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BRIEF COMMUNICATION

The feasibility and test–retest reliability of the Dutch Swal-Qol adapted interview version for dysphagic patients with communicative and/or cognitive problems

Jessie Lemmens · Gerrie J. J. W. Bours ·
Martien Limburg · Anna J. H. M. Beurskens

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Abstract

Purpose The adaptation of the Dutch Swal-Qol questionnaire to an interview format suitable for dysphagic patients with communicative and/or cognitive problems and evaluation of the feasibility and test–retest reliability.

Methods An observational study with two measurements within a 2-week time period in a sample of 57 stroke patients with dysphagia in a nursing home environment. The interview version of the Swal-Qol was evaluated in the total group and in subgroups of patients with and without communicative and/or cognitive problems.

Results The constructed interview version was considered feasible from an expert's and patient's point of view. The overall score and seven subscales of the Swal-Qol showed an excellent test–retest reliability ($k > 0.75$), and two subscales were considered good ($k > 0.60$).

Conclusions This study showed that using a structured, and at the same time flexible, interview format tailored to the individual needs of stroke patients enhances the feasibility and does not compromise the test–retest reliability.

Keywords Test–retest reliability · Feasibility · Dysphagia · Quality of life · Swal-Qol

Introduction

Health Related Quality of Life (HRQOL) scales are patient-reported outcome measures for gaining information

about a patient's own health situation [1, 2]. When assessing patients with communicative and/or cognitive problems, caution is needed when using traditional HRQOL scales since difficulties in understanding or answering may occur [3–5]. Several studies give recommendations for adjustments for patient groups with communicative and cognitive problems [6–9]. McHorney et al. [10] developed the Swal-Qol questionnaire to evaluate the impact of dysphagia on quality of life and was shown to be a reliable and valid tool for measuring quality of life in outpatients [11–14]. However, the current self-report version is not feasible for patients as half of them need assistance in filling it out [11, 13, 15]. Therefore, the aim of this study was to adapt the Swal-Qol questionnaire for dysphagic stroke patients with and without communicative and/or cognitive problems and evaluate its feasibility and test–retest reliability.

Methods

Design

A cross-sectional, clinimetric study design was used with two measurements in a 2-week time period in a sample of dysphagic stroke patients in a nursing home environment.

Materials and methods

The Swal-Qol consists of 44 items divided in 10 scales regarding quality of life: (1) burden, (2) eating duration, (3) eating desire, (4) food selection, (5) communication, (6) fear, (7) mental health, (8) social functioning, (9) fatigue and (10) sleep that could be rated on a 5-point

J. Lemmens (✉) · G. J. J. W. Bours · M. Limburg ·
A. J. H. M. Beurskens
Zuyd University of Applied Sciences, Heerlen, The Netherlands
e-mail: je.lemmens@hszuyd.nl

Likert scale. In addition, there are scales on symptom frequency, nutrition intake (tube, consistency of food and/or liquids), assistance with filling out, general health and some demographics [14]. We adapted the Dutch translation of the Swal-Qol [15] into an interview version by using a two-step response method with supportive visual aids [6–9]. The adaptation process is described in Box 1.

Participants

Stroke patients with dysphagia were recruited by speech and language therapists (SLTs) responsible for dysphagia treatment in nursing homes. Patients were eligible when they were physically and mentally fit enough to participate. Patients were excluded if they did not speak Dutch. The SLTs gave eligible patients oral and written information

Box 1 Swal-Qol adaptations, from self-report to interview version

Step 1: developing a standardized interview format

Purpose: enabling patients to portray their own perspective, instead of depending on proxy reports[3].

The interviews format was adjusted to the communicative capabilities of the patients by:

- using questions instead of statements [4-8],
- administrating scales and items in a flexible order,
- giving explanations or demonstrations of unclear items such as 'clearing throat' [9].

Step 2: simplifying instructions and items

Purpose: limiting item sampling errors.

The comprehension of items was enhanced by:

- using directive speech [6],
- rephrasing items in which vague language or negative phrasing was used [14],
- changing the recall time from 'last month' to 'last week' [8].

Step 3: revising the five-point Likert scale

Purpose: designing a suitable ordinal scale for patients for whom Likert scales are problematic [8, 18], by:

- creating a two step responds method (see example).

Step 4: designing visual aids

Purpose: supporting verbal communication which benefits comprehension, focus and memory.

Different layout styles were designed:

- a) enlarged font, b) key words in bold/underlined, c) separate pages for each item,
- d) separate response cards,
- vertical response cards for patients with a neglect or hemianopia [10].

Step 5: involvement of experts

Purpose: combining theoretical and practical insight and getting independent approval for practical use.

Five independent SLT's with at least three years of experience with dysphagic stroke participated by:

- giving suggestions for tailoring the original Swal-Qol,
- confirming the suitability of the adapted interview, instructions, items and response scales.

Example:

Interviewer asks : 'Is it difficult to deal with your swallowing problem?

Patient answers: 'yes', 'no' or comes up with a more specific answer for example: 'depends on the day' or 'I don't know'.

If yes: the interviewer nods and responds (in neutral tone while observing the patients reaction): 'ah, it is'. Then asks a second question: 'Is it very difficult (1), remotely difficult (2) or a little bit difficult (3) for you?'

If no: the interviewer shakes his head and responds (in neutral tone while observing the patients reaction): 'ah, it is no problem for you'. Then asks a second question: 'Is it never a problem (5) for you or occasionally (4)?'

In case a patient doesn't know, the interviewer checks if the patient doesn't recall or if the item is unclear and then gives a suitable explanation.

If necessary the interviewer repeats every answer option separately or suggests to use a visual aid.

Dealing with my **Swallowing Problem** is very **difficult**

| | | | | |
|------------------|--------------------|----------------------|--------------------------|------------------------|
| Very True | Partly True | A Little true | Almost never true | Not true at all |
| 1 | 2 | 3 | 4 | 5 |

and asked permission for the interviewers to approach them. If patients were not able to give written consent, permission was asked in the presence of family members. If at 2-week follow-up patients did not recall giving consent, it was asked for again.

Measurements

Patient characteristics

Communicative problems as dysarthria and aphasia were diagnosed by a SLT. Cognitive problems were defined as neuropsychological symptoms following stroke and were diagnosed by a psychologist. The severity of dysphagia was determined by feeding status. Dysphagia was considered ‘severe’ when patients were fed by tube (with and without oral intake), ‘moderate’ when there was oral intake with adjusted consistency and ‘mild’ in the case of normal oral intake with adaptive strategies.

Feasibility

Feasibility was defined as time to complete the interview, use of visual aids, item comprehension and burden from an observer’s and patient’s perspective. Burden was described as to what extent the interview had been tiresome for the patient. Regarding the patient’s perspective, two questions on a three-point scale about comprehension and burden were asked.

Test–retest reliability

Test–retest reliability was assessed by administering two identical Swal-Qol interviews with the same interviewer. A 2-week time interval was considered enough time for patients not to remember their previous answers.

Procedures

The SLTs and psychologist diagnosis were derived from the patients’ medical records to gather information on communication and cognition. Two trained assessors, one interviewer and one observer, conducted all the interviews. All patients were asked whether they preferred to use visual aids. The interviewer administered the Swal-Qol interview and wrote down the answers given by the patient; the observer reported the feasibility aspects. The use of visual aids and explanations were standardized in the second interview to guarantee that both interviews were identical. Before the second interview, the assessors checked whether no major changes had occurred in health status.

Data analyses

The Predictive Analytics Software (PASW, version 18) program was used for data analyses. Patient characteristics were reported in frequencies. Subgroups were formed based on the presence of communicative and/or cognitive problems. Feasibility aspects were analyzed using descriptive techniques (i.e., mean, standard deviation, frequencies). Subscales with at least one incomplete answer were excluded from test–retest analyses. The test–retest reliability for each subscale and overall score was reported by the weighted kappa and is considered good between 0.40 and 0.75 and excellent above 0.75 [16, 17]. To compare the data with previous published studies, the Spearman’s rho correlation coefficients and the intraclass correlation coefficients (ICC) were calculated.

Results

Participants

A total of 61 patients met the inclusion criteria of whom 57 gave their consent and 56 participated in both interviews. Data were collected from April 2008–December 2009 in seven nursing homes in the Netherlands. The average age was 75.1 (\pm SD 12.1). Communication problems were present in 30 (53 %) patients. The most frequent diagnosis was aphasia or dysarthria ($n = 24$). Three patients had both speech and language problems. Cognitive problems occurred in 12 (21 %) patients and existed mostly of amnesia or neglect ($n = 11$; Table 1). Two patients had cognitive as well as communicative problems of whom one only participated in the feasibility study.

Feasibility

The average time to complete the interviews was 41 (\pm SD 28) min, and 29 (37 %) patients needed 30 min or more. There were no major differences between the group with and without communicative and/or cognitive problems.

Visual aids were used in 30 (53 %) interviews. Half of the patients without communicative or cognitive problems ($n = 8$) preferred visual aids. Only the enlarged font questionnaire ($n = 11$: 19 %) and separate response cards ($n = 18$: 32 %) were applied, mainly to help patients sustain attention.

Difficulties in comprehension were reported in all 44 items of the Swal-Qol. In 12 (21 %) interviews, a pause was needed, prolonging the administration time. Item comprehension was easy to 45 (78 %) patients and difficult to three (5 %) patients. The majority of the patients (82 %) found the burden acceptable to low.

Table 1 Sample characteristics ($n = 57$)

| | <i>n</i> (%) |
|---|--------------|
| Gender | |
| Male | 24 (42) |
| Age | |
| Mean (SD) | 75.1 (12.1) |
| Min | 46 |
| Max | 94 |
| Highest completed education | |
| Elementary school | 22 (39) |
| High school | 16 (28) |
| Vocational training | 14 (25) |
| University | 5 (9) |
| Dysphagia | |
| Severe: tube feeding | 9 (16) |
| Moderate: oral intake with adjusted consistency | 25 (47) |
| Mild: normal oral intake with adaptive strategies | 21 (37) |
| Communication and/or cognitive problems ^a | 41 (72) |
| Communication problems ^a | 33 (58) |
| Aphasia (language) | 12 (21) |
| Dysarthria (speