Original article

Factors related to the uncertainty mild stroke patients experience during treatment

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Journal of Japanese Academy of Neuroscience Nursing 5 (2)
15 July 2019

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Abstract

[Purpose] The purpose of this study was to clarify the factors associated with the uncertainty patients with mild stroke experience regarding their illness.

[Method] The participants in the study included stroke patients who had suffered a stroke but were able to communicate without cognitive impairment in an outpatient clinic or who were being hospitalized in a stroke care unit (SCU) or ward. Uncertainty regarding their illness was investigated using the Universal Uncertainty in Illness Scale (UUIS) (26 item, 6 subscale measurement scale, with scores ranging from 26–130) and Health-Related Quality of Life (QOL) SF-8 (8 item, 5–6 level Likert system) questionnaire. Data extracted from medical records included patient age, sex, type of stroke, time since onset, overlapping diseases, presence or absence of recurrent stroke, the National Institutes of Health Stroke Scale (NIHSS), ADL assessments using the Barthel Index (BI), and the presence or absence of family members living in the same house. For the analysis, Spearman rank correlation coefficients were calculated for the correlation between UISS and SF-8 in stroke patients after analyzing basic statistics. Comparisons of UUIS scores based on age, stroke type, BMI, time since onset, stroke severity (NIHSS), and ADL (BI) between the three groups were performed using the Kruskal-Wallis test, and comparisons between the two groups based on sex, the presence or absence of overlapping diseases, the presence or absence of stroke recurrence, the presence or absence of stroke sequelae, and the presence or absence of cohabitating families were performed using the Mann-Whitney test. Subsequently, multiple regressions with UUIS as an independent variable were performed on factors that showed significant differences in order to explore the factors related to UUIS. Approval was obtained from the Institutional Review Board of Tokushima University Hospital (Approval number 3134-1).

[Results] Responses were obtained from 146 stroke patients. The mean age was 65.9 years (*SD* 13.9), 82 were men (56.2%), 64 were women (43.8%), 38 were acute phase patients (26.0%), 39 were recovery phase patients (26.7%) and 69 were maintenance phase patients (47.3%). The mean UUIS score in stroke patients was 72.0 (*SD* 23.1) and was high, at 82.0 (*SD* 23.3), in acute phase patients, in particular. In addition, significant differences in UUIS were seen based on age (p = .031), stroke type (p = .031), time since onset (p = .006), the presence or absence of stroke sequelae (p = .013), stroke severity (NIHSS) (p = .000), and ADL (BI) (p = .001). In multiple regression analyses, stroke severity, time since onset, and age were associated with stroke patient uncertainty (R^2 = .221).

[Conclusions] Stroke patients were characterized by uncertainty based on age, stroke type, time since onset, stroke severity (NIHSS), and ADL (BI). In particular, the uncertainty of acute phase stroke patients was higher compared to other chronic diseases due to time since onset, stroke severity (NIHSS), and ADL (BI). The three factors of stroke severity, time since onset,

Received 31 May 2019
Accepted 24 June 2019

and age were associated with stroke uncertainty. In patients with high stroke severity (NIHSS 2 or higher), there was an indication that careful explanation and supplementation of information regarding the disease was required and that complicated information, such as disorders caused by the stroke and treatments, should be carefully explained to those 75 years and older (older people) as well as patients who experienced disease onset within less than 1 month.

Keywords: uncertainty in illness, mild stroke patients, nursing care

Introduction

In the treatment of stroke, thrombolytic therapy (intravenous t-PA therapy) has been performed for patients with hyperacute cerebral infarction since 2005, with 38% after 3 weeks, and 50% of patients after 3 months, improving to levels that do not interfere with daily activities, showing very good results (Yamaguchi et al., 2006). In addition, the overall survival of patients with cerebral hemorrhage and subarachnoid hemorrhage has increased dramatically, and the mortality rate for stroke ranks third; however, this is showing a declining trend according to the demographic statistics of the Ministry of Health, Labour and Welfare (MHLW) (2017). However, according to the MHLW's Comprehensive Survey of Living Conditions (2016), stroke is the primary disease precipitating nursing care [category 5 (bedridden)]. Furthermore, according to the MHLW's Patient Survey (2017), the primary disease associated with the number of hospitalization days (excluding psychiatric and neurological diseases) is stroke, which contributes to an increase in medical and nursing care expenses in Japan. On the other hand, according to Kobayashi et al. (2015), the incidence of initial neurological symptoms after the onset of stroke is very high, with 49% experiencing hemiplegia, 24% experiencing aphasia and dysarthria, and 20% experiencing consciousness disorder, and very few seeing remarkable improvement in these symptoms. This means that, after the onset of a stroke, the individual must live with a disorder such as hemiplegia and is at risk for recurrent stroke throughout their life. Therefore, stroke patients not only have difficulty performing independent daily tasks in their lives due to associated physical disabilities, but also have difficulty fulfilling social roles, and are further pushed into dealing with various issues they have never experienced before, leading to a very high psychological burden (Takeuchi, 2009). As a concept influencing the physical, social and psychological coping mechanism, uncertainty with their illness is particularly noteworthy.

Mishel (1988) defined uncertainty with illness as a condition where, for a variety of illness-related events, it is hard to find meaning, and also defined it as a cognitive condition that occurs when structuring or categorization cannot be successfully performed since there are no adequate clues regarding a certain event. Mishel also stated that uncertainty is affected by three prior requirements, Stimuli Frame, Structure Providers, and Cognitive Capacities, and that cognitive capacities are not factors that directly affect uncertainty, but rather those that affect stimulus factors, which in turn affects uncertainty. Previous studies on the uncertainty experienced by stroke patients overseas include those focused on the 4th day after onset (Ni et al., 2018).

On the other hand, in Japan, Nogawa (2012) clarified the reliability and validity of the UUIS in Japanese patients with various diseases. Ukai (2016) reported that the perceived uncertainty experienced by patients with chronic obstructive pulmonary disease (51 patients) 6 months to 5 years after the onset of symptoms is related to their perceived difficulty in breathing that leads to a loss in confidence to battle their disease, and that the uncertainty experienced by patients with inflammatory bowel disease (170 patients) (Tomita & Kataoka, 2016) is associated with a loss in confidence due to the realization that they will live a long life with the disease. However, there has been no research regarding the uncertainty experienced by patients who experience a sudden onset of stroke.

It has been confirmed that depression indicating a psychological tendency after the onset of stroke reduces the quality of life (QOL) of patients (Sawa et al., 2001), and anxiety and depression have been identified as highly correlated with

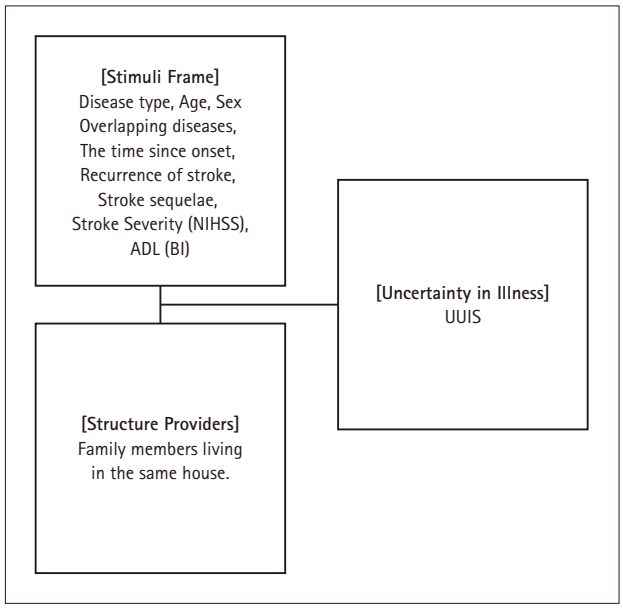

Fig. 1. Conceptual Framework UUIS: Uncertainty in Illness Scale
NIHSS: National Institutes of Health Stroke Scale
ADL: Activities of daily living, BI: Barthel Index

uncertainty (Nogawa, 2012). The speculation is that uncertainty in stroke patients is highly associated with QOL. Therefore, by clarifying the degree of correlation between uncertainty with illness and QOL in stroke patients in this study, factors related to uncertainty with illness can be identified and support that is tailored to the patient's psychological state could be provided.

Conceptual Framework and Operational Definition of Terminologies

Based on Mishel's (1988) uncertainty with illness theory, a conceptual framework to illustrate the uncertainty with illness perceived by stroke patients was created for this study, with Igai (2017) used as references (Fig. 1). In addition, the definition of uncertainty with the disease experienced by stroke patients used in this study was based on Mishel's (1988) and Nogawa's (2012) definition of the disease being "a cognitive state that occurs when stroke patients are unable to interpret the meaning of events related to their disease and cannot accurately structure or categorize these events because they do not have enough clues."

Research Methods

1. Study design

This was a cross-sectional study.

