lack of sleep and limitations in carrying out daily activities. Fatigue is one of the physical complaints felt by caregivers. Fatigue is described as a condition experienced by a person that occurs because of a distress, and results in a decrease in the ability to function which is closely related to the loss of body energy. Ostwald et al., (2009) in their research said that from the start of stroke recovery, limited mobility and inability of patients to carry out daily activities, became one of the reasons for changes in the physical abilities of caregivers in carrying out daily activities. In addition, caregivers also feel a change in sleep and rest patterns. Disorders that arise during sleep vary between each caregiver, where they often wake up to supervise and assist the activities of stroke sufferers.

Aspects assessed in psychological health include self-image and appearance, negative feelings, positive feelings, self-concept, thinking, learning, memory and concentration, spirituality, religion and personal beliefs. The results showed that more than half (61.8%) of the caregivers had a good psychological domain. More than half of caregivers said it was difficult to concentrate in daily life (56.6%). Nurses feel they are not concentrating at work because they are worried about the condition of the stroke patient.

Based on the aspect of the social domain, more than half (63.2%) of caregivers have a good social domain. The results of the study showed that more than half of the caregivers said they were normal in social relations, sexual life and the support they received from friends. Based on the aspect of the environmental domain, more than half (57.9%) of the caregivers had a bad environmental domain, more than half of the caregivers said it was difficult to have opportunities to have fun or recreation (64.5%) due to lack of time freedom and feeling tied down with his role.

Based on the length of care for stroke patients, more than half (69.7%) of caregivers have cared for stroke patients for 6 to 12 months. More than half of the caregivers have a poor quality of life (54.7%). The length of time caring for patients will cause feelings of stress and depression in caregivers, this can negatively affect the quality of life of caregivers.

The Relationship between Burden and Quality of Life for Caring for Stroke Patients

Based on the results of bivariate data analysis using the *Chi-Square test* , the results obtained were $p = 0.005$ ($p < 0.05$). That statistically there is a relationship between burden and the quality of life of caregivers of stroke sufferers. The results of this study are in line with the results of a study conducted by McPherson et al., (2011), it was found that caregivers have a poor quality of life, caring for stroke patients who have many limitations on bodily functions and burdens related to the quality of life of caregivers. A study by MOOgunlawa et al., (2014), found that caregivers of stroke sufferers have a poor quality of life and have a burden in caring for stroke sufferers. Research by McCullagh et al., (2005), found that there is a relationship between burden and the quality of life of caregivers ($p < 0.001$).

The burden of caregivers is a factor that greatly influences the quality of life of caregivers (Nir et al., 2009). The role of caregivers is very important, because nurses greatly influence the response of stroke sufferers to their illness and play a role in the successful recovery of stroke patients, nurses also play a role in preventing stroke complications and recurrent strokes. Research by Kumar et al., (2015), found that there is a correlation between the burden of caregivers, there is a negative relationship between the burden of caregivers and physical aspects (r=-0.565, p<0.01), psychological (r=-0.796, p< 0.01), social (r=-0.599, p<0.01) and environmental (r=-0.763, p<0.01) which are aspects of a person's quality of life. Fall (2007) states that caregivers tend to neglect their physical, emotional and spiritual health while caring for a sick family member. This will lead to the onset of the problem of exhaustion and long-lasting hopelessness. Caregivers often do not recognize when they are experiencing fatigue, so that in the end they cannot function effectively, and may even suffer from illness.

The results showed that 34.2% of caregivers who felt the burden was moderate had a poor physical domain, caregivers said they were dissatisfied with sleep (32.9%) and ability to work (30.3%). This is because they have to care for and supervise stroke patients who experience limited body functions. Nurses who feel moderate burden have a good psychological domain (28.9%), nurses say it is difficult to concentrate in daily life because they are worried about the condition of stroke patients. Carers who feel a light burden have a good social domain (30.3%). Nurses who feel a moderate burden have a poor environmental domain (31.6%), caregivers say it is difficult to have opportunities to have fun or recreation because of a lack of freedom of time and feel tied to their role.

Post-stroke care usually takes a long time. This will change the interaction patterns, habits and lifestyle of caregivers which can cause stress and boredom for caregivers. Research conducted by Pierce et al., (2008) regarding the side of life of caregivers for stroke patients recounts the experiences of caregivers, where they feel burdened, do not have enough time for themselves and experience psychosocial disorders. Various changes in fulfilling basic needs were experienced by caregivers while caring for stroke patients. Changes in the fulfillment of basic needs experienced are not only physical needs, but also psychological, social and spiritual needs. The neurological deficit experienced by stroke survivors is one of the challenges that must be faced by caregivers to achieve successful recovery for stroke survivors.

CONCLUSION

Based on the results of research that has been conducted regarding the relationship between burden and quality of life of stroke caregivers at the RSSN Bukittinggi Polyclinic, the following conclusions can be drawn: 1. Less than half of the caregivers have a moderate burden of caring for stroke patients. 2. More than half of caregivers have a poor quality of life. 3. There is a relationship between the burden and the quality of life of stroke caregivers.

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