Moyamoya Health Behavior scale for adolescent patients: Measurement tool development and psychometric evaluation

Won-oak Oh

Korea University

Insun Yeom (✉ ruthin76@yuhs.ac)

Severance Hospital <https://orcid.org/0000-0001-9914-9486>

Sung Hyun Lim

Korea University

Dong-Seok Kim

Yonsei University College of Medicine

Kyu-won Shim

Yonsei University College of Medicine

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Abstract

Purpose: The aim of this study was to develop a measurement tool to assess health-related behavior of adolescents with moyamoya disease.

Design: This was a methodological study to develop and validate the Moyamoya-Health Behavior scale (Moyamoya-HB scale) for adolescent patients.

Methods: The initial 108 items of the preliminary Moyamoya-HB scale for adolescent patients were generated based on extensive literature reviews and in-depth focus-group interviews with eight moyamoya-suffering adolescents and 12 parents. Group interviews were conducted by six experts (two pediatric neurosurgeons, one psychologist and three nurses). Psychometric testing was performed with a convenience sample of 120 hospitalized adolescents with moyamoya disease recruited from Y University hospitals in South Korea. The construct validity, convergent validity and discriminant validity were tested by exploratory and confirmatory factor analysis. For criterion validity, concurrent validity was confirmed by using the Korean adolescents' health behaviors tool. To confirm the reliability of the Moyamoya-HB scale, the construct reliability and Cronbach's alpha coefficients were calculated.

Findings: The final 12-item Moyamoya-HB scale for adolescents was categorized by three sub-domains: implementation of treatment for moyamoya disease, health promoting behavior for moyamoya disease and health coping behavior for moyamoya disease. Overall, these factors explained 68.97% of the total variance. The result of the confirmatory factor analysis supported the construct, convergent and discriminant validity of the three sub-domains. The Moyamoya-HB scale for adolescents also demonstrated a concurrent validity with the Korean adolescents' health behaviors tool ($r = .59, p < .001$). Reliability analysis showed an acceptable-to-high Cronbach's alpha of .865 in total, and the subscales ranged from .800 to .841.

Conclusion: The Moyamoya-HB scale is a valid and reliable instrument for evaluating the awareness of hospital safety among hospitalized children. Clinical relevance: The Moyamoya-HB scale should be able to contribute to building empirical- and evidence-based data for the development and application of various intervention programs for health promotion of adolescents with moyamoya disease and the prevention of hospital-related accidents among children.

Background

Moyamoya disease is a rare chronic progressive cerebrovascular obstructive disease that forms an abnormal microcirculatory loop in the base of the brain due to stenosis or occlusion of one or both of the major branches of the Willis Circle^{1,2}.

The precise cause and mechanism of the disease have not yet been determined, but several epidemiological characteristics have been investigated. Moyamoya disease is more common in Northeast Asia, including Korea, Japan, China and Taiwan, than in Europe or North America. In Washington State, USA, the prevalence rate is 0.086 per 100,000³, while the prevalence rate is 3.16 in Japan and 18.1 in Korea. In particular, the prevalence of moyamoya disease in Korea increased nearly threefold from 6.3 in 2005 to 18.1 in 2015. Although there are some differences among countries depending on gender, there is a higher incidence rate for females in Japan (1:1.18 male-to-female ratio) and Korea (1:1.43)². The age-specific prevalence is 21.6% for 10-19 year-olds and 30% for 50-59 year-olds⁴.

Especially since adolescent health is directly related to adulthood health, proper healthcare during this period is very important.

The main clinical manifestations of moyamoya disease are life threatening neurological symptoms of transient ischemic attack (TIA), cerebral infarction and cerebral hemorrhage, which cause symptoms such as dyspepsia, speech disorders and abnormal sensations. Blood flow disorders in the brain lead to temporary or permanent brain dysfunctions such as seizures and higher brain dysfunction⁵⁻⁸. In particular, the most common triggering factors for cerebral ischemic attacks are related to hyperventilation, such as singing, blowing into a musical instrument, severe crying, excessive exercise and eating hot or spicy foods⁴. Also, children with moyamoya disease cannot enjoy the same physical activities or lifestyle as their friends at the same age, depending on the characteristics of the disease⁹. This may be a result of accumulation of physical activity limitations related to the manifestation of symptoms, which may also result in experiencing personal stress, thus causing additional symptoms. In addition, cerebral ischemic attacks can occur in stressful situations. In this case, the symptoms immediately improve within a few seconds to a few minutes, but the longer the duration of the cerebral ischemia the more likely it will impact daily life, so stress management is required^{4,10,11}. Currently, when surgery is applied, it is expected to reduce the risk of stroke, cerebral infarction and cerebral hemorrhage¹¹⁻¹⁶, but cannot cure the disease. Therefore, healthy behaviors in the everyday life of adolescents with high stress are encouraged.

The adolescent period is a transitional period in which development and normal physical, psychological and social changes are experienced in transition, and health behaviors formed during this period have a significant effect on adulthood health status¹⁷. It is very important to develop a strategy for promoting health. Adolescence is also the most physically healthy period in the life cycle and the beginning of the greatest number of health risk behaviors¹⁸⁻²¹. In particular, when adolescents are diagnosed with chronic diseases such as adolescent moyamoya disease, physical and mental stress increase due to the diagnosis²². In the end, this stress can lead to a vicious cycle in which brain ischemic attacks, which are the main symptom of moyamoya disease, occur more frequently.

To promote normal growth and development, adolescents with moyamoya disease need specific intervention strategies that can mitigate the effects of their disease, namely, moyamoya disease-specific disease management and health behaviors. In order to do this, an accurate understanding of the health behavior of adolescents with moyamoya disease is necessary. Based on these results, it can be essential to set goals and plan programs for promoting healthy activities for adolescents with moyamoya disease¹². The results can also be linked to program effectiveness assessment and ongoing monitoring systems. Accurate and well-documented data can contribute to the efficient use of limited resources and ultimately promote health behaviors that are needed by moyamoya-suffering youth²⁴.

However, research on adolescent moyamoya disease is very limited, and there are no measurement tools to identify health-related behavior for sufferers. Kwon ²⁵ investigated seven health-related behaviors such as exercise and drinking by modifying tools used in Europe and the Centers for Disease Control's Youth Risk Behavior Surveillance System (YRBSS) Behaviors. Byun and Lee ²⁶ used a modified Youth Risk Behavior Survey (YRBS) and the Korean Adolescents' Health Behaviors Tool ²⁷. The subscales of these measures consist of criteria such as exercise, drinking, sleep, stress and mental health, eating habits and physical activity. The subscales of the Korean Adolescents' Health Behaviors Tool are smoking, drinking, weight control, sleep, stress, suicide, oral health, soundness of thinking and violence.

Although these measures of health behaviors include health-threatening behaviors, health-protection behaviors and health-promoting behaviors of adolescents, they don't have the ability to measure health behaviors in consideration of the characteristics of moyamoya disease. Therefore, in order to understand the health behaviors of adolescents with moyamoya disease and to further develop strategies for mediating health behaviors using them, understanding of the characteristics of moyamoya disease and management of major risk factors such as respiration, disease-related psychology and emotional control are needed. It is necessary to develop a tool to measure specific health hazards related to moyamoya disease that can specifically measure health behaviors and behaviors that should occur when symptoms occur.

The purpose of this study was to evaluate the validity and reliability of a moyamoya disease scale which measures the health behaviors of adolescents with moyamoya disease.

Methods

1. Research Design

This is a methodological study that develops tools for measuring the health-related behaviors of adolescents with moyamoya disease and verifies their reliability and validity.

2. Process of tool development

The tool development process was performed in two stages. In the first phase of development, a preliminary study was conducted by drawing up the conceptual framework and preliminary questions for health behavior of adolescents with moyamoya disease. The second phase was the evaluation stage. The validity and reliability of the tool were verified by a questionnaire developed through preliminary study.

1) Development stage: Identification of preliminary questions

(1) Review of literature and consideration of existing tools

We reviewed domestic and foreign literature and youth health-related scales published before 2017 in order to construct sub-domains of health-related behavior of adolescents suffering from moyamoya disease. The key phrases "adolescent health behavior," "moyamoya disease health behaviors" and "moyamoya disease adolescent health promotion" were used for searches using Pubmed and the Korea Education and Research Information Service (KERIS). As a result, 30 articles were screened. In addition, we reviewed six aspects of the Shin ²⁷ Youth Health Behavior Scale and related theses. As a result, we classified adolescent health activity domains into the responsibility for one's health domain, physical activity domain, nutrition domain, psychological domain, interpersonal domain and stress management domain. However, these areas were found to have limitations in measuring health-related behaviors associated with moyamoya disease after we conducted in-depth interviews.

(2) In-depth interviews for initial questions

In-depth interviews were conducted with eight moyamoya-suffering adolescents and 12 parents. Group interviews were conducted by six experts (two pediatric neurosurgeons, one psychologist and three nurses). One-to-one in-depth interviews using semi-structured questions were conducted from February to April 2017, and group interviews were conducted from March to April 2017. Each was performed for about 40 to 70 minutes. The interviewees were asked:

1) "What do you think is the most important question to ask when interviewing about the health-related behaviors of adolescents with moyamoya disease?"; 2) "What behaviors of adolescent moyamoya sufferers maintain and promote their health?"; 3) "What behaviors are risky behaviors?"; and 4) "What behaviors prevent such youths from maintaining and promoting health?" The qualitative data collected through the interviews were analyzed at the same time as data was being collected, and the traditional qualitative content analysis method was used ²⁸. We used reliability, applicability, consistency and neutrality according to the qualitative research criteria of Lincon and Guba ²⁹ for the validity and reliability of qualitative in-depth interviews.

(3) Development of preliminary questions through verifying validity of initial questions

Based on the conceptual framework and constituent factors, the initial criteria of the tool were constructed on the basis of previous research, existing measurement tools and interview data. A total of 102 statements were made and a total of 65 initial questions were developed by integrating similar statements. The initial questions consist of nine domains: lifestyle, physical activity, health coping, future design, safety, nutritional habits, social support, mental health and moyamoya treatment. The physical activity domain consisted of activities related to the disease and regular exercise. Health coping includes emergency coping related to the disease and the control of the risk factors, and future design consists of activities for the positive stage of development in adolescence. The safety and nutrition habit domains are composed of specific general health safety guidelines. The social support and mental health domains consisted of healthy activities to utilize their resources and positive understanding of the meaning of life and stress management. The range of treatment included regular check-ups, medication and daily life guidance implementation, which was deemed necessary to confirm the

implementation of treatment instruction through the review of the literature^{30,31}. Statements consisted of answers from the 5-point Likert scale (e.g. one point for “not at all” to five points for “always”).

In order to verify the validity of the results, nine people, including two pediatric neurosurgeons, three pediatric nursing professors, two nursing specialists in pediatric neurosurgery, one psychologist and one resident, formed a team. The items were revised and supplemented according to the opinions of the experts, and the deletion and addition of items that were not related to the health behavior of adolescents with moyamoya disease were done. The CVI results of the total 65 items and the item level content validity index of the 59 items were 0.90 ~ 1.00, which was above the reference value of .78³². As a result, a total of 59 preliminary questions were identified for the evaluation phase of the Moyamoya-HB tool.

2) Evaluation stage: Validity and reliability verification

(1) Participants

The evaluation of the Moyamoya-HB tool was conducted by Yonsei University Hospital in Seoul, Korea. The study subjects were made to understand the purpose of the study and agreed to participate. The expected number of subjects using G * Power³³, a sample size program according to Cohen's sampling formula, was set at significance level .05, power of .80 and effect size of .30 for 128 persons. The initial data were collected from 130 persons, but inappropriate data were removed. A total of 120 subjects were included in the analysis of the final data of this study.

(2) Item Analysis

The item analysis was conducted with (a) a corrected item-to-total correlation coefficient and (b) an inter-item correlation matrix, and (c) the item-to-total correlation coefficient was selected from .30 to .80³⁴ to assess the contribution of items and avoid collinearity. The final 25 selected items were put into EFA and CFA analysis for validity and reliability verification.

(3) Validity testing

After analyzing the questionnaire, Exploratory Factor Analysis (EFA), Confirmatory Factor Analysis (CFA), item convergence and a validity test were conducted to validate the construct of the Moyamoya-HB tool. The criteria-related validity was confirmed using concurrent validity analysis.

A. EFA and CFA

Exploratory factor analysis is a method of generating a model or structure by exploring features inherent in the data without special assumptions about the number or structure of the tools³⁵. The items of the preliminary tools developed in this study were developed without any assumptions about structure. Therefore, by exploratory factor analysis, the number of factors and structure of the health behavior measurement scale of moyamoya-suffering adolescents were confirmed. After EFA, CFA was conducted to verify whether the collected data and the conceptual framework were valid.

B. Convergent / Discriminatory Validity

A multi-trait / multi-item matrix analysis was conducted to examine the convergent and discriminant validity of the items. The questionnaire verified the convergent validity of the items by checking whether the items overlapped with the sub-domains in which each item was included and the correlation coefficient with the total score of the calculated sub-domain was at least .40. The validity of each item was shown to be highly correlated with the sub-domain in which each item of the developed tool subtracts itself from its sub-domain, and had a low correlation to distinguish it from the domain other than the sub-domain³⁶. The correlation coefficient between the sub-region and the other region is greater than twice the standard error of correlation coefficient³⁶.

C. Criteria-related Validity

We used the concurrent validity test method to verify the validity of the developed tools. In order to test the concurrent validity of this tool, the correlation with the Korean adolescents' health behaviors tool²⁷ was a total of 72 items, and 14 factors of health behavior. Each questionnaire used a 4-point Likert scale.

However, in order to validate the validity of the tools of this study, items such as sexual intercourse, hygiene, food intake and weight, which were not directly related to health behavior associated with moyamoya disease, were excluded. Cronbach's value of all instruments at the time of development was .82 and the test - retest correlation coefficient was .85. The alpha value in this study was .81.

D. Reliability Verification

Cronbach's value of internal consistency reliability was used to verify reliability. A Cronbach's value of between .70 and .80 indicates that internal consistency reliability is good, .80 and .90 is very high, but .90 and above based on the DeVellis³⁵ criterion suggests that the number of questions should be reduced.

3. Ethical considerations

This study was conducted after approval by the Institutional Review Board (IRB) of Y University Hospital (IRB No.: 4-2017-0884). Interview participants, survey subjects and caregivers were asked to disseminate explanations of the purpose and method of the study to the study participants' and received their consent. The consent form stipulated that the personal information acquired through this study would be used only for research purposes and that the subject freely participated in the study and could withdraw from the study at any time.

4. Data Analysis

The analysis was conducted using IBM SPSS / WIN 22.0 program (SPSS, Chicago, Illinois, USA) and AMOS version 20. Exploratory Factor Analysis (EFA) was performed by using principle component analysis with varimax rotation. In conducting Confirmatory Factor Analysis (CFA), the model fit was verified on the basis of the chi-square test, normal fit index (NFI), comparative fit index (CFI), root-mean-square error of approximation (RMSEA), the goodness of fit index (GFI) and the standardized root mean square residual (SRMR). Reliability coefficients were calculated to verify reliability, stability, homogeneity and internal consistency. In addition, the Pearson correlation test was used to examine the correlation between scores from the Moyamoya-HB scale and the Korean Adolescents' Health Behaviors Tool ²⁷ to test for concurrent validity among criterion-related validity

Results

1. General characteristics of participants

The mean age was 15.00 (standard deviation = 1.60), and the mean follow-up was conducted 35.64 (standard deviation = 30.94) months later. The general characteristics of the additional diseases were as follows (Table 1).

Table 1 Characteristics of participants

N=120

Variable	Category	Number of Patients (%)	Mean (±SD)
Suzuki stage	2		3.18 (±0.54)
	3		
	4		
Diagnostic path	Clinical symptoms	114 (95.00)	
	Medical checkup	6 (5.00)	
	During examination for other diseases	0 (0.00)	
Disease severity	Very serious	6 (5.00)	
	Serious	34 (28.33)	
	Average	56 (46.67)	
	Not so serious	24 (20.00)	
	Not at all serious	0 (0.00)	
Influence on normal life	None	10 (8.33)	
	Slight	74 (61.67)	
	Some	13 (10.83)	
	Moderate	23 (19.17)	
	Severe	0 (0.00)	
Frequency of symptom (last month)	Never	6 (5.00)	
	Rarely	44 (36.67)	
	Sometimes	32 (26.67)	
	Very Often	32 (26.67)	
	Constant	6 (5.00)	
Cerebral hemorrhage / cerebral infarction (history)	Infarction	27 (22.50)	
	Hemorrhage	0 (0.00)	
	Both	0 (0.00)	
	Neither	93 (77.50)	
Seizure	Yes	113 (94.17)	
	No	7 (5.83)	
Experienced TIA	Yes	119 (99.17)	
	No	1 (0.83)	
TIA more than once a month	Yes	91 (75.83)	
	No	29 (24.17)	
Surgery (EDAS)	No	2 (1.67)	
	Both	86 (71.67)	
	One	32 (26.67)	

SD: Standard Deviation

TIA: Transient Ischemic Attack

EDAS: Encephalo-duro-arterio-synangiosis

2. Item Analysis

In order to confirm the cluster possibility and contribution of the items, we conducted a questionnaire consisting of 59 items that were tested through content validity. As a result, we eliminated 34 data points such as "I do not depend on sleeping pills," "I do not eat," "I do not drink," "I eat breakfast," "I am not afraid of a new experience," "I am not afraid of new experience" and "I maintain a proper weight" that were more than 75% in correlation with a value less than .30

³⁴. In addition, these 34 items also correlated to .35 ~ .40 in the item-to-total correlation coefficient analysis ³⁷, and the 25 remaining items were properly confirmed as .51 ~ .80, and 34 items were removed from the EFA.

3. Validity Verification

(1) Construct validity

Exploratory Factor Analysis (EFA)

In order to test the adequacy of the EFA, the KMO and Bartlett's KMO (Kaiser-Meyer-Olkin) values were found to be higher than .509 for the 25 items identified in the item analysis of this study. Also, Bartlett's chi-square test of sphericity ($\chi^2 = 3586.07$, $p < .001$), and the validity of the analysis was established in EFA ³⁷. Factor analysis was performed using principal component analysis and the orthorectic rotation of Varimax. The eigenvalues of each factor were scaled by one or more and scree plotted according to Kaiser's rule application. The commonality of each item was .20 or more. The common variance is the part where each item is explained by a common factor. If the value is less than .20, the variance explained by the common factor is considered to be small, which means that the factor coefficient is highly correlated to only one factor ³⁸. In addition, there is no absolute criterion to judge the significance of the factor loadings of the items ³⁹, but it is suggested that .40 is a conservative level of significance ⁴⁰. In this study, we selected the items with an absolute value of factor load of .60 or more.

As a result of the first factor analysis, three factors were extracted. Thirteen items with an absolute value of factor load less than .60 were deleted and one item with factor complexity was included in the other items to measure similar concepts. The first 12 items were selected.

Three factors were extracted by the second factor analysis for these 12 questions. Factor analysis of the tool by Varimax rotation showed that three factors were extracted in the same way as the factor with an eigenvalue of one or more. The scree plot also shows a nearly horizontal change after the third eigenvalue decline. Table 2 shows that the explanatory variables of the three factors were 22.3% for the first factor, 21.7% for the second factor, and 19.8% for the third factor (Table 2).

Table 2 Factor Loading of Questionnaires

Factors	Item card No.	Communalities	Factor loading		
			Factor1	Factor2	Factor3
Factor1 (Implementation of treatment for moyamoya disease)	health08	0.660	0.656	0.405	-0.256
	health38	0.809	0.838	0.139	0.296
	health55	0.698	0.803	0.122	0.195
	health56	0.687	0.774	-0.062	0.290
Factor2 (Health promoting behavior for moyamoya disease)	health03	0.613	0.308	0.673	0.257
	health15	0.799	0.058	0.861	0.232
	health16	0.781	-0.027	0.859	0.205
	health42	0.564	0.147	0.721	0.151
Factor3 (Health coping behavior for moyamoya disease)	health19	0.725	0.308	0.361	0.707
	health47	0.561	0.205	0.081	0.716
	health51	0.713	-0.028	0.241	0.809
	health57	0.667	0.315	0.308	0.688
Explained variance		8.276	2.733	2.944	2.599
Explained (%)		68.974	22.778	24.535	21.661
KMO=.749, Bartlett's $\chi^2= 763.95$ ($p < .001$)					

Factor 1 is "Treatment Instructions for Moyamoya Disease," which consists of items corresponding to the implementation of healthy behavior in the process of treating moyamoya disease. Factor 2 is named as "Moyamoya Health Promotion Acts," consisting of items corresponding to healthy life and habits associated with moyamoya disease in order to maintain and promote health. The third factor is related to the illness coping behaviors of adolescent moyamoya sufferers, mainly coping with risk factors and coping behaviors related to clinical symptoms. The factor 3 is health care items related to illness characteristics called "health coping behavior for moyamoya disease."

Confirmatory Factor Analysis (CFA)

Confirmatory Factor Analysis (CFA) was conducted to elicit more precise results on the validity of the Moyamoya-HB scale with 12 items. Indices of χ^2 , GFI, CFI, IFI, SRMR, and RMSEA were used to determine the adequacy of fit of the model. The $\chi^2=763.95$ was not significant ($p < .001$). However, because the χ^2 statistic is highly sensitive to sample size and may overstate the lack of a fit of a model⁴¹, the fit of the model should be interpreted on the criteria of other indices, such as normed $\chi^2 < 3$, GFI $> .90$, CFI $> .90$, NFI $> .90$, SRMR $< .05$, and RMSEA $< .08$. Therefore, the HSS-Kids model showed a good fit because it met, or approximated, all additional indices criteria (Figure 1).

(2) Concurrent validity

In order to test the concurrent validity of the Moyamoya-HB scale, we did a correlation with the Korean Adolescents' Health Behaviors Tool. We found there was a statistical correlation ($r = .59$, $p < .001$) between health behavior of adolescents using both tools.

(3) Convergent validity and discriminant validity

The results of this study were as follows: 1) The standardized factor loadings for each item for convergent validity of health-related behavior items of moyamoya-suffering adolescents should be at least .50 and over .70 should be preferred⁴⁰. All the items in the study were found to meet the minimum criteria except for one item, and all the remaining seven items were found to be more than .70 (Table 3).

Table 3 Convergent / Discriminant Validity and Reliability from CFA

Theoretical Variables	Measurement Variables	Estimated λ	Standard Error	Standardized Estimate	C.R.	P	SMC	AVE	Construct reliability	Chronbach's Alpha	*SMC (**CC)
Factor1	Item08	1.000	-	0.494	-	-	0.244	0.510	0.798	0.807	factor1
	Item 38	2.033	0.354	0.946	5.742***	<.001	0.895				&
	Item 55	1.417	0.273	0.750	5.199***	<.001	0.563				factor2
	Item 56	1.162	0.231	0.707	5.032***	<.001	0.500				0.102 (0.320)
Factor2	Item 03	1.000	-	0.654	-	-	0.428	0.544	0.824	0.841	factor2
	Item 15	2.172	0.275	0.905	7.893***	<.001	0.820				&
	Item 16	1.720	0.233	0.834	7.392***	<.001	0.696				factor3
	Item 42	1.426	0.228	0.651	6.266***	<.001	0.424				0.371 (0.609)
Factor3	Item 19	1.000	-	0.863	-	-	0.745	0.543	0.763	0.800	factor1
	Item 47	0.594	0.090	0.587	6.590***	<.001	0.345				&
	Item 51	1.134	0.159	0.628	7.144***	<.001	0.394				factor3
	Item 57	1.095	0.109	0.831	10.075***	<.001	0.690				0.371 (0.609)

*SMC= Squared Multiple Correlation. **CC= Correlation coefficient

As an alternative method for discriminative validity, we calculated the variance extraction index based on the standardized fit of the latent variables and the error of the measured variables.

Conceptual reliability refers to the degree of coherence between measured variables, which indicates the shared variance among the measured variables of a constituent concept. The results of confirmatory factor analysis were calculated from the derived factor loadings and the error variance (Table 3).

When the variance extraction index of the corresponding latent variable is greater than the square of the correlation with all other factors⁴², the correlation coefficient between Factor 1 and Factor 3 was .609 [$(0.609)^2 = 0.371$] when 'Factor1<->Factor3' was applied, and the Average Variance Extracted (AVE) of Factor 1 was .510 and AVE of Factor 3 was .543. Both AVE values were greater than the square of the correlation coefficient.

In order to determine the discriminant validity of the Moyamoya-HB scale, the correlation coefficient and correlation standard error $(\sqrt{\frac{1-r^2}{n-2}})$ between factors were calculated. A discriminant validity is established when the confidence interval of the correlation coefficient $(r-2 \times S.E. \sim r+2 \times S.E.)$ is less than one (Woo, 2016). The correlation coefficient of Factor 2 and Factor 3, which showed the highest correlation coefficient, was calculated as 0.863 ~ 0.905, and it was judged to be valid because it was less than one. The confidence interval of the correlation coefficient between the other factors was less than one as well. As a result, the discriminant validity of Moyamoya-HB scale was confirmed.

4. Reliability

To confirm the reliability of Moyamoya-HB scale, the AVE (≥ 0.5) and construct reliability (≥ 0.7) were calculated of CFA (37) and Cronbach's alpha coefficients (Table 3). As the AVE ranged from 0.453 to 0.798, and construct reliability ranged from 0.763 to 0.824, the reliability of all factors in the Moyamoya-HB scale was confirmed.

For the 12 items of the Moyamoya-HB scale, Cronbach's alpha values for the overall scale, and the subscales were high. The total Cronbach's alpha was .86; for Factor 1 (implementation of treatment for moyamoya disease) it was .807, for Factor 2 (health promoting behavior for moyamoya disease) it was .841, and for Factor 3 it was (health coping behavior for moyamoya disease) .763.

Discussion

The purpose of this study is to provide basic data on nursing practice and research considering the characteristics of adolescents with moyamoya disease by developing a health behavior scale for these adolescents.

As a result of the study, the Moyamoya HB-scale for measuring health behaviors of adolescents with moyamoya disease ended up with 12 items in 3 sub-domains: implementation of treatment for moyamoya disease, health promoting behavior for moyamoya disease and health coping behavior for moyamoya disease, all on a 5-point Likert Scale. Factor 1 is "implementation of the treatment of moyamoya disease" consisting of four items, which has the second most powerful explanatory power (22.78%). It is a core activity that should be performed during the treatment of moyamoya disease. In other words, it corresponds to the behavior associated with essential clinical prescriptions in the treatment of moyamoya disease⁴³⁻⁴⁵. Water intake is important for patients with moyamoya disease because dehydration can cause neurologic (clinical) symptoms^{2,46,47}. Adolescents with moyamoya disease also spend a lot of time at school, and thus treatment instructions should be learned for emergency situations that may occur at school. Also, regular check-ups should be done and basic rules for taking medication should be followed in the course of treating of moyamoya disease. This reflects the implementation of the directive.

The second factor, at 24.54%, was the most important factor in the measurement of health behaviors among adolescents with moyamoya disease. This factor, "health promoting behavior for moyamoya disease," includes healthy behavior and habits which maintain and promote the health of adolescents with moyamoya disease. In other words, we were able to measure posture in order to keep the cerebral blood circulation healthy, essential items to be brought in when going out, useful information collection for disease management strategy and support for specific health promotion through information networks. This is seen as a similar concept to self-health promotion behaviors such as health education, social care, and disease prevention in other group health behavior measurement tools⁴⁸.

The third factor was "explanatory power" (21%), and the term "health coping behavior for moyamoya disease" relates to adolescents with moyamoya disease taking appropriate action related to the disease. That is, behaviors related to management of stress, hyperventilation and mental health, because stress can cause clinical symptoms, and ineffective resolution of stress can also affect individual health behaviors, including negative emotions such as depression and anxiety. Also, negative emotions can cause stressful situations.

The purpose of this study is to develop a tool to measure health behaviors in consideration of the characteristics of illnesses of moyamoya-suffering adolescents. It is also important to verify the validity and reliability of the Moyamoya-HB scale from various angles. It provides strong evidence that can be used as a useful tool in various research fields. In the development of tools, it is necessary to present a rational basis for tool use by presenting diverse and logical analysis for validating the tool⁴⁹. In terms of reliability, Cronbach's α value, which is generally presented as .86, shows high internal reliability, which proves this to be a highly reliable tool.

In addition to verifying the validity and reliability of the Moyamoya-HB scale, this study has the following significance. The Moyamoya HB-scale, consisting of sub-domains of cognition, practice and emotion, maintains a relatively high explanatory variance of 68.97%. In the first factor analysis, the 12 items were reduced from 25 items, but maintaining a relatively high explanatory variable means that the construct validity should not be threatened due to the reduction of the items in the tool development⁵⁰. Second, there is significance for the first development of health behaviors of young people with moyamoya disease, a rare incurable disease. This is also important as a basic study for programs for patients with moyamoya disease that should be studied in the future.

It is expected that the development and application of this Moyamoya-HB scale will provide basic data on the development of various intervention strategies for the health promotion of moyamoya disease adolescents in nursing and medical care environments.

In addition to the significance of the above study, in order to overcome the restriction of the recruitment of subjects through a hospital and the disease consultation, we tried to satisfy the construct validity through various methods. This is a limitation of this study. This suggests follow-up studies of additional confirmatory factor analysis should be conducted. Second, we suggest the application of this scale to the development of scales for other school-aged and adult subjects suffering from other diseases through practical clinical application.

Conclusion

The Moyamoya-HB scale was developed to evaluate and verified as an acceptable assessment tool to measure health behavior of adolescent with moyamoya disease through a variety of psychometric evaluations. It is a self-report form tool composed of three sub-domains: implementation of treatment for moyamoya disease, health promoting behavior for moyamoya disease and health coping behavior for moyamoya disease, using a 5-point Likert scale. The purpose of this study was to identify the essential elements of health behaviors of adolescents with moyamoya disease when considering the health characteristics that are important for health maintenance and life management. It is meaningful for developed and evaluated tools to be available. We hope that this study will be useful as a theoretical basis and evaluation index for the development and application of various intervention programs for health promotion of adolescents with moyamoya disease.

Abbreviations

AVE: average variance extracted

CC: correlation coefficient

CFA: confirmatory factor analysis

EDAS: encephalo-duro-arterio-synangiosis

EFA: exploratory factor analysis

GFI: goodness of fit index

HB: health behavior

IRB: institutional review board

KERIC: Korea Education and Research Information Service

KMO: Kaiser-Meyer-Olkin

NFI: normal fit index

RMSEA: root-mean-square error of approximation

SD: standard deviation

SMC: square multiple correction

SRMR: standardized root mean square residual

TIA: transient ischemic attack

YRBS: youth risk behavior survey

YRBSS: youth risk behavior surveillance system

Declarations

Ethics approval and consent to participate

The authors state that the experimental protocols of this study were approved by Yonsei University Health System, Severance Hospital, Institutional Review Board (Case No. 4-2017-0884). The study met the guidelines of the Republic of Korea Ministry of Health. Written consent was obtained from all patients or their guardians if they were minors.

Consent for publication

Not applicable.

Availability of data and materials

The datasets during and/or analysed during the current study available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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This study had no funding.

Authors' contributions

WOO contributed to the design of the work and the acquisition, analysis and interpretation of data. ISY contributed to the design of the work; the acquisition, analysis and interpretation of data; and drafted the work or substantively revised it. SHL contributed to the design of the work. DSK contributed to the design of the work; interpretation of data; and the creation of new software used in the work. KWS contributed to the design of the work and interpretation of data. All authors have read and approved the manuscript.

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Figures

Figure 1

Confirmatory factor analysis

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