

## Cognitive and functional impairment, and perception of illness in acute stroke patients

Yuda Turana, Tara Puspitarini Sani, Eva Suryani, Adrian A. Kaptein

### Summary

**Objectives:** Stroke, the leading cause of death and disability in Indonesia, has a substantial impact on patients' life. However, only a few studies have assessed the psychological functioning in stroke patients. This study contributes to the need to map out psychological functioning in stroke patients by assessing their illness perception.

**Methods:** This is a cross-sectional, descriptive-analytical study. We used a structured questionnaire which consists of a standardized collection of socio-demographic and clinical characteristics, brain CT-scan results, the severity of neurological deficit using NIH Stroke Scale (NIHSS), cognitive assessment tests, as well as Brief Illness Perception Questionnaire (BIPQ) as an instrument to assess illness perception.

**Results:** There were 56 stroke patients recruited as participants. The average age was  $55.34 \pm 10.25$ , with 30.4 % had formal education less than 9-year compulsory education. Cognitive impairment in 64.3% of subjects was associated with lower coherence ( $p < 0.005$ ). Subjects with higher education had higher personal control, treatment control and coherence ( $p < 0.05$ ). Subjects with mild neurological impairment had lower treatment control and coherence ( $p < 0.05$ ).

**Conclusions:** Stroke patients with mild neurological impairment who had been discharged had a more positive perception on the timeline, personal and treatment control. Cognitive impairment is associated with lower coherence, which underlines the importance of establishing the cognitive baseline before assessing illness perception in stroke patients.

**cognitive, illness perception, stroke**

### INTRODUCTION

Stroke is the leading cause of death and disability in Indonesia [1] with a prevalence of 10.9% according to Indonesia's Basic Health Research 2018 [2]. Those who survive from stroke gener-

ally suffer disability due to the neurological impairments. Aside from its significant effects on physical functioning, stroke also has a great impact on psychological well-being.

In the realm of psychosocial factors, illness perception plays an important role. Patient's illness perception is important in the therapeutic process because it affects how the patient responds to his/her illness and complies with the therapy [3, 4]. Patients with a positive representation of their illness perceive health problems as more curable and controllable. They also view their level of disability due to the illness

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as low [5]. In patients with myocardial infarct (MI), negative illness perception has been associated with more complications, higher rates of rehospitalisation and mortality rate one year after the acute event [6,7]. The systematic review by Richardson *et al.* has summarised the associations between illness perceptions, coping behaviours and illness outcome.<sup>8</sup> Often, doctor and patient have a different perception of the illness suffered by the patient. Exploring and discussing the patient's perception of his/her illness together between doctor and patient is an essential part of therapy.

The present study contributes to the need to map out psychological functioning in stroke patients by assessing illness perceptions and their associations with socio-demographic and clinical characteristics including cognitive function; comparing illness perception in first and recurrent stroke patients.

## METHODS

### *Patients and study design*

This is a cross-sectional, descriptive-analytical study investigating illness perception of stroke patients. All patients with Transient Ischemic Attack (TIA), ischemic stroke, hemorrhagic stroke, aged over 18 years old admitted to Atma Jaya Hospital between December 1, 2014, to September 30, 2015 were included. Exclusion criteria were death as an endpoint, discharged against medical advice before assessment, aphasia, traumatic hemorrhagic stroke, deafness and blindness, refusal to join the study due to any reason. Patients were identified through a prospective registry of all consecutive stroke patients. We used a structured questionnaire to collect socio-demographic and clinical characteristics, the severity of neurological deficit used NIH Stroke Scale (NIHSS), cognitive assessment as well as Brief Illness Perception Questionnaire (BIPQ) as an instrument to assess illness perception. Based on brain CT-scan findings, the participants were classified into patients with hemorrhagic and ischemic strokes.

NIHSS consists of 11 components: level of consciousness, language, neglect, visual field test, eye movement, facial palsy, upper and lower ex-

trimities motoric functions, limb ataxia, aphasia, dysarthria, sensory function [9]. A total score of less than 5 shows mild neurologic impairment, 6-14 moderate impairment, 15-24 moderate to severe impairment, and 25 or higher shows severe impairment [10].

**Table 1.** Baseline characteristics of demography, clinical signs, cognitive and BIPQ

Variabel	n=56
Age (Mean±SD: 55.34±10.25)	
< 60 years	33 (58.9%)
≥60 years	23 (41.1%)
Sex	
Male	28(50%)
Female	28(50%)
Education	
High (>9 years)	39 (69.6%)
Low (≤ 9 Years)	17 (30.4%)
Marital status	
Married	51(91.9%)
Widow/Single	5(8.9%)
Ethnic	
Javanese	32(57.1%)
Chinese	12(21.4%)
Sundanese	5(8.9%)
Others	7(12.5%)
Working	
No	29 (51.8%)
Yes	27 (48.2%)
Type of stroke	
Ischemic stroke	47(83.9%)
Hemorrhagic	9(16.1%)
Extremity motoric strength	
Right Upper	
Grade < 4	7 (12.5%)
Grade ≥4	49 (87.5%)
Right Lower	
Grade < 4	8 (14.3%)
Grade ≥4	48 (85.7%)
Left Upper	
Grade < 4	18 (32.1%)
Grade ≥4	38 (67.9%)
Left Lower	
Grade < 4	17 (30.4%)
Grade ≥4	94 (69.6%)
MoCA Ina (Mean±SD: 18.00±9.63)	
Impairment	36 (64.3%)
Normal	20 (35.7%)

NIHSS In	
Moderate neurological deficit	29 (51.8%)
Mild neurological deficit	27 (48.2%)
NIHSS Out	
Moderate neurological deficit	16 (28.6%)
Mild neurological deficit	40 (71.4%)
Delta NIHSS*	
No Improvement	33 (58.9%)
Improvement	23 (41.4%)

\*Comparing score at admission and discharge

*NIHSS: National Institutes of Health Stroke Scale;*  
*MoCA Ina: Montreal cognitive assessment Indonesia*  
*version*

#### *Instrument*

Cognitive function was assessed at discharge using Montreal Cognitive Assessment – Indonesian version (MoCA-Ina). MoCA-Ina consists of 11 groups of question. Variables addressed in MoCA-Ina are attention-concentration, executive function, memory, language, visuoconstructional ability, conceptual thinking, calculation, and orientation. Maximum total score is 30. For patients with 12 years or less of formal education, 1 point is added to the total score. A total score of 26 or higher shows normal cognitive function [11,12].

Brief Illness Perception Questionnaire (B-IPQ) is a self-report questionnaire used to assess patients' illness perception. B-IPQ contains eight questions to score on a scale from 0 to 10 and one open-ended question. The instrument assesses nine dimensions: consequences, timeline, personal control, treatment control, identity, illness concern, coherence, emotional representation, and causal factor. The 'causal factor' item is open-ended and asks patients to name the three most contributing factors to their illness [13]. The interviewer can help in explaining or reading the questions if patients had difficulty in understanding them.

#### *Statistical analysis*

Data analysis was done using SPSS 20.0. Univariate analysis was used to see the distribution of respondents' characteristics. Bivariate analysis was conducted to determine the statistical relationship to each risk factor using statistical tests that were adjusted for data distribution (T test, Man Whitney test, and Kruskal Wallis test). The regional ethical committee approved the study and written informed consent was obtained from each.

## RESULTS

#### *Study population*

During the study period, there were 89 stroke patients documented in the Stroke Registry. Thirty-three patients from the study population were excluded due to traumatic hemorrhagic stroke (2), death as endpoint (6), aphasia (8), deafness and blindness (1), discharged against medical advice before BIPQ assessment could take place (1), decided not to join the study without knowing the objectives/due to personal reasons (15). The average age of participants were  $55.34 \pm 10.25$ . Length of stay 1-29 days (median: 5.00).

#### *Association between illness perception, socio-demographic, clinical characteristics and severity of neurological impairment*

Several sociodemographic and clinical characteristics showed association with illness perception. Age was not correlated with illness perception (Table 2). On the other hand, female subjects had significantly longer timeline dimension than male subjects ( $p < 0.05$ ) and scored higher in identity dimension, which can be concluded as perceiving their illness in a more negative view. Female subjects also had lower knowledge (coherence) about their illness than male subjects ( $p < 0.05$ ). Apart from sex, patients' illness perception of coherence also showed a statistically significant relationship with the level of cognitive function which was measured by MMSE ( $p < 0.05$ ).

**Table 2.** The relation between characteristics of demography, clinical signs, cognitive and BIPQ

	Consequences	Time Line	Personal control	Treatment Control	Identity	Concern	Coherence	Emotional response
Age								
< 60 y.o	6.7 ± 3.1	4.0± 2.8	6.5±2.9	8.0 ± 2.1	6.7±2.7	7.6 ± 2.3	5.8 ± 2.8	5.7 ±2.8
≥ 60 y.o	6.7 ± 2.3	4.3 ± 2.4	5.3 ±2.7	7.3 ±2.3	6.3 ± 2.4	7.4 ±3.0	5.5 ± 3.2	6.8 ± 2.8
Sex								
Male	6.6± 2.9	3.3± 2.5**	6.8±2.8	7.7± 2.6	5.8±2.6**	7.2± 2.8	6.5 ±3.1**	6.0 ±3.2
Female	6.8 ± 2.6	5.0 ± 2.4	5.3 ±2.8	7.8 ±1.8	7.3 ± 2.3	7.8 ±2.4	4.9 ± 2.5	6.3 ± 2.4
Education								
≤ 9 years	7.1 ± 2.5	4.3± 2.5	5.4±2.7**	7.2 ± 2.3**	6.8±2.5	7.5 ± 2.5	4.9 ± 2.6**	5.9±2.5
> 9 years	5.7 ± 3.2	3.8 ± 2.7	7.5 ±2.8	8.9 ±1.4	6.1 ± 2.7	7.7 ±2.8	7.4 ± 2.9	6.5 ± 3.4
Marital Status								
Widow/Single	7.0 ± 3.7	3.6± 2.7	4.6±3.8	6.0 ± 3.8	6.2±3.6	6.8 ± 3.6	2.8 ± 3.1**	6.6 ±3.9
Married	6.7 ± 2.7	4.2 ± 2.6	6.2 ±2.8	7.9 ±1.9	6.6 ± 2.5	7.6 ±2.5	5.9 ± 2.7	6.1 ± 2.7
Ethnic								
Javanese	7.0 ± 2.7	4.5± 2.7	6.0±2.6	7.8 ± 1.7	6.8±2.4	7.8 ± 2.6	6.3 ± 2.4***	6.5 ±2.4
Sundanese	6.8 ± 2.6	4.2 ± 1.3	4.2 ±3.0	8.2 ±1.9	6.4 ± 2.6	5.4 ±2.1	2.4 ± 1.5	4.4 ± 2.1
Chinese	6.5 ± 3.4	2.9 ± 2.2	6.4 ±3.6	7.5 ±3.1	6.3 ± 2.9	8.0 ±2.6	5.9 ± 3.6	6.3 ± 3.9
Other	6.3 ± 2.8	4.3 ± 3.2	7.0 ±2.5	7.3 ±2.9	6.0 ± 3.0	6.9 ±2.3	4.9 ± 3.3	5.7 ± 2.7
Working								
No	6.3 ± 2.5	4.5± 2.6	5.2±2.8*	7.3 ± 2.4	6.5±2.4	7.3 ± 2.9	5.0 ± 2.9	6.2 ±2.6
Yes	7.1 ± 2.9	3.8 ± 2.6	7.1 ±2.6	8.2 ±1.9	6.6 ± 2.7	7.7 ±2.3	6.4 ± 2.7	6.1 ± 3.1
NIHSS								
Moderate	6.7± 2.4	4.5 2.6	5.5±2.7	7.1± 2.5*	6.7±2.2	7.8± 1.9	4.7± 2.5**	6.6±2.5
Mild	6.6 ± 3.2	3.7 ± 2.6	6.7 ±2.9	8.4±1.6	6.3± 2.9	7.2 ±3.2	6.7± 3.0	5.6± 3.0
Delta NIHSS								
No Improvement	7.1± 2.5	4.5± 2.5	6.2±2.6	8.1± 1.6	6.7±2.5	7.7± 2.7	6.4± 2.6**	6.2±2.9
Improvement	6.0 ± 3.0	3.5 ± 2.6	5.9 ±3.2	7.2±2.8	6.4± 2.6	7.2 ±2.4	4.7± 3.1	6.1± 2.7
MMSE								
Imparment	6.9± 2.6	4.7± 2.3	5.3±2.9	7.3± 2.2	6.9±2.3	7.8± 2.2	4.4± 2.9**	5.8±2.6
Normal	6.5 ± 2.9	3.7 ± 2.8	6.6 ±2.8	8.1±2.2	6.3± 2.7	7.3 ±2.9	6.6± 2.6	6.3± 2.9
Cognitive								
Imparment	6.6± 6.8	4.2± 2.4	5.6±2.8	7.4± 2.3	6.5±2.4	7.2± 2.6	4.8± 3.0**	5.7±2.9
Normal	4.2± 3.9	3.9± 2.9	6.9 ±2.9	8.3±1.9	6.5± 2.8	8.1 ±2.5	7.2± 1.9	7.0± 2.5
Stroke								
Non-Hemorrhagic	6.5± 2.8	4.2± 2.6	5.9±2.8	7.5± 2.3	6.4±2.6	7.2± 2.7	5.6± 2.9	5.9±2.8
Hemorrhagic	7.5 ± 2.8	3.8 ± 2.5	7.1 ±2.9	8.8±1.4	7.1± 2.4	9.0 ±1.1	6.3± 3.3	7.3± 2.7
Motoric strength Right Upper								
Grade < 4	6.4 ± 2.2	4.4± 2.7	4.0±3.4	7.3 ± 2.3	7.0±2.3	7.9 ± 0.7	3.7 ± 2.4	6.7 ±1.8
Grade ≥4	6.7 ± 2.9	4.1 ± 2.6	6.3 ±2.7	7.8 ±2.2	6.5 ± 2.6	7.5 ±2.7	5.9 ± 2.9	6.1 ± 2.9

Right Lower								
Grade < 4	7.3 ± 2.6	5.3 ± 2.4	3.5 ± 2.9**	7.3 ± 1.8	7.8 ± 1.4	7.4 ± 1.2	3.1 ± 2.0**	5.9 ± 1.8
Grade ≥ 4	6.6 ± 2.7	3.9 ± 2.6	6.5 ± 2.7	7.8 ± 2.3	6.3 ± 2.7	7.5 ± 2.8	6.1 ± 2.8	6.2 ± 2.9
Left Upper								
Grade < 4	7.4 ± 2.2	4.9 ± 2.7	5.5 ± 2.8	6.7 ± 2.9	6.8 ± 2.4	8.3 ± 1.4	5.5 ± 2.5	7.2 ± 1.9
Grade ≥ 4	6.3 ± 2.9	3.8 ± 2.5	6.3 ± 2.9	8.2 ± 1.6	6.4 ± 2.5	7.1 ± 2.9	5.8 ± 3.1	5.6 ± 2.9
Left lower								
Grade < 4	7.4 ± 1.9	5.1 ± 2.4	5.5 ± 2.8	6.5 ± 2.7**	6.4 ± 2.3	7.9 ± 1.9	5.3 ± 2.6	6.9 ± 2.0
Grade ≥ 4	6.3 ± 3.0	3.7 ± 2.6	6.5 ± 2.9	8.3 ± 1.7	6.6 ± 2.6	7.3 ± 2.8	5.9 ± 3.1	5.8 ± 3.0

\*p value < 0.05 with t-test

\*\* p value < 0.05 with Man Whitney test

\*\*\* p value < 0.05 with Kruskal Wallis test

Sociodemographic characteristics (age, gender, socioeconomic status, marital status, ethnic background, occupation) were derived from the medical records of patients.

Level of education also influenced illness perception. Patients with higher education level had better personal control, treatment control and coherence ( $p < 0.05$ ). We did not analyze the marital status and ethnic variables due to the limitation of the sample in the subgroup of single/divorced/widowed subjects (8.9% of total subjects). Patients who were unemployed scored lower in personal control ( $p < 0.05$ ).

Patients who had lower motoric strength on the right side < 4 reported lower personal control and coherence ( $p < 0.05$ ). The degree of neurologic impairment (delta NIHSS) showed a statistical correlation with coherence, patients with mild neurologic impairment or NIHSS had lower treatment control and coherence ( $p < 0.05$ ).

### Causal Factor

From 56 patients, we compiled 108 answers about perceived causal factors of stroke. Psychological factor (16.7%), diet (14.8%), fatigue (14.8%) and hypertension (14.8%) were identified as the four common causal factors of stroke according to the patients.

## DISCUSSION AND CONCLUSION

### Discussion

Many factors influence the impact of illness on psychological and physical functioning, such as socio-demographic factors, the clinical con-

ditions itself, as well as treatment and psychosocial factors. Female subjects viewed their illness as more severe (identity) and would last longer (timeline) compared to the male subjects. They also reported less knowledge (lower coherence score) of stroke. In contrast, Marx *et al.* (2009) found in their study that women had better knowledge about symptoms of stroke and first response in a stroke event [14]. However, the findings of Arauz *et al.* (2014) showed that female is associated with a higher risk of vascular cognitive impairment, which might implicate in lower coherence [15]. Our female subjects mostly had a lower educational background (59%) and/or had cognitive impairment (62.5%), and this might contribute to lower coherence.

In addition to lower coherence, subjects with lower educational background had lower personal and treatment control. This showed that formal education is very crucial in several aspects of illness perception, so physicians should pay attention to the patient's formal education level in explaining the illness to the patient. Ramirez-Moreno, *et al.* found that higher education level was associated with adequate knowledge of stroke [16].

Only half of the patients who had moderate to very severe neurological deficit were unemployed (43.8%). Despite better NIHSS score, unemployed subjects reported less personal control than employed patients ( $p < 0.05$ ). This might be caused by lower self-esteem in subjects due to lack of job security. In a study on the self-esteem of tuberculosis patients, being a housewife

or unemployed was associated with worse self-esteem [17]. Moreover, being jobless is also independently associated with a rise in all-cause mortality risk especially among men, despite other socio-demographic and health risk factors [18].

In this study, patients with mild neurologic impairment at discharge had lower timeline score, as well as better personal and treatment control. This result showed us that subjects with mild neurologic impairment perceived their illness in a more positive view.

In this study, subjects with left upper extremity weakness, which is commonly caused by a lesion in the right hemisphere, had a stronger emotional response. Although a higher rate of depression has been associated with the left hemisphere lesion, emotion is classically associated with the right hemisphere. Wittling and Roschmann (1993) studied subjective emotional response to emotion-related qualities films, and their findings suggested a higher involvement of the right hemisphere in emotional experience [19]. In another study by Wei *et al.* (2014), right hemisphere stroke could be a predictor for sub-acute phase of post-stroke depression [20].

Weakness in right upper extremities was associated with lower personal control score in this study. This is consistent with the fact that all of our subjects are right-handed; therefore weakness on right hand would limit their activities of daily living (ADL) and in turn, reduce their control.

It is estimated that more than half of stroke patients suffer from cognitive impairment, especially in attention and executive functions [10]. This problem can be present for an extended period and in various degree of stroke severity, including a patient who only had mild stroke [13]. Often in the acute phase, patients have not recognized the presence of cognitive impairments. This study showed that subjects with cognitive impairment had lower coherence score. Therefore, it can be concluded that we need to observe subjects' cognitive baseline before assessing illness perception, especially in diseases which affect cognitive function, such as stroke.

Data from Table 2 showed the strongest perception in treatment control and concern dimension in stroke patients. This indicates that although stroke is still perceived as a severe ill-

ness, the subjects believe that their treatments were beneficial.

We compared the illness perception of patients with stroke to those of patients with another vascular disease (Myocardial Infarction/MI) from the other study with the similar epidemiological background, risk factors and pathophysiology [13]. When the mean scores of eight BIPQ items from our subjects were compared to that of MI patients (mean age of 54.7 + 8.1 and 88.3% female), more negative illness perceptions in stroke patients could be observed (Table 3) [13]. Treatment control and concern were items with the two highest mean score, while the other illness perception scores clustered around the mid-range of the items. Our subjects showed a higher score in the identity dimension, compared to that of MI patients. Stroke patients also tended to have more negative perceptions in the dimensions of consequence, personal and treatment control, concern, coherence, as well as emotional response. This may indicate that stroke is perceived as a more severe illness, due to its impact on disability.

**Table 3. Comparison between illness perception of stroke and myocardial infarction**

BIPQ DIMENSIONS	Mean ± SD <sub>MI13 (n=103)</sub>	
	Stroke (n=56)	
Consequences	6.7± 2.8	4.1±2.8
Time Line	4.1± 2.6	7.2±3.1
Personal control	6.1±2.9	7.7±1.7
Treatment Control	7.7± 2.2	8.8±1.2
Identity	6.6±2.5	3.1±2.6
Concern	7.5± 2.6	6.2±3.4
Coherence	5.7± 2.9	8.0±2.2
Emotional response	6.1±2.8	4.2±3.1

*MI: Myocardial Infarction*

All of our subjects stayed in the third-class ward on government's support during hospitalization. It could be inferred that most of them had low socioeconomic status. Thus, our patients' lower coherence might be associated with this fact, which is consistent with the study results of Ramirez-Moreno *et al.*, in which lower family income was associated with non-adequate knowledge of stroke [16].

Indonesia is a multi-racial and multi-religion country. However, the religious factor was not included as a variable in this study. The majority of our subjects came from Javanese and Chinese racial background, but racial factor was not analyzed due to relatively small study population, and we were unable to compare our findings with the local population as there were still minimal studies on illness perception in Indonesia. Nevertheless, several studies did indicate that the racial factor does influence illness perception. For instance, in a study on illness perception among critically ill patients in US, African-Americans tend to be more optimistic compared to Caucasian patients (Ford *et al.* 2010) [21]. Another study on illness perception among breast cancer patients in Netherlands and Japan showed stronger concern about the illness in Japanese subjects [22]. It is crucial for clinicians to be aware of this issue in order to have better communication with patients from different racial backgrounds.

Psychological factor (16.7%) was most frequently attributed as the factor which the subjects deemed very likely causing the stroke, followed by diet, fatigue, and hypertension. The causal attributions documented in the present study were mostly modifiable factors. If this evidence of causal attributions toward modifiable factors is applied in the general population, it will be beneficial in designing stroke awareness-raising campaign as well as helping to identify possible conditions in the community that contribute to stroke but still able to be modified.

## CONCLUSION

Female was associated with a longer timeline, lower coherence, and stronger identity perception in stroke patients. Patients with mild neurologic impairment at discharge had lower timeline score and showed better personal and treatment control. Cognitive impairment was associated with lower coherence, which underlined the importance of establishing a cognitive baseline before assessing illness perception in stroke patients.

### *Practice implication*

*In the clinical settings, acknowledging and considering patients' attributional beliefs in practice could improve treatment efficacy, which is particularly crucial in stroke*

*patients, whose symptoms are often severe and/or persistent and require long-term treatment.*

### *Conflict of interest*

*The writers declare that there is no conflict of interest regarding the publication of this paper.*

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