2. Study participants

To observe the uncertainty of patients who experience a sudden stroke, participants were patients with either initial or recurrent stroke, cerebral infarction, cerebral hemorrhage, and subarachnoid hemorrhage, which are representative types of stroke. Patients were those who were urgently admitted into stroke care units (SCU) in Hospital B in Prefecture A who were visiting neurosurgery outpatient clinics for check-ups after being discharged and had scores of 4 or less in the old version of the National Institutes of Health Stroke scale (NIHSS), and were able to communicate verbally without cognitive impairment as determined based on NIHSS (language 0, 1) and had normal cognitive function with a Hasegawa Dementia Scale (HDS-R) score of 21 or higher.

3. Survey method

The data collection period was from July 17, 2018, to April 30, 2019. The survey was conducted using a questionnaire and basic information was obtained from medical records. The survey was administered in a location in the institution where privacy could be ensured. If participants reported that they could not complete the survey due to disorders such as hemiplegia, the researchers completed the questionnaires in the patient's stead and collected and placed the completed forms in envelopes after completion.

4. Survey content

The survey was conducted using the UUIS to measure uncertainty with illness and the SF-8 to assess QOL.

The UUIS is a questionnaire that can be used regardless of whether the patient is hospitalized, is an outpatient, or is receiving home care, and was developed for, and for which reliability and constructional validity have been verified, in Japanese patients (Nogawa, 2012). The UUIS is a measurement scale that consists of 26 items in 6 subscales, where responses are given based on the five-point Likert scale and scores range from 26 to 130, with higher scores

corresponding to higher uncertainty. The 6 subscales correspond to [unpredictability of life] with 8 questions, [complexity of interpreting information interpretation) with 4 questions, [lack of clues to the meaning of illness] with 4 questions, [ambiguity of the nature of the illness] with 4 questions, [unpredictability or recovering from illness] with 3 questions, and [loss of confidence in fighting illness] with 3 questions.

The SF-8 is a widely-used health-related QOL questionnaire also used in Japan (Fukuhara & Suzukamo, 2005), for which the reliability and validity have been verified, that is able to measure 8 health-related domains. Since the questions consist of 8 items and responses are to be given in a five to six-point Likert scale, the questionnaire was considered usable without adding considerable burden to patients in the acute phase. The questionnaire can be completed within 7–14 minutes, and the burden of administering psychological tests to respondents is minimized.

Other patient information was obtained from medical records. Data to be extracted included patient age, sex, disease type, overlapping diseases, time since onset, the presence or absence of recurrent stroke, stroke sequelae, NIHSS, ADL assessments using the Barthel Index (BI), and the presence or absence of family members living in the same house. The time from onset was classified into 3 groups, the acute phase (< 1 month from the onset), recovery phase (1 month to < 18 months), and maintenance phase (18 months or more) in which rehabilitation has been completed for the time being. The NIHSS is a scale used to assess the neurological severity of stroke based on 11 items, including level of consciousness, motor paralysis, sensory impairment, and speech function, with total scores ranging from 0 to 42 and a higher score indicating more severe disease (The Japan Stroke Society Stroke Guidelines Committee 2017). Although the NIHSS is an assessment of stroke severity in the acute phase, since this study includes long-term healthcare providers, the assessment of severity at the time of the survey was standardized with the NIHSS. The rationale for setting 0 to 4 levels in the NIHSS was to follow the categorization proposed by Kobayashi (2015). Overlapping diseases were defined as those for which continuous medical treatment is required, such as various cancers and renal insufficiency. Stroke sequelae included hemiplegia, with headache and excretion disorders added as sequelae of which the patient is aware.

5. Analysis method

For the analysis of the data, descriptive statistics were used to show basic attributes. Subsequently, with the aim of evaluating the degree of correlation of UUIS in stroke patients, Spearman's rank correlation coefficients and SF-8 were calculated, and Cronbach's alpha coefficients were calculated to investigate reliability.In addition, the uncertainty scores of stroke patients were analyzed using the Kruskal-Wallis test for comparisons based on age, type of stroke, time since onset, stroke severity (NIHSS), and ADL (BI) among the three groups, and the Mann-Whitney test was used for comparisons between the two groups based on sex, the presence or absence of overlapping diseases, the presence or absence of recurrent stroke, the presence or absence of stroke sequelae, and the presence or absence of cohabitating family members. In addition, to evaluate factors related to uncertainty in stroke patients, multiple regressions were performed using the stepwise method, with items that were significantly different in the test used as independent variables and UUIS used as a dependent variable, to calculate the Durbin-Watson statistic. The statistical software used was IBM SPSS Statistics Ver. 25, and the significance level was set as less than 5% in both instances.

6. Ethical considerations

To conduct this study, approval was obtained from the Institutional Review Board of Tokushima University Hospital (Approval No. 3134-1). In addition, after obtaining permission from the neurosurgery manager of the collaborative research study hospital, referrals were obtained from the attending physician and the head nurse and the study was conducted. Information was obtained using questionnaire surveys and from medical records under the consent of study participants. As ethical considerations for research participants, a full explanation was given so that each of the participants may understand the content, purpose, and methods of the research, that participation in the research was voluntary and could be discontinued at any time, that discontinuing participation or opting not to participate would not lead to disadvantages, and that privacy

would be maintained. An explanation regarding future publications was provided orally and in writing, and consent was obtained from research participants by asking the participants or their families to sign a consent form, with ethical considerations given. The UUIS questionnaire was used with permission from the measurement scale developer. Permission to use the SF-8™ was also requested and the instrument was used after permission was obtained.

Results

1. Overview of study participants (Table 1)

Responses were obtained from 146 individuals who provided consent. The mean age was 65.9 (*SD* 13.9) years, 82 were males (56.2%) and 64 were females (43.8%). The disease type was cerebral infarction for 89 patients (61.0%), cerebral hemorrhage for 20 patients (13.7%), and subarachnoid hemorrhage for 37 patients (25.3%). 60 patients (41.1%) had overlapping diseases, and 51 patients (34.9%) had experienced a recurrence of their stroke. The time since onset was at acute phase (< 1 month from the onset) for 38 patients (26.0%), recovery phase (1 month to < 18 months) for 39 patients (26.7%), and maintenance phase (18 months or more) for 69 patients (47.3%). There were 83 patients (56.8%) with stroke sequelae, 67 patients had a stroke severity (NIHSS) of 0 (45.9%), 43 had a stroke severity of 1 (29.5%), and 36 has a stroke severity of 2 or higher (24.6%). The mean ADL (BI) was 86.2 (*SD* 24.4) and 24 patients has scores less than 60 (16.4%), 12 had scores greater than 60 but less than 85 (8.2%), and 110 had scores of 85 and above (75.4%).

Table 1. Overview of study participants *n* = 146

Age (years)	Mean (*SD*)	65.9 (13.9)
	40–64	51 (34.9%)
	65–74	52 (35.6%)
	75–89	43 (29.5%)
Sex	Male	82 (56.2%)
	Female	64 (43.8%)
Disease type	Cerebral infarction	89 (61.0%)
	Cerebral hemorrhage	20 (13.7%)
	Subarachnoid hemorrhage	37 (25.3%)
Overlapping diseases	Presence	60 (41.1%)
	Absence	86 (58.9%)
Recurrence of stroke	Presence	51 (34.9%)
	Absence	95 (65.1%)
The time since onset	Acute phase (< 1 month from the onset)	38 (26.0%)
	Recovery phase (1 month to < 18 months)	39 (26.7%)
	Maintenance phase (18 months or more)	69 (47.3%)
Stroke sequelae	Presence	83 (56.8%)
	Absence	63 (43.2%)
Stroke severity (NIHSS)	0	67 (45.9%)
	1	43 (29.5%)
	2–4	36 (24.6%)
ADL (BI)	Mean (*SD*)	86.2 (24.4)
	0– 59	24 (16.4%)
	60– 84	12 (8.2%)
	85–100	110 (75.4%)
Family members living in the same house.	Presence	126 (86.3%)
	Absence	20 (13.7%)

NIHSS: National Institutes of Health Stroke Scale
ADL: Activities of daily living
BI: Barthel Index

2. Correlations between UUIS and SF-8 in stroke patients (Table 2)

To evaluate the coexistence of validity of the UUIS used for stroke patients, the relationships between the UUIS total score and each subscale score with each measure of SF-8 was evaluated. The results showed that in the UUIS total score and all measurement scales of the SF-8, a ρ-value of -.17 to -.53 was seen, with weak to moderate negative correlations observed ($p < .05$). In addition, for each UUIS subscale and the SF-8, with the exception of Bodily Pain, all subscales had a ρ-value of -.16 to -.51, showing weak to moderate negative correlations ($p < .05$).

The reliability of the UUIS used in stroke patients was confirmed. The average UUIS total score was 72.0 (*SD* 23.1), Cronbach's alpha coefficient was .906, and reliability with internal consistency was confirmed.

3. UUIS scores of stroke patients (Table 3)

Differences in the mean UUIS scores based on age, sex, disease type, BMI, overlapping diseases, time since onset, the presence or absence of recurrence, the presence or absence of stroke sequelae, NIHSS, ADL (BI), and cohabitating family members was evaluated (Table 3). Age-specific significant differences in [total score], [unpredictability of life], [complexity of interpreting information], [ambiguity of the nature of the illness] ($p = .031$, $p = .033$, $p = .000$, $p = .035$) were observed and patients aged 75 years and older

Table 2. Evaluation of the validity and reliability of the UUIS in stroke patients *n* = 146

UUIS / SF-8	Total score	Unpredictability of life	Complexity of interpreting information	Lack of clues to the meaning of illness	Ambiguity of the nature of the illness	Unpredictability of recovering from illness	Loss of confidence in fighting illness
General Health	-0.376 **	-0.296 **	-0.189 *	-0.385 **	-0.204 *	-0.407 **	-0.346 **
Physical Functioning	-0.404 **	-0.334 **	-0.230 **	-0.294 **	-0.242 **	-0.450 **	-0.354 **
Role Physical	-0.425 **	-0.427 **	-0.191 *	-0.366 **	-0.163 *	-0.383 **	-0.387 **
Bodily Pain	-0.167 *	-0.118	-0.033	-0.213 **	0.064	-0.302 **	-0.167 *
Vitality	-0.422 **	-0.340 **	-0.156 *	-0.359 **	-0.245 **	-0.383 **	-0.414 **
Social Functioning	-0.533 **	-0.501 **	-0.333 **	-0.360 **	-0.217 **	-0.411 **	-0.463 **
Mental Health	-0.532 **	-0.507 **	-0.190 *	-0.414 **	-0.201 *	-0.508 **	-0.500 **
Role Emotional	-0.470 **	-0.410 **	-0.185 *	-0.372 **	-0.272 **	-0.459 **	-0.452 **

UUIS: uncertainty in illness scale, *$p < .05$, **$p < .01$
Spearman rank correlation coefficients
QOL: Quality of Life

experienced higher uncertainty compared to patients aged < 65 years. Significant differences between cerebral infarction and subarachnoid hemorrhage in [total score], [complexity of interpreting information], and [ambiguity of the nature of the illness] among stroke types were observed ($p = .031$, $p = .021$, $p = .021$), with significantly higher values

Table 3. UUIS scores of stroke patients *n* = 146

			UUIS Total score	*p*-value	UUIS subscales											
					Unpredictability of life	*p*-value	Complexity of interpreting information	*p*-value	Lack of clues to the meaning of illness	*p*-value	Ambiguity of the nature of the illness	*p*-value	Unpredictability of recovering from illness	*p*-value	Loss of confidence in fighting illness	*p*-value
		n	Mean (*SD*)		Mean (*SD*)		Mean (*SD*)		Mean (*SD*)		Mean (*SD*)		Mean (*SD*)		Mean (*SD*)	
All patients		146	72.0 (23.1)		24.6 (22.3)		10.9 (4.9)		9.6 (4.8)		12.3 (4.4)		7.5 (4.1)		7.1 (4.2)	
Age (years)	b 40–64	51	66.5 (22.3)	0.031	22.6 (9.7)	0.033	8.7 (4.0)	0.000	9.8 (4.9)	0.925	11.6 (4.5)	0.035	7.1 (3.9)	0.663	6.8 (3.9)	0.718
	65–74	52	71.4 (21.9)	*	24.0 (9.2)	*	11.2 (5.0)	***	9.5 (4.8)		11.9 (4.1)	*	7.5 (4.0)		7.3 (4.4)	
	75–89	43	79.0 (23.9)		27.5 (8.2)		13.0 (4.9)		9.5 (4.8)		13.8 (4.3)		7.9 (4.4)		7.4 (4.3)	
Sex	a Male	82	71.0 (20.4)	0.571	24.2 (8.6)	0.629	11.2 (4.7)	0.326	9.1 (4.5)	0.176	12.7 (4.3)	0.257	7.2 (4.0)	0.284	6.5 (3.9)	0.051
	Female	64	73.2 (26.2)		25.0 (10.1)		10.4 (5.3)		10.2 (5.1)		11.9 (4.5)		7.9 (4.2)		7.9 (4.4)	
Disease type	b Cerebral infarction	89	75.0 (22.5)	0.031	25.4 (9.1)	0.184	11.7 (5.1)	0.021	9.7 (4.8)	0.100	13.1 (4.2)	0.021	7.8 (4.1)	0.096	7.2 (4.1)	0.300
	Cerebral hemorrhage	20	71.2 (25.0)	*	25.1 (9.7)		8.6 (4.3)	*	9.6 (5.0)		11.7 (4.2)	*	8.2 (4.7)		8.1 (4.6)	
	Subarachnoid hemorrhage	37	65.0 (22.5)		22.1 (9.2)		10.1 (4.4)		9.3 (4.7)		10.8 (4.6)		6.2 (3.6)		6.4 (4.1)	
Overlapping diseases	a Presence	60	69.2 (22.8)	0.221	23.8 (9.0)	0.386	9.9 (5.2)	0.053	9.2 (4.9)	0.390	12.3 (4.6)	0.983	7.5 (3.9)	0.942	6.5 (4.2)	0.129
	Absence	86	73.9 (23.2)		25.1 (9.4)		11.5 (4.7)		9.9 (4.7)		12.4 (4.3)		7.5 (4.2)		7.6 (4.2)	
The time since onset	b Acute phase (< 1 month from the onset)	38	82.0 (23.3)	0.006	28.3 (8.6)	0.013	12.8 (5.5)	0.014	11.1 (4.3)	0.045	13.0 (4.0)	0.321	8.5 (3.8)	0.154	8.4 (4.3)	0.075
	Recovery phase (1 month to < 18 months)	39	66.6 (22.7)	** *	23.0 (9.6)	*	9.7 (4.4)	*	8.5 (4.9)	*	11.5 (4.7)		6.7 (3.9)		7.1 (4.3)	
	Maintenance phase (18 months or more)	69	69.5 (21.7)		23.4 (8.9)		10.4 (4.7)		9.4 (4.9)		12.5 (4.4)		7.4 (4.3)		6.5 (4.0)	
Recurrence of stroke	a Presence	51	73.3 (22.6)	0.603	24.2 (8.2)	0.694	11.0 (5.1)	0.807	9.7 (4.9)	0.888	13.1 (4.0)	0.128	8.1 (4.1)	0.167	7.3 (4.3)	0.793
	Absence	95	71.2 (23.4)		24.8 (9.8)		10.8 (4.9)		9.6 (4.8)		11.9 (4.6)		7.1 (4.0)		7.1 (4.1)	
Stroke sequelae	a Presence	83	76.1 (23.9)	0.013	25.5 (9.7)	0.174	10.9 (5.2)	0.983	10.8 (4.7)	0.001	12.8 (4.2)	0.176	8.6 (4.1)	0.000	7.7 (4.3)	0.065
	Absence	63	66.6 (20.8)	**	23.4 (8.6)		10.9 (4.7)		8.1 (4.6)	**	11.8 (4.6)		6.1 (3.7)	***	6.4 (4.0)	
Stroke severity (NIHSS)	b 0	67	63.8 (20.1)	0.000	21.8 (8.7)	0.000	10.5 (4.4)	0.171	7.8 (4.2)	0.000	11.3 (4.7)	0.009	6.0 (3.7)	0.000	6.3 (3.9)	0.014
	1	43	72.7 (25.3)	* ***	24.4 (10.2)	***	10.3 (5.4)	** ***	10.9 (5.2)	***	12.5 (4.0)	**	7.6 (4.0)	***	7.1 (4.5)	**
	2 or higher	36	86.2 (18.4)		29.8 (6.9)	*	12.2 (5.2)		11.5 (4.1)		14.1 (3.7)		10.0 (3.6)	*	8.8 (3.8)	
ADL (BI)	b 0–59	24	86.4 (24.0)	0.001	28.8 (7.9)	0.025	13.0 (5.4)	0.020	12.1 (4.4)	0.021	14.2 (4.4)	0.082	9.5 (4.0)	0.006	8.9 (4.2)	0.048
	60–84	12	76.8 (22.4)	**	26.6 (9.5)	*	12.4 (4.6)	*	9.2 (5.1)	*	12.2 (3.4)		8.9 (3.8)	**	7.5 (3.9)	*
	85–100	110	68.3 (21.7)		23.4 (9.3)		10.2 (4.8)		9.1 (4.7)		12.0 (4.4)		6.9 (4.0)		6.7 (4.1)	
Family members living in the same	a Presence	126	71.3 (23.6)	0.868	24.4 (9.3)	0.641	11.0 (5.1)	0.376	9.6 (4.7)	0.696	12.4 (4.4)	0.749	7.4 (4.2)	0.528	7.1 (4.2)	0.757
	Absence	20	72.8 (20.0)		25.5 (9.2)		10.0 (4.0)		10.0 (5.6)		12.1 (4.1)		7.9 (3.0)		7.4 (4.0)	

UUIS: uncertainty in illness scale, NIHSS:National Institutes of Health Stroke Scale, BI: Barthel Index, BMI:Body Mass Index
a: Mann-Whitney test, b:Kruskal-Wallis test *$p < .05$, **$p < .01$, ***$p < .001$

for cerebral infarction. For the time since onset of stroke, significant differences were observed among acute phase, recovery phase, and maintenance phase groups in the five measurement scales of [total score], [unpredictability of life], [complexity of interpreting information] and [lack of clues to the meaning of illness] (p = .006, p = .013, p = .014, p = .045), and were significantly higher in the acute phase group than in the other group. Significant differences between patients with and without stroke sequelae in [total score] and [lack of clues to the meaning of illness] and [unpredictability of recovering from illness] (p = .013, p = .001, p = .000) were observed, and were significantly higher in patients with stroke sequelae. For stroke severity (NIHSS), the severe group (NIHSS) had significantly higher scores than the mild group in [total score], [unpredictability of life], [lack of clues to the meaning of illness], [ambiguity of the nature of the illness], [unpredictability of recovering from illness] and [loss of confidence in fighting illness] (p = .000, p = .000, p = .000, p = .009, p = .000, p = .014). For ADL (BI), significant differences in [total score], [unpredictability of life], [complexity of interpreting information], [lack of clues to the meaning of illness], [unpredictability of recovering from illness] and [loss of confidence in fighting illness] (p = .001, p = .025, p = .020, p = .021, p = .006, p = .048) were observed, and were significantly higher in the low BI group than the high BI group.

No significant differences were found based on sex, overlapping diseases, the presence or absence of recurrence of stroke, or the presence or absence of cohabitating family members.

4. Identifying factors related to uncertainty in stroke patients (Table 4)

To identify factors associated with uncertainty, age, type of stroke, time since onset, the presence or absence of stroke sequelae, NIHSS, and ADL (BI), for which significant differences were found, were used as independent variables and UUIS was used as a dependent variable in a stepwise method, and the subscales were subjected to multiple regressions using the forced input method (Table 4). The results showed that there were associations between NIHSS (standard-deviation regression coefficients β = .303, p < .001), time since onset (β = -.190, p < .05), and age (β = .180, p < .05), and the adjusted coefficient of determination (R^2) was .221. The correlation coefficient between each variable was r = -.336–.389 and, since the VIF was 1.0–1.2 and tolerance was .82–.98 for each variable, the assessment was that there was no collinearity. Residuals based on Durbin-Watson were 1.751–2.021, and no autocorrelation was observed for all dependent variables.

Discussion

1. Overview of study participants

The participants in this study were patients who continued medical treatment after experiencing a sudden onset of stroke, and both hospitalized patients and outpatients were included. In addition, the patients had to have a stroke severity (NIHSS) of 4 points or less and had to be able to communicate verbally without cognitive impairment.

Table 4. Identifying factors related to uncertainty in stroke patients n = 146

	Total score a		UUIS subscales b											
			Life unpredictable		Complexity of information interpretation		Lack of clues for sick meaning		Ambiguity of disease nature		Ill recovery Unpredictability		Fluctuations in self-confidence	
	β	p	β	p	β	p	β	p	β	p	β	p	β	p
Stroke severity (NIHSS)	0.303	0.000 ***	0.274	0.001 **	0.175	0.027 *	0.289	0.001 **	0.220	0.013 *	0.342	0.000 ***	0.169	0.049 *
The time since onset	-0.190	0.017 *	-0.140	0.101	-0.244	0.015 *	-0.122	0.161	-0.057	0.521	-0.099	0.245	-0.156	0.081
Age	0.180	0.022 *	0.180	0.021 *	0.326	0.000 ***	-0.058	0.461	0.182	0.024 *	0.048	0.537	0.035	0.664
R^2	0.221		0.169		0.186		0.128		0.101		0.160		0.078	
Durbin-Watson	1.916		2.021		2.034		1.894		1.951		1.849		1.751	

UUIS: uncertainty in illness scale, NIHSS: National Institutes of Health Stroke Scale
R^2: Adjusted determination factor, β: Standard partial regression coefficient
*p < .05, **p < .01, ***p < .001
Multiple regressions, a: Stepwise method, b: Forced input method

Therefore, patients with mild disease accounted for about half of the stroke patients included (Yamaguchi & Kobayashi, 2014). Compared to the mean age of 70.5 (12.9) years (Araki & Kobayashi, 2015) reported for acute stroke patients registered in the stroke database, the participants were approximately 5 years younger. The proportion of patients with subarachnoid hemorrhage, which is more common in the younger age group, was also higher than that in the stroke database (Araki & Kobayashi, 2015). The reason for the higher number of patients with subarachnoid hemorrhage is that Hospital B in Prefecture A is a comprehensive stroke center (CSC) and is an acute care facility for stroke patients. The ratio of outpatients to hospitalized patients among the participants in this study was approximately 2:1, leading to a relatively high number of ADL independent (BI) patients who could visit the hospital, which may have biased the population toward individuals with milder disease.

2. Correlations between UUIS and SF-8 in stroke patients

Since there have been no studies to date using UUIS in stroke patients who experience rapid onset, the correlations between the two questionnaires was confirmed using QOL (SF-8). The UUIS total score and SF-8 were found to be negatively correlated ($p < .05$) and the internal reliability of the UUIS was confirmed; therefore, the UUIS was considered applicable to stroke patients.

For each subscale of the UUIS and the SF-8, with the exception of Bodily Pain, all measurement scales had a ρ-value of -.16– -.51, showing weak to moderate negative correlations ($p < .05$). The thinking is that pain may not have been significantly correlated since, depending on the appropriateness of pain control management, QOL and UUIS are affected.

3. Uncertainty in stroke patients

The results of the UUIS total score in the present study showed significant differences in six factors, including age, stroke type, time since onset, the presence or absence of stroke sequelae, stroke severity, and ADL (BI).

By age, patients younger than 65 years old had significantly lower uncertainty on the UUIS [total score], [unpredictability of life], [complexity of interpreting information], [ambiguity of the nature of the illness] subscale compared to patients 75 years and older. Since the complexities of collecting information and interpreting information about illnesses worsens with age and since this may create psychological circumstances that affect uncertainty, the suggestion is that, for older people, particularly those aged 75 years or older, a careful explanation must be given regarding their illness.

In the assessment of UUIS total score based on time since onset, the uncertainty score in patients in the acute phase was the highest, which decreased during the recovery phase but increased again in the maintenance phase. For stroke patients, the maximum duration of hospitalization in a stroke rehabilitation ward after being discharged from an acute care hospital is 180 days from onset and, for short-term intensive rehabilitation in geriatric nursing care facilities, this is set at 3 months. Although the uncertainty regarding the period in which the patient can receive abundant medical treatment and nursing support is reduced, the patient will not receive sufficient medical support for the rehabilitation in the long-term afterwards. It should be pointed out that there is a necessity for medical and nursing support for stroke patients during the long-term course.

For the presence or absence of sequelae, stroke severity (NIHSS), and ADL (BI), patients who had sequelae, NIHSS 2 stroke severity disease, and lower ADL of 60 points or less had significantly higher uncertainty with illness. The actual gist was revealed to be a lack of clues to the meaning of illness, unpredictability of recovering from illness, and strong loss of confidence in fighting illness. Since, in the clinic, it is presumed that patients with severe disease, high NIHSS and sequelae have high uncertainty with their disease, nursing care such as supplying reasons regarding the onset of stroke and clues on the disease, explaining the predictions for recovery, and providing support to fight their disease is required.

Subsequently, a comparison of the UUIS in stroke patients with the UUIS in other diseases was performed. The mean UUIS in stroke patients was 72.0 (*SD* 23.1) and was particularly high in acute phase patients at 82.0 (*SD* 23.3). Psychological situations such as unseen anxieties due to neurological symptoms and stroke sequelae, and

impediments to ADL may be responsible for the increased UUIS score in stroke patients. In the future, results in severe stroke patients also need to be evaluated.

Multiple regression analysis revealed three factors (i.e., stroke severity, time since onset, and age) associated with uncertainty in stroke patients. In patients with high stroke severity, since these patients experience uncertainty with their illness in terms of [unpredictability of life], [lack of clues to the meaning of illness], [ambiguity of the nature of the illness], [unpredictability of recovering from illness], and [loss of confidence in fighting illness], careful explanation and further supplementation regarding their illness were confirmed as being necessary. However, there are limitations in generalization since the participants had milder disease with NIHSS 0–4 stroke severity.

Since patients with a mild stroke and who were relatively young were included in this study, data bias needs to be considered and is a limitation of the current study. These need to be considered in the future.

Acknowledgements

We would like to express our sincere gratitude to those who cooperated with this research and the participants who agreed to participate in this study. We also wish to thank the staff at the research institutions for understanding the purpose of this study and for providing a comfortable place for us to conduct our research. We would also like to express our sincerest thanks to Dr. Akihiro Haga, professor of medicine and dentistry at Tokushima University Graduate School of Medicine and Dentistry, for his guidance on the statistical analysis, and Dr. Michiko Nogawa, professor emeritus at Hokkaido Medical University, for allowing our use of the measurement scale.

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