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POST-STROKE QUALITY OF LIFE PERCEIVED BY PATIENTS AND CAREGIVERS

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Abstract

The quality of life (QOL) of post-stroke patients can be assessed from the reports of patients themselves obtained through a structured interview or a questionnaire. However, some individuals are unable to comprehensively describe their QOL because of language disorders, cognitive effects caused by stroke, or pre-existing conditions. This study aims to identify differences in post-stroke QOL perception between patients and caregivers. A cross-sectional design involving 115 stroke patients and 115 caregivers was adopted, and Mann–Whitney test was used for statistical analysis. Results showed no significant difference in QOL perception ($p = 0.166$; $\alpha < 0.05$), particularly in the physical ($p = 0.278$; $\alpha < 0.05$), psychological ($p = 0.068$; $\alpha < 0.05$), social relationship ($p = 0.976$; $\alpha < 0.05$), and environmental ($p = 0.157$; $\alpha < 0.05$) domains between patients and caregivers. Therefore, information from caregivers can be used to assess QOL when patients are incapable of reporting their condition.

Keywords: caregiver, perception, quality of life, stroke

Abstrak

***Kualitas Hidup Pasca Stroke yang Dipersepsikan oleh Pasien dan* Caregiver**. *Kualitas hidup pasien pasca stroke dapat diketahui berdasarkan laporan dari pasien stroke dengan wawancara terstruktur atau dengan pengisian kuesioner. Namun, beberapa dari pasien stroke tidak dapat menggambarkan kualitas hidup mereka karena adanya gangguan bahasa dan efek kognitif lainnya akibat stroke atau kondisi yang sudah ada sebelumnya. Penelitian ini bertujuan mengidentifikasi perbedaan persepsi kualitas hidup antara perspektif pasien pasca stroke dan* caregiver. *Penelitian ini menggunakan desain* cross sectional *yang melibatkan 115 pasien dan 115* caregiver *dengan menggunakan analisis statistik Mann Whitney. Hasil analisis menunjukkan tidak terdapat perbedaan secara signifikan antara persepsi kualitas hidup dari pasien dan* caregiver *($p = 0{,}166$; $\alpha < 0{,}05$), khususnya pada domain fisik ($p = 0{,}278$; $\alpha < 0{,}05$), psikologis ($p = 0{,}068$; $\alpha < 0{,}05$), hubungan sosial ($p = 0{,}976$; $\alpha < 0{,}05$), dan lingkungan ($p = 0.157$; $\alpha < 0{,}05$) dari kualitas hidup yang dipersepsikan oleh pasien dan yang dipersepsikan oleh* caregiver. *Informasi dari* caregiver *dapat digunakan saat pasien tidak dapat memberikan informasi terkait kualitas hidupnya.*

Kata Kunci: caregiver, *kualitas hidup, persepsi, stroke*

Introduction

Stroke is the leading cause of long-term disability (Singhpoo et al., 2012), the 2nd leading cause of death after ischemic heart disease, and the 3rd leading cause of disability in the world (World Health Organization [WHO], 2015). In Indonesia, WHO reported stroke as the first cause of death that killed 21.2% or 328,500 people in 2012 (WHO, 2015). In 2013, the number of stroke sufferers in Indonesia was estimated at 1,236,825 people (7.0‰) on the basis of the diagnosis of health workers alone and 2,137,941 people (12.1‰) on the basis of symptoms and the diagnosis of health workers (Ministry of Health Republic of Indonesia, 2014). Basic Health Research in 2013 states that the North Sulawesi Province is the area with the highest prevalence of stroke (10.8‰) according to the diagnosis of health workers (National Institute of Health Research and Development, 2013).

This stroke condition causes neurological deficits and disability in patients that interfere with their daily activities. The prevalence of disability due to stroke is estimated at 33–460 per 100,000 population (Carod-Artal, 2012). Quality of life (QOL) is affected by neurological deficits and disability after recovery from diseases such as hemiplegia, impaired balance and ambulation, difficulty in swallowing and speaking, impaired visual perception, and loss of bowel and bladder control (Rachpukdee et al., 2013).

Health-related QOL is an important list of post-stroke patient outcomes. The QOL of post-stroke patients can be assessed from patients themselves through structured interviews or questionnaires. This measure is useful in understanding the patient's reaction to illness and in monitoring the effectiveness of health care interventions (Gbiri & Akinpelu, 2012). However, approximately 25% stroke survivors fail to report their status due to language or other cognitive deficits. Therefore, functional assessment from another individual, usually family members or physicians, is used to replace the patient's perspective (Jette et al., 2012). Family members are categorized as family or informal caregivers who are not paid or trained by an institution and are usually spouses, children, children-in-law, or close friends of the patient (Francois et al., 2014). These caregivers are expected to provide an assessment of their perceptions toward the QOL of stroke patients.

Vellone et al. (2011) assessed caregivers' reliability to measure the QOL of stroke patients and found that the average QOL from patients is similar to that from caregivers and ranges between 19.1 and 16.2 for the hand function domain and between 83.81 and 81.85 for communication domain. However, this study explained that caregivers tend to give a poor assessment of the patient's QOL, though the values were not significantly different. Only a few studies have attempted to identify differences in QOL perception between post-stroke patients and caregivers Therefore, differences in QOL perception between post-stroke patients and caregivers must be examined. The current work aims to identify the differences in QOL perceived by post-stroke patients and caregivers.

Methods

This quantitative research used a cross-sectional design to identify differences in QOL perception between post-stroke patients and caregivers. Non-probability purposive sampling was adopted. The total sample size was 115 caregivers and 115 patients. Inclusion criteria for post-stroke patients were as follows: old and new patients undergoing treatment at the neurology polyclinic, physical medicine polyclinic, and medical rehabilitation; ≥ 18 years old; good orientation of people, places, and times; no aphasia, no dysarthria, dementia, and Transient Ischemic Attack (TIA) based on medical diagnosis; accompanied by a caregiver; can read and write; can understand Indonesian; and willing to be a respondent. Exclusion criterion for patients was not having a partner. Inclusion criteria for caregivers were as follows: patients' partner; ≥ 18 years old; can read and write; can understand Indonesian; and willing to be a respondent. Exclusion criterion for caregivers was not living at the same home with the patient. Drop out criteria (could not be continued as a research sample) were established during the study as follows: suddenly experienced a health problem and withdrew from the study for some reasons.

Results

The majority of post-stroke patients and caregivers were categorized in middle adulthood. Table 1 shows that 85 post-stroke patients (73. 9%) and 87 caregivers (75.7%) are aged 41–65 years. According to frequency distribution on gender, the majority of post-stroke patients are males (56.5%), and that of caregivers are females (56.5%). In terms of education background, 64 post-stroke patients (55.7%) and 63 caregivers (54.8%) graduated from senior/vocational high school. With regard to depression, 96 post-stroke patients (83.5%) and 101 caregivers (87 .8%) were in the null depression category.

Table 2 shows the results of Kolmogorov–Smirnov normality test. The data on the perception variable of QOL by patients ($p = 0.000$; $\alpha < 0.05$) and caregivers ($p = 0.000$; $\alpha < 0.05$) were not normally distributed. Thus, bivariate analysis was carried out using non-parametric statistical tests. Table 3 show no significant difference in the QOL perceived by patients and caregivers ($p = 0.166$; $\alpha < 0.05$). In particular, Table 4 shows no significant difference in the physical ($p = 0.278$; $\alpha < 0.05$), psychological ($p = 0.068$; $\alpha < 0.05$), social relationship ($p = 0.976$; $\alpha < 0.05$), and environmental ($p = 0.157$; $\alpha < 0.05$) domains of QOL perception between patients and caregivers.

