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Validity and Reliability of Health-related Quality of Life of Post-stroke Patients

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Abstract

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BACKGROUND: Stroke has become a serious problem in Indonesia. Its prevalence tends to increase every year. Individuals who have had a stroke are unable to live independently. In continuing their daily activities, post-stroke patients must be able to adapt and unite their desires and life goals with physical, psychological, social, role, and spiritual changes compared to before suffering a stroke. Failure in the adaptation process makes the quality of life of post-stroke patients significantly decrease. The WHO considers the potential use of health-related quality of life (HRQL) as an instrument to measure the quality of life of post-stroke patients which has been commonly used in many studies.

AIM: This study aimed to analyze the validity and reliability of HRQL questionnaire on post-stroke patient. It also analyzes the psycho-social, role, and spiritual dimensions of the quality of life of post-stroke patients using sociology theoretical approach utilizing structural functionalism theory and social change theory.

METHODS: HRQL, consists of 37 questions including physical, psychological, social, role, and spiritual dimensions, was applied to measure the quality of life. Pearson product moment and Cronbach's alpha were used as validity and reliability test. Analysis of the sociological approach was carried out using Talcott Parsons Sociology.

RESULT: Forty-four post-first stroke attack respondents from two hospitals in Surabaya East Java and Klaten Central Java, Indonesia, were obtained. Construct validity test showed that six questions were not valid study ($p > 0.05$, $r < 0.297$) and 31 questions were valid. The reliability test exhibited that all valid questions were reliable (Cronbach's $\alpha=0.888$).

CONCLUSION: The HRQL is a reliable and valid instrument with good psychometric properties. The scale is recommended for assessing quality of life of post-stroke patients.

Introduction

Based on the Basic Health Research of the Indonesian Ministry of Health in 2013, Riset Kesehatan Dasar (RISKESDAS), the prevalence of stroke in Indonesia is 7% per 1000 Indonesian population. This prevalence continues to increase with age. The prevalence of stroke increased in 2018 by 10.9% per 1000 population. The results of RISKESDAS show that stroke is more common in men (11%) than women (10.9%) with the highest prevalence (per mil) is in the age range above 75 years (50.2%), followed by the age range of 65–74 years (45.3%), 35–64 years (32.4%), 25–34 years (1.4%), and 15–24 years (0.6%)

Strokes arise as a result of sudden, rapid, and progressive brain damage due to blood circulation disorders of the brain that is not traumatic, which cause disorders such as paralysis of part of the face or limbs and speech disorders [1]. According to the WHO, stroke is a clinical sign that develops rapidly due to focal brain disorders with symptoms that last for 24 h or more and can cause death in the absence of any other obvious

cause other than [2]. The present study from Peixoto et al., in Portuguese aims to determine the predictive variables of QoL and its dimensions in Portuguese patients during the physical rehabilitation process following a first stroke [3], [4].

A person who suffers a stroke will generally lose some or all of certain body functions. The blood supply that has stopped causes the body to no longer function properly [5]. Identifying the cause of stroke from the beginning is very important. Post-stroke patients intervention to minimize disability and improve quality of life [6]. In general, stroke patients are no longer able to be independent. Most of them have difficulty controlling their emotions. The patients easily feel scared, restless, angry, and sad because of their physical and mental shortcomings. This condition makes patients feel uncomfortable because they tend to feel excessive worry about the possibility of bad things that will happen. This is supported by the study of Spielberger, Liebert, and Morris. They have conducted experiments to measure the anxiety experienced by individuals and then the anxiety is defined as a concept consisting of two main dimensions, namely, worry and emotionality [7].

In continuing their daily activities, post-stroke patients must be able to adapt and unite their desires and life goals with physical, psychological, social, role, and spiritual changes compared to before suffering a stroke. The daily activities of post-stroke patients involving people close to them such as husband, wife, children, relatives, family, neighbors, and friends are something that must be done to facilitate the adaptation process. Adaptation intervention programs for post-stroke patients have focused on training patients to be able to control stimuli, use adaptive coping, and display effective adaptive behavior immediately after a patient has had a stroke. The adaptive response²³own by patients after stroke is the key to achieving a patient's¹⁵ quality of life [8]. Failure in this process will make the quality of life of post-stroke patients significantly decrease. To the adaptation run well, the quality of life of post-stroke patients must be monitored properly and regularly.

One of the instruments that can be used to measure the level of quality of life in patients is health-related quality of life²⁵ (HRQoL). HRQoL is a measurement model from Wilson and Cleary. In this model, the dimensions of quality of life in post-stroke patients can be grouped as five main dimensions: Physical dimensions, psychological dimensions, social dimensions, role dimensions, and spiritual dimensions [8]. Physical dimensions can be seen from the individual's subjective expression of physical symptoms and their ability⁴² to perform physical activities after suffering a stroke. The results⁴¹ of a systematic study conducted by Bakas *et al.* who found that the three²¹ most commonly used quality of life models were the Wilson and Cleary Model (Wilson & Cleary, 1995), the Ferrans Model (Ferrans, Zerwic, Wilbur, & Larson, 2005), and the WHO International Classification of Functioning Disability and Health (WHO, 2007). However, in many researches, the most commonly used model is the HRQoL model which developed from Wilson and Cleary model [9]. In Indonesia, HRQoL according to Martin Romero, David Vivas-Consuelo, and Nelson Alvis-Guzman, the implementation of HRQoL in several countries and regions may differ from one another due to methodological and socioeconomic differences [10]. In this case, it is possible to make some changes to adjust to the cultural and environmental conditions of a country's society.

In Indonesia, HRQoL has been⁴⁵ widely translated and used in studies that measure the quality of life of patients with chronic diseases such as stroke. One of them is HRQoL which has been translated by Darma [11].¹⁵ used this translated HRQoL instrument to measure the quality of life of post-stroke patients in Surabaya and Klaten. Then we held expert discussion to improve content validity of the instrument. We aimed to analyze further about the psycho-social, role, and spiritual dimensions of the quality of life of post-stroke patients using HRQoL. We also analyze the quality of life

with sociology theoretical approach utilizing structural functionalism theory and social change theory from Talcott Parsons.

Daily activities of post-stroke patients involving others are it husband, wife, children or relatives, family or neighbors, and friends as a need that is still being done. Support from those closest to you will help the recovery of post-stroke patients. As stated by Jansen, about the importance of stroke patients still interact with their environment³² as a form of adaptation. A study by Janssen, evaluating enriched environments that included social interaction, found positive results in terms of activity [12]. Adaptation, according to Talcott Parsons, is part of four functions of human action to meet one or more needs of the human living system.

Methods

Participants

An observational quantitative analytic study was conducted with cross-sectional approach. Samples were selected with simple random and 44 post-first attack strokes were obtained from two hospitals in Surabaya East Java and Klaten Central Java, Indonesia.

Interview and focus group discussions (FGD)

We conducted interview to collect primary data²⁵ from the post-first stroke attack respondents. We used the health-related quality-of-life questionnaire to get the data. The interview was held in the hospital or at the patient's home. Before the interview, we had run a FGD with doctors, nurses, and all researchers for the preparation of research instruments. We discussed to determine the compatibility of the indicators contained in the instrument with related theories and concepts. The experts involved gave some inputs of subvariables and indicators that must be corrected, removed, or added. There were physical, psychological, social, role, and spiritual dimensions to measure how the quality of life of post-first stroke attacks patients. After that, we scored it on the Likert scale.

Statistical analysis

Statistical analyses were conducted²⁹ using the SPSS 21 Statistics for Windows, V.17.0 (IBM, Armonk, New York, USA); $p < 0.05$ was considered to be statistically significant. From the validity test, as many as 37 questions were further tested for rehabilitation with the help of SPSS V.17. It is said that the value (α) $> 0.6\%$ (Wiratna Sujarweni, the first print of 2015) [13].

Validity and reliability

For a questionnaire to be construct validity, all items together should represent the underlying construct (HRQOL). Construct validity can be determined by internal consistency test using Pearson product moment correlation formula, which correlates the score of each item with the total score. The item was said to be valid, if the result of the value correlation was above or equal to the value from the table with a sample size of 44 ($r = 0.297$), or the significance value was below the limit ($p = 0.05$). Reliability was investigated by Cronbach's α values. Cronbach's α gives a score of between 0 and 1, a value of >0.6 indicating good reliability.

Sociological analysis

Existing data were analyzed further utilizing Talcott Parsons Sociology. Sociology Theory, according to Talcott Parsons, was a part of four functions of human action to meet one or more needs of the human living system. The data were anatomized by four functional imperatives that characterize the entire system – adaptation, goal attainment, integration, and latency or pattern maintenance [11].

Results

Participants

This validation study was part of a multicenter cohort study including post-first attack stroke persons within stable condition. This study was conducted on outpatient unit in two hospitals in Surabaya East Java and Klaten Central Java, Indonesia, during March until October 2021.

Table 1 shows the sociodemographic of the 44 participants. More than a half of the participants were a male. The median age was 50 years (range 36–68 years). Most of them were senior high school graduate (55%) and private employee (55%). About 43% of the patients got a stroke incident at 1–3 years before the interview was run, followed by 1–3 months before (30%), 4 months till 1 year before (13%), 3–5 years (7%), and more than 5 years before (7%). Hypertension became an underlying disease of almost participants. Only one person has non-hypertension disease as a main cause of the stroke incident.

Validity

There were 37 questions on the questionnaire. It was divided into five dimensions below: Physical mobility dimension consists of nine questions, psychological dimension (12 questions), social dimensions (10 questions), role dimension (one question), and spiritual

Table 1: Participants sociodemographic characteristic

	Response (n = 44)
Gender, n (%)	
Female	17 (38)
Male	27 (62)
Age, n (%) (years old)	
36–45	5 (11)
46–55	20 (45)
56–65	18 (41)
Above 65	1 (3)
Education, n (%)	
Bachelor	6 (14)
Diploma	1 (2)
Senior high school	24 (55)
Junior high school	4 (9)
Elementary school	8 (18)
No education	1 (2)
Work status, n (%)	
Government employee	3 (7)
Private employee	24 (55)
Pensionary	4 (9)
Unemployed	13 (29)
Marital status, n (%)	
Married	41 (94)
Widow	2 (4)
Widower	1 (2)
Time of stroke incident, n (%)	
1–3 months ago	13 (30)
4 months ago until 1 years	6 (13)
1–3 years ago	19 (43)
3–5 years ago	3 (7)
More than 5 years ago	3 (7)
Underlying disease, n (%)	
Diabetes mellitus	1 (2)
Hypertension	43 (98)

dimension (five questions). We ran validity test using Pearson product moment. Due to their invalid result, six questions were excluded after the validity test had finished. The remaining valid questions are shown in Table 2.

In the physical mobility dimension, there were seven valid questions: Walking activities capability, help from others, frequency of exercise activities, independence when going to the hospital, walking at home, and eating and bath by themselves. It is said that physical dimensions affect the quality of life of post-stroke patients. Stroke was a major cause of long-term disability. Disorders of the cerebral tissue caused disability to perform daily activities, emotional mental disorders, and decreased productivity so that these conditions had an impact on the quality of life. Although, in some cases, physical health declines, mental health is still good or satisfactory, disabilities and quality of life must continue to be studied [14].

In the social dimension, we found that all questions which include on three subdomains (social relationship with family, community activities, and recreation) were proven to be valid. Post-stroke patients generally also cannot live independently because they need interaction and help from others to carry out their daily activities [2].

The next dimension was the role dimension. This dimension only consisted of one valid question: What is the role of post-stroke patients in their families, for example, the role of post-stroke patients as the head of the family who has to earn a living, or as a housewife. The role in the family is legitimately used in measuring the quality of life of post-stroke patients. Due to weakness and loss of some their abilities, they

Table 2: Validity test result

No.	Dimension	Variable	Value count	Significant (α)	Description
1	Physical mobility	Walking	0.595	0.000	Valid
		Help others in walking	0.621	0.000	Valid
		Frequency of exercise activities	0.534	0.000	Valid
		Independence when going to the hospital	0.475	0.001	Valid
		Walking at home by themselves	0.713	0.000	Valid
		Eating by themselves	0.401	0.007	Valid
2	Psychological	Bathing by themselves	0.800	0.000	Valid
		Mood			
		Presence of others	0.310	0.040	Valid
		Appetite	0.369	0.000	Valid
		Loss of confidence	0.667	0.047	Valid
		Personality			
		Easily angry	0.301	0.047	Valid
		Disappointed with the illness	0.298	0.050	Valid
		Easily disturbed	0.451	0.002	Valid
		Concentration			
		Focus on daily activities	0.697	0.000	Valid
		Focus on work activities	0.392	0.009	Valid
		Taking medication on time	0.389	0.009	Valid
		Memory			
		Forgetful	0.317	0.036	Valid
3	Social	Remembering old memories	0.564	0.000	Valid
		Social relationships with family, neighbors, and friends			
		Neighbors interaction	0.471	0.001	Valid
		Sibling interaction	0.441	0.002	Valid
		Physical state interferes with social life	0.539	0.000	Valid
		Others communication	0.348	0.020	Valid
		Community activities			
		Community participation	0.424	0.005	Valid
		Joint society activities	0.470	0.001	Valid
		Recreation			
4	Role	Going recreation	0.304	0.045	Valid
		Pattern of spousal relationships	0.323	0.033	Valid
5	Spiritual	Family role	0.600	0.000	Valid
		Self-acceptance			
		Understanding the disease experienced	0.571	0.000	Valid
		Acceptance of the current situation	0.550	0.000	Valid
		Quality of worship			
		Performing worship	0.538	0.000	Valid
		Feelings after worship	0.345	0.022	Valid

feel unable to work anymore, rely on their family, and are not as strong as they used to be before the stroke.

The last dimension is spiritual dimension. This dimension had self-acceptance and quality of worship as its subdimensions. Understanding the disease and acceptance of the current situation were the valid questions on the first subdimension, whereas performing worship and feelings after worship were the valid questions on the other subdimension. The patients have needs to reflect their spirituality. Some their spiritual needs are the need for love, hope, trust, forgiveness, respect, and the need for dignity. They also require value, creativity, connecting with God, being a member of the community, pray with others, perform ceremonies together, forgive, and make someone else happy (13). As an ordinary human being has a sense of acceptance of his illness and the need to get closer to his God according to his religious beliefs, this spiritual dimension deserves to be studied further related to the quality of life of post-stroke patients.

Reliability

Reliability test was run using Cronbach's alpha. Because of invalid result on validity test, six questions were excluded for reliability test, abandoning 31 questions for further analysis. We found that this questionnaire had a good reliability Cronbach's alpha = 0.888. The results of the statistical test are shown in Table 3.

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Table 3: Reliability test statistics

Cronbach's alpha	No. of items
0.888	31

Discussion

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According to the WHO, quality of life refers to a subjective evaluation, which is embedded in a cultural, social, and environmental. Thus, quality of life cannot be equated with the terms "health status," "lifestyle," "life satisfaction," "mental state," or "well-being." The WHO quality of life (WHOQoL) focuses on respondents' "perceived" quality of life. Thus, it is not expected that WHOQoL can measure any detailed symptoms, diseases, or conditions nor disability as objectively judged, but rather the perceived effects of disease and health interventions on the individual's quality of life. Therefore, the WHOQoL is an assessment of a multidimensional concept incorporating the individual's perception of health status, psycho-social status, and other aspects of life. From the result above, we got some invalid questions. The excluded questions were questions about complaints during physical activity and needing help to go to the hospital on the physical mobility dimension, question about irritability due to annoying people's attitudes on the psychological dimension, questions about doing hobbies and frequency of having sex on the social dimension, and question about the routine of worshipping in the spiritual dimension. We decided not to modify the six invalid questions, because

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it could be represented by another question so that all invalid questions were excluded from the questions list and the final questionnaire consisted of only 31 questions. For more details, we have included the Indonesian version of HRQoL in Appendage 1 at the end of the manuscript.

The qualitative findings described the self-deprecating element for not accepting disability. Patients with depression often said that they "should still" be capable and sometimes called themselves as "useless;" whereas patients who were not depressed commonly reported having accepted stroke-related disability. These findings suggest that personal beliefs about accepting disability are associated with emotional adaptation following stroke (14).

According to Talcott Parsons in Sociology Theory, adaption is part of four functions of human action to fulfill the needs of the human living system. Parsons believes that there are four functional imperatives needed to shape the characteristics of an overall system – adaptation, goal attainment, integration, and latency or pattern maintenance. Taken together, these functional imperatives are called the AGIL scheme. To survive, the system must perform all four functions.

Adaptation means that the system must respond to situational needs that come from outside. It must be able to adapt to the environment and, on the other hand, it must be able to make the environment according to their needs. Goal attainment implies that the system must be able to define and achieve its main goals. Integration matters that the system must be capable to regulate the relationship of all parts of its components and interactions between the three functional imperatives (A, G, and L). Latency or pattern maintenance means that the system must be capable to complement, maintain, and renew individual motivations and the cultural patterns that create motivation itself [15].

Parsons understands AGIL as a scheme consisting of four functions that describe social reality, AGIL is also understood as a "functioning structure," wherein the social structure is conceptualized by it as an institutionalized system of action. The AGIL scheme captures this system through four prerequisites which, in combination, serve to make various community institutions work in an orderly and organically integrated manner (from families, schools, universities, companies, associations, countries, and so on) [15].

AGIL is carried out by post-stroke patients to adjust themselves with the condition of physical changes in community life. Goals and integration are the goals to be achieved, integrated with changes in psychology, social, role, and spiritual according to ability after suffering a stroke. Latency or pattern maintenance is performed by post-stroke patients to survive, including the acceptance of the disease, and

trying to motivate themselves with family support to complement each other.

The system is required to adapt to the environment and its changes, including how the behavior of individuals in the system can adapt to the environment. This adaptation function also refers to the ability of the system to fulfill its needs from the environment and distribute the required resources into the system [16].

Physical activity of post-stroke patients is aimed to recovery, social support is needed from family, hospital, and the surrounding environment. Post-stroke rehabilitation exercises are activities that must be adapted to the patient's physical abilities. This activity can be an easy activity and done daily [17].

In the control hierarchy, integration stands between the functions of pattern maintenance and goal attainment. The system as a whole is related to the allocation of rights and responsibility. For each social system, the integrative function is focus of its most distinctive properties and processes [18]. Systems must complement, maintain, and enhance both individual motivation and the cultural patterns that create and sustain motivation.

The transformation of tension of conflict into something functional for the system can disturb the body system especially for level of blood glucose, for example, getting higher blood glucose, higher blood tension and disturbance of emotional. Based on the belief, the conflict is an unavoidable necessity, so that it can be worse condition of the patient [19].

To increase the success of therapy, the patient must be able to adapt to their environment. This is evidenced by the study of Kusnanto *et al.* regarding patients with diabetic foot ulcer (DFU). In addition to receiving therapy from medical staff, DFU patients must be able to control their psychological conditions to ensure that their blood sugar is properly regulated [18], [19].

As a form of adaptation from the physical mobility dimension, post-stroke patients can still carry out activities such as walking, exercising, eating, and bathing. In the social dimension, post-stroke patients can still interact with their family, friends, and neighbors to be able to integrate themselves with others. As a compliance of psychology dimensions, patients can still concentrate on work and controlling their mood as a form of adaptation and integration with those around him over the disease. Role dimensions, particularly roles in the family such as become a husband or father, as a wife or mother, and the role of the child, can still be performed by post-stroke patients. This fact indicates that the patients still have the ability to run latency management from him and his illness. Adjustment of the spiritual role can be seen from the patient's activities who can still doing worship according to their religion. They can go to the mosque or church or worship at home. Respondents also have a spiritual

feeling that their illness is a gift from the God which must be accepted sincerely, as a form of handling the strain of the illness that they suffer from beyond their expectations.

Conclusion and Suggestions

The HRQoL is a reliable and valid instrument with good psychometric properties. The scale is recommended for assessing quality of life of post-stroke patients. The quality of life is influenced by physical, psychological, social, role, and spiritual dimensions. It is very important for post-stroke patients to think positively, be enthusiastic, and relax in life. Support from family, friends, and the environment is very much needed to maintain the quality of life of post-stroke patients.

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