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ORIGINAL RESEARCH

Validation of the Japanese translation of the Dysphagia Handicap Index

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Background: We developed, and examined the reliability and validity of, a Japanese version of the Dysphagia Handicap Index (DHI; DHI-J), which is a self-reported measure to assess the quality of life (QOL) of individuals with dysphagia.

Participants and methods: The DHI-J was developed via the back-translation method: the DHI was translated into Japanese and then translated back into English by a native English speaker. The back translation was discussed with and approved by the DHI's lead author. A total of 229 patients (119 males, 110 females; median age: 66 years) who underwent videofluorography at our hospital between January and December 2013 and 65 controls (23 males, 42 females; median age: 44 years) were included in the study. All the subjects completed the DHI-J and self-reported their dysphagia severity. Twenty-three patients repeated the procedure 1 week later. Patients' swallowing function was classified as "normal", "moderately impaired", or "severely impaired", and the DHI-J total scores were compared between the severity groups.

Results: The internal consistency of the DHI-J was high (Cronbach's α=0.95), as was the test–retest reliability of the 23 patients who answered the questionnaire twice (intraclass correlation coefficient =0.98, $P<0.01$). The DHI-J total score and its three subscale scores were significantly higher among the patients than among controls. A significant correlation (ρ=0.85) was observed between the DHI-J total score and self-reported dysphagia severity score. Regarding the comparison of DHI-J scores by severity groups, the DHI-J total scores significantly differed between the normal and moderately impaired groups, and the normal and severely impaired groups. However, the moderately and severely impaired groups showed no significant difference in scores.

Conclusion: The DHI-J is a reliable and valid questionnaire for assessing the QOL of patients with dysphagia. However, we did not survey patients with cerebrovascular diseases; thus, the questionnaire must be validated for that patient group.

Keywords: dysphagia, quality of life, videofluorography, reliability, self-reported severity

Introduction

There are a variety of self-reported questionnaires for assessing the quality of life (QOL) of patients with dysphagia, including disease-specific questionnaires such as the M.D. Anderson Dysphagia Inventory[1] (which targets those with eating and swallowing disorders due to head and neck cancers) and the Dysphagia Goal Handicap[2] (which targets those with esophageal-phase dysphagia) as well as more generic questionnaires such as the Swallowing Quality-of-Life Questionnaire (SWAL-QOL),[3] which can be used for any disease. The SWAL-QOL has proven to have high internal consistency and a moderate degree of validity, and is commonly used worldwide.[4–6] The Dysphagia Handicap Index (DHI) was developed with the aim of creating a more concise and easier-to-complete measure of QOL than the SWAL-QOL for patients with dysphagia.[7]

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The DHI comprises 25 items, including 9 items to assess the physical aspect of QOL (the person's self-perception of the physical discomfort caused by dysphagia), 9 items to assess the functional aspect (the impact of the dysphagia on the person's daily activities), and 7 items to assess the emotional aspect (the person's affective response to his/her dysphagia). Higher scores are associated with lower QOL. The DHI has been shown to have high internal consistency and strong test–retest reliability, making it a reliable questionnaire. Furthermore, it is sufficiently valid because of its correlations with self-reported dysphagia severity score among patients.[7]

Although there is a Japanese version of the SWAL-QOL,[8] it contains numerous questions along with the technical term "gag reflex", which is not known to laypeople. Therefore, we developed a Japanese version of the DHI (DHI-J), which is much simpler and easier to comprehend, and examined its reliability and validity. Additionally, we compared QOL scores with swallowing function determined by videofluorography (VF) to see if the swallowing function is related to QOL associated with dysphagia.

Participants and methods

This study was approved by the ethics committee of the National Center of Neurology and Psychiatry (A2012-099), and all procedures performed in this study were in accordance with the 1964 Helsinki declaration and its later amendments.

Participants

The participants were 229 patients (119 males, 110 females; median age: 66 years) who visited our hospital for a consultation between January and December 2013 and who provided their written informed consent to participate. We also had 65 controls (23 males, 42 females; median age: 44 years). The controls were recruited from the community where our facility was located by placing announcements in municipal publications. Patients who were unable to write their answers completed the questionnaire by having a family member or another designated person write the patients' answers in their stead. The inclusion criteria for patients were as follows: having a disease that might cause dysphagia, taking daily meals orally, being 20 years of age or over at the time of evaluation; and being able to understand the questionnaire. The exclusion criterion for both the controls and patients was having a diagnosis of dementia. The diseases represented were Parkinson's syndrome (n=128), muscular dystrophy (n=28), spinocerebellar degeneration (n=21), motor neuron diseases (n=19), myopathy (n=12), myositis (n=6), and others (n=15). The swallowing function of every patient was assessed using VF. This involved having patients swallow 10 mL of two fold diluted 110% w/v liquid barium (Baritop 120; Kaigen Pharma Co., Ltd, Osaka, Japan). The patients were video recorded from a lateral angle at a rate of 30 frames per second while they swallowed the liquid barium in a seated position.

The inclusion criteria for the controls were as follows: being 20 years of age or over, being able to understand the questionnaire, no eating or swallowing disorder, no history of head or neck cancer or surgery (with the exception of adenotonsillectomy), not taking any psychotropic drug at the time of the study, and assessed as normal (ie, a score of 11 or lower) on the Swallowing Disturbance Questionnaire.[9]

Development of the DHI-J

To develop the DHI-J, we first obtained permission from the lead author of the DHI. Then, we had two translators whose native tongue was Japanese translate the DHI from English into Japanese. The Japanese translation was then translated back into English by a native English speaker. We sent the back translation to the lead author of the DHI, and proceeded to discuss the quality of the Japanese translation for about 4 months. Several difficulties arose in the translation process, owing to differences between the two cultures. The most problematic of these difficulties was the translation of the word "handicap". This word is often transcribed into Japanese letters and read as "handi-cappu", but it was feared that this word of English origin would be difficult to understand for some elderly Japanese, because elderly people are not used to words of English origin. As a Japanese equivalent term was not easily found, it took some time to finalize the translation. After we finally obtained the approval of the lead author of the DHI, DHI-J was considered complete[10] (Figure S1). As with the original version, scores of 0, 2, and 4 were assigned to answers of "never", "sometimes", and "always", respectively, for each item.

Examination of reliability

We computed the Cronbach's α for the DHI-J total and subscale scores (ie, the physical, functional, and emotional aspect scores). To confirm the test–retest reliability, we asked 23 patients who responded to the DHI-J to complete it a second time a week later. We then calculated the intraclass correlation coefficient between their scores of the first and second times. We made sure to confirm that there was no change

in patients' physical symptoms, internal medications used, or food texture modifications between the two assessments by the DHI-J.

Examination of validity

To determine the convergent validity of the DHI-J, we calculated the correlation between the DHI-J total score and the self-reported severity score using Spearman's rank correlation coefficient. All patients completed the DHI-J and the self-reported dysphagia severity measure 1 month before or after their VF. This measure used a 7-point scale, ranging from 1 (normal) to 7 (very severe). The participants selected the option that best reflected their swallowing disorder severity. To determine the known-group validity, we compared the total and subscale scores between patients and controls using Mann–Whitney *U* test.

Relationship with VF-evaluated swallowing disorder severity

Four examiners classified each patient's severity of swallowing disorder as "normal", "moderately impaired", or "severely impaired" using the VF image, and the evaluation criteria as follows: participants who showed neither aspiration nor pharyngeal residue were classified as "normal"; those who showed pharyngeal residue after swallowing but did not show aspiration or awkward oral transit were classified as "moderately impaired"; and those who showed aspiration as well as pharyngeal residue after swallowing were classified as "severely impaired". We used this method because we could not find a standardized evaluation in Japanese for assessing swallowing functions comprehensively (ie, including information on oral transit or pharyngeal residue as well as penetration and aspiration).

We compared the DHI-J total and subscale scores according to swallowing disorder severity (as assessed by VF) as follows: first, we performed a Kruskal–Wallis test to determine the dispersion of the DHI-J scores. Next, we compared the DHI-J total and subscale scores between the various swallowing disorder severity groups using Mann–Whitney *U* test.

Significance level

Because we performed multiple comparisons and used several statistical tests, we corrected the significance level using Bonferroni method. Thus, the significance level for the comparison of the DHI-J total and subscale scores between patients and controls was set at $P<0.013$, and that for the comparison between the VF severity groups was set at $P<0.017$. For all other statistical tests, the significance level was set at $P<0.05$.

Results

Reliability

The internal consistency (Cronbach's α) of the DHI-J total score and the physical, functional, and emotional aspect scores was high, at 0.95, 0.83, 0.89, and 0.90, respectively (Table 1). The test–retest reliability, based on the 23-patient sample, was high (intraclass correlation coefficient =0.98; $P<0.01$).

Validity

The correlation between the DHI-J and self-reported severity score was strong ($P<0.01$), with a Spearman's ρ of 0.85 for both the patients and the controls (Figure 1). The control group's median total score on the DHI-J was 2, whereas that of the patients was 10; this difference was significant ($P<0.01$). Regarding the subscale scores, the median scores on the physical, functional, and emotional aspects among the controls were 2, 0, and 0, respectively, while among the patients, they were 4, 2, and 2, respectively. The scores were significantly higher among the patients than among the controls ($P<0.01$; Table 2). The validity of the DHI-J was confirmed.

Relationship with VF-evaluated swallowing disorder severity

According to the VF evaluation criteria mentioned above, 154 patients were classified as having normal swallowing function, 36 as having moderately impaired function, and 38 as having severely impaired function. The median DHI-J total and physical, functional, and emotional aspect scores were 6, 4, 2, and 0 for the normal group; 17, 6, 6, and 4 for the moderately impaired group; and 30, 10, 11, and 10 for the severely impaired group, respectively. These results indicated significant dispersion ($P<0.01$) in the DHI-J total scores among the three severity groups. Additionally, significant differences were found between the normal and

Table 1 A comparison of the internal consistency reliability between the DHI-J and the DHI

Cronbach's α	DHI-J	DHI
Total	0.95	0.94
Physical	0.83	0.78
Functional	0.89	0.91
Emotional	0.90	0.86
Test–retest reliability	0.98	0.83

Abbreviations: DHI-J, Japanese version of the Dysphagia Handicap Index; DHI, Dysphagia Handicap Index.

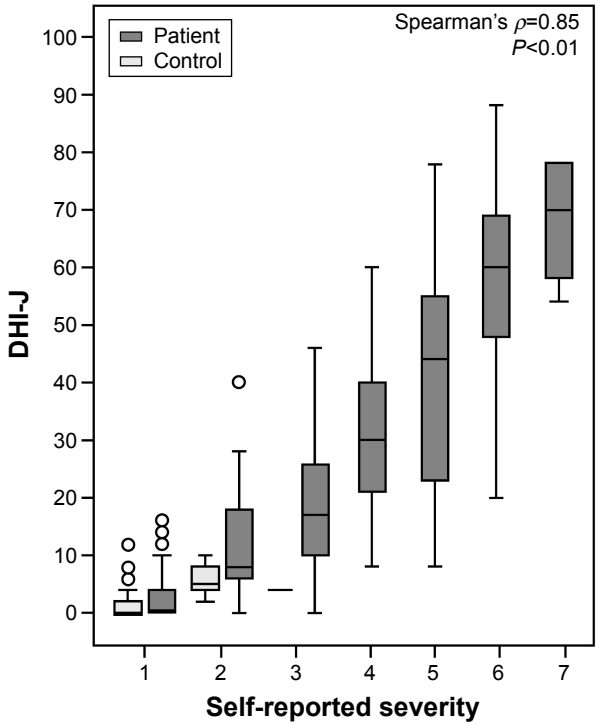

Figure 1 Relationship between DHI-J and the self-reported severity.
Notes: Spearman's ρ between DHI-J and the self-reported severity was 0.85. There was a significant strong correlation between the two ($P<0.01$).
Abbreviation: DHI-J, Japanese version of the Dysphagia Handicap Index.

moderately impaired groups and between the normal and severely impaired groups for all DHI-J scores (all $P<0.01$). However, we observed no significant difference between the moderately and severely impaired groups in terms of DHI-J total score or any subscale scores (Table 3).

Discussion

The original DHI study reported a Cronbach's α of 0.94, an intraclass correlation coefficient of 0.83, and a Spearman's ρ with self-reported dysphagia severity of 0.77. The current study of the DHI-J reported equivalent or higher values of the Cronbach's α, intraclass correlation coefficient, and Spearman's correlations with self-reported dysphagia severity. These comparable values indicated that the DHI-J is a reliable and valid questionnaire. Furthermore, the content

Table 2 Comparison of DHI-J scale scores between patient (n=229) and control (n=65) groups

DHI-J subscales	Total*	Physical*	Functional*	Emotional*
Median (IQR)				
Patient	10 (2–24)	4 (0–10)	2 (0–8)	2 (0–8)
Control	2 (0–4)	2 (0–3)	0 (0–0)	0 (0–0)

Note: *$P<0.013$ for all scales.
Abbreviation: DHI-J, Japanese version of the Dysphagia Handicap Index; IQR, interquartile range.

Table 3 DHI-J scores according to the clinical severity of dysphagia based on VF results

Clinical severity	n	DHI-J scale (median)				
		Median age (yr)	Total[a]	Physical	Functional	Emotional
Normal[b]	155	65	6	4	2	0
Moderate	36	64	17	6	6	4
Severe	38	72	30	10	11	10

Notes: [a]The total score and score of each aspect of the DHI-J showed significant variability across the different groups for the severity of impairment of swallowing function ($P<0.01$ for all scales). [b]Significant differences were found between the normal and moderately impaired groups and between the normal and severely impaired groups ($P<0.017$ for all scales).
Abbreviations: DHI-J, Japanese version of the Dysphagia Handicap Index; VF, videofluorography; yr, years.

of the DHI-J questionnaire was mostly unaffected by cultural differences, given that eating and swallowing are common across all cultures.

A study of 36 Parkinson's disease patients that assessed their dysphagia by food texture modifications, water swallowing test, and oral motor movement evaluations found that patients with dysphagia had a significantly lower QOL (as assessed by the SWAL-QOL) than did the patients without dysphagia for all items of the SWAL-QOL except for sleep.[11] Similarly, in a study of 30 patients with amyotrophic lateral sclerosis, patients who were determined to have dysphagia by VF demonstrated significantly lower SWAL-QOL scores than those without dysphagia.[12] While both of these studies looked at a specific disease, respectively, they nevertheless indicated that dysphagia was associated with lower QOL.

We further found that the patients' DHI-J scores (total and all three subscales) were consistently lower than those of the controls. This suggests that dysphagia influences not only the physical and functional aspects of the patients' QOL but also the emotional aspect. In a survey of 360 elderly subjects who had difficulty swallowing, many stated that they did not want to eat meals with others because of their swallowing problems, or because they were afraid of choking on the food while eating. Furthermore, more than half of these elderly adults answered that they were unable to enjoy life because of their dysphagia.[13] In another study on 73 patients who had either undergone otolaryngological or maxillofacial surgery, or had a neurological disorder or senile deterioration in swallowing function, many of the subjects answered that they had begun avoiding meals in public or no longer enjoyed having meals because of their swallowing difficulties. The authors of this latter study emphasized the negative impact of dysphagia on QOL, particularly in the social and emotional aspects.[14] These two studies illustrate the necessity of assessing the QOL of patients with dysphagia, particularly in Japan, where

there has not been a questionnaire other than the SWAL-QOL (which, as we already mentioned, includes terminology that makes it difficult for laypeople to understand). Silbergleit et al reported significant negative correlations between DHI scores and dysphagia severity.[7] Similarly, a study of the relationship between QOL and clinical severity of dysphagia as assessed by VF among head and neck cancer patients found a significant difference in QOL scores between the "normal" and "mild" swallowing disorder groups and between the "moderate" and "severe" disorder groups.[15] These findings partially accord with our own, which showed a significant difference in DHI-J scores between the "normal" and "moderately impaired" groups and between the "normal" and "severely impaired" groups; however, we found a non-significant difference between the "moderately impaired" and "severely impaired" groups. These findings indicate the possibility that the severity of swallowing disorder does not always predict the QOL of dysphagia patients. Therefore, it seems important to have a measure of QOL separate from the assessment of swallowing function.

Limitations

Although the DHI-J has proven to be a reliable questionnaire for evaluating the QOL of patients with dysphagia, it might be difficult to precisely determine what effects on QOL are directly caused by swallowing problems. For example, some diseases causing dysphagia also lead to clumsy movements in the hands; such patients might hesitate to eat in public not because of their difficulty in swallowing but because they do not want others to see their clumsiness. Moreover, we did not include individuals with cerebrovascular diseases in our study. Swallowing problems are similar regardless of the underlying disease, and DHI-J may be applicable to patients of cerebrovascular diseases. However, the onset of a cerebrovascular disease is acute and the disease progression is significantly different from that of the degenerative neurological diseases that are the subject of this study. Therefore, the QOL scores in relation to swallowing problems associated with a cerebrovascular disease may be quite different. A validation for cerebrovascular diseases may also be necessary.

Conclusion

The DHI-J was demonstrated to have good reliability and validity for assessing the QOL of patients with dysphagia. Specifically, we found that patients with impaired swallowing function (as determined by VF) had a lower QOL than the controls. However, we observed no significant difference in QOL between patients with moderate swallowing disorder and patients with severe swallowing disorder, indicating that patients' swallowing function assessed by VF is not necessarily a reliable indicator of their QOL. Therefore, it would be important to evaluate QOL separately from the swallowing function.

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Disclosure

The authors report no conflicts of interest in this work.

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Supplementary material

Please circle appropriate responses to the questions about your swallowing

	Never	Sometimes	Always
1P I cough when swallowing liquids.			
2P I cough while eating solid food.			
3P My mouth feels dry.			
4P I cannot swallow food without washing it down with liquid.			
5P I have lost weight due to swallowing problems.			
1F I avoid certain kinds of food due to swallowing problems.			
2F I changed the way I swallow to make it easier to eat.			
1E I hesitate to eat in public.			
3F It takes longer to eat than before.			
4F I often eat smaller portions of food due to swallowing problem.			
6P It takes extra time to get the food down when swallowing.			
2E I get depressed because I cannot eat what I want.			
3E I do not enjoy eating as much as before.			
5F I don't socialize as much due to swallowing problems.			
6F I avoid eating due to swallowing problems.			
7F I eat less due to swallowing problems.			
4E I am nervous about swallowing problems.			
5E I feel impaired because I have difficulty in swallowing.			
6E I get annoyed with myself because of swallowing problems.			
7P I cough as I take my medicine.			
7E I have a fear that I may choke and suffocate with food in the throat because of my swallowing problems.			
8F I have to use an alternative method of eating (such as tube feeding) because of my swallowing problems.			
9F I changed the dietary composition due to swallowing problems.			
8P My throat feels tight when swallowing.			
9P I have coughing fits after swallowing.			

Self-reported Dysphagia Severity Scale.

Please circle the number that best describes the severity of your swallowing difficulty (1= no difficulty in swallowing, 4= somewhat of a problem, 7= the worst problem for me).

1 2 3 4 5 6 7

Normal Moderate problem Severe problem

Figure S1 Back translation of the Japanese translation of the Dysphagia Handicap Index.