Table 1. Characteristics of Respondents

Variable		Patient		Caregiver		Total	
		n	%	n	%	n	%
Age	Early adulthood (18–40 y/o)	4	3.5	5	4.3	9	4.8
	Middle adulthood (41–65 y/o)	85	73.9	87	75.7	172	73.9
	Late adulthood (> 65 y/o)	26	22.6	23	20	49	21.3
Gender	Male	65	56.5	50	43.5	115	50.0
	Female	50	43.5	65	56.5	115	50.0
Education	Low Education (with any education, graduated from elementary, graduated from junior high school)	18	15.7	24	20.9	42	18.3
	Senior/Vocational High School	64	55.7	63	54.8	127	55.2
	Higher Education (Diploma 3, Bachelor Degree, Master Degree)	33	28.7	28	24.3	61	26.5
Depression	Null depression	96	83.5	101	87.8	197	85.7
	Mild depression	16	13.9	12	10.4	28	12.2
	Moderate depression	3	2.6	2	1.7	5	2.2

Table 2. Quality of Life (QOL) Perceived by Patients and Caregivers

Variable	Group	N	Mean	Median	Min–Max	95% CI Min–Max
QOL perception	Patient	115	117.57	115	90–152	114.86–120.27
	Caregiver	115	114.80	113	74–152	112.14–117.46

Table 3. Differences in Quality of Life (QOL) Perceived by Patients and Caregivers

Variable	Group	n	p
QOL perception	Patient	115	0.166
	Caregiver	115	

**Mann–Whitney Test* ($\alpha < 0.05$)

Table 4. Differences in the Physical, Psychological, Social Relationship, and Environmental Domains of Quality of Life (QOL) Perceived by Patients and Caregivers

Variable	Group	n	p
Physical domain	Patient	115	0.278
	Caregiver	115	
Psychological domain	Patient	115	0.068
	Caregiver	115	
Social relationship domain	Patient	115	0.976
	Caregiver	115	
Environmental domain	Patient	115	0.157
	Caregiver	115	

*Mann–Whitney Test ($\alpha < 0.05$)

Discussion

In this study, the majority of post-stroke patients were 41–65 years old and thus categorized into middle adulthood. These results differ from the research of Purnomo et al. (2016), who found that the majority of 455 stroke patients (212 patients) were aged 60 years. Age is a risk factor of stroke i.e., the incidence of stroke increases with age. This condition is also highly threatening for the elderly. Elderly stroke patients have a higher mortality rate and receive lower quality of care than younger stroke patients (Pei et al., 2016).

The majority of post-stroke patients were male. This findings is in line with the study of Purnomo et al. (2016), who reported that 268 out of 455 stroke patients were males. By contrast, the participants in the research of Pinedo et al. (2017) were dominated by females (92 females out of 157 stroke patients). The justification for the study of Pinedo et al. (2017) differ from those of the current work and the research of Purnomo et al. (2016) due to their varying sample populations. Purnomo et al. (2016) used a male-dominant group; hence, the results reflected that men are relatively at risk of stroke. By contrast, Pinedo et al. (2017) employed a female-dominated population; hence, the results classified women as relatively at risk of stroke.

The majority of post-stroke patients (64, 55.7%) graduated from senior/vocational high school. Chuluunbaatar et al. (2016) also found the similar result that around 48% of post-stroke patients had a lower level of education than college. A strong education may be important in navigating health care and making choices about lifestyle and personal health behaviors (Zimmerman & Woolf, 2014).

The majority of post-stroke patients were in the category of null depression (83.5%). A systematic review and meta-analysis of 50 studies conducted by Ayerbe et al. (2013) revealed that the prevalence of depression was 29% (95% CI 25–32), which remained stable up to 10 years after stroke and had a cumulative incidence of 39–52% within 5 years of stroke (Ayerbe et al., 2013). Recovery rates from depression among post-stroke patients ranged 15–57% at 1 year after stroke. The main predictors of depression were disability, pre-stroke depression, cognitive impairment, stroke severity, and anxiety (Ayerbe et al., 2013). One of the most common and most problematic neuropsychiatric consequences is depression, whose incidence increases substantially after stroke (Carey, 2012). People with depression experience sadness, anxiety, and emptiness beyond what they can control (Carey, 2012) and often feel hopeless, guilty, worthless, irritable, and restless. They may also experience disturbances in natural functions such as sleep, appetite, initiative, and desire (Carey, 2012). High self-esteem and support from partners contribute positively to patients. Hence, the status quo for post-stroke patients is no depression.

The majority of caregivers were in middle adulthood category (41–65 years). Kniepmann (2012) reported that the age of female caregivers ranges 22–65 years. By contrast, the National Alliance for Caregiving and AARP (2015) state that most caregivers are 18–49 years old. Caregivers who are in middle adulthood (41–65 years old) already have a mature age while providing care to post-stroke patients.

In this study, 56.5% of the caregivers are females. The dominance of female caregivers explains the role of women as service providers (Anjos et al., 2014). The majority of the caregivers graduated from senior/vocational school (63, 54.8%). This finding is in line with the data from the National Alliance for Caregiving and AARP (2015). Education is important in developing life skills and competencies, including how to care for stroke patients. Owing to their secondary school background, the caregiver respondents were assumed to have limited knowledge about stroke but have a tendency to comply with every provision in the care of stroke patients.

This research found that approximately 87.8% of caregivers did not experience depression. Meanwhile, the previous researches indicate the various percentage of caregivers who experienced depression, that is 18% (Balhara et al., 2012), 26.5% (Hu et al., 2018), and 71% (Guo & Liu, 2015). Further, Hu et al. (2018) stated that gender, time of care per day, and method of medical payment affect caregiver depression.

No significant difference in QOL perception was found between stroke patients and caregivers. This finding is in line with the study of Vellone et al. (2011), who identified the reliability of caregivers in assessing the QOL of stroke patients and found no difference in their QOL assessment. In particular, the current research found no significant difference in the physical, psychological, social relation, and environmental domains between patients and caregivers.

According to Vellone et al. (2011), the QOL assessment by patients in the domains of hand function and communication tends to be the same as that by caregivers. Physical function is another variable associated with stroke and affects the QOL of stroke patients. Stroke can limit the daily living activities of patients (Rouillard et al., 2012), which can then reduce their participation in work, household responsibilities, and social and recreational activities. As a result, the patients experience role changes, social isolation, and low emotional and mental QOL (Rouillard et al., 2012).

The perceived QOL of caregivers was poorer than that by stroke patients, though the results showed no significant difference. This finding is in line with the study of Vellone et al. (2011), who found that caregivers tend to give a low rating for the QOL of stroke patients. However, another research reported that caregivers give a high rate for the patient’s QOL. Oczkowski and O’ Donnell (2010) conducted a systematic review on the reliability of caregivers in assessing the activity of daily living (ADL) and the QOL of stroke patients and found that caregivers overestimate their patient’s status. In addition, the caregiver's reliability in measuring the ADL scale is substantial to excellent, and that in measuring the QOL scale is moderate to substantial.

At 3 months post-stroke, many family caregivers reported a high burden that is closely related to their perceived level of difficulty (Lui et al., 2011). Hence, the caregivers give a lower rate for the QOL of stroke patients compared with that from the patients themselves. This assessment is motivated by the functional status of the caregiver. Although the QOL perceived by the caregiver was lower than that perceived by the patient, the difference is minimal. Statistical results showed no significant difference in the QOL perceived by patients and caregivers. Therefore, nurses can assess the QOL of incapable stroke patients by using the information provided by caregivers to get accurate results.

Conclusion

In this study, the majority of post-stroke patients were males, in the middle adulthood stage, had secondary education, and do not experience depression. The majority of caregivers were females, in the middle adulthood age, had secondary education, and do not experience depression. Analysis revealed no significant difference in QOL perception between patients and caregivers.

For health service provision, caregivers must be involved in the assessment of the QOL of post-stroke patients. For the development of nursing science, materials about the role of caregivers in providing nursing care to stroke patients must be incorporated in the nursing curriculum. Further studies must be conducted on the patient's QOL from the perspective of the patient's real abilities.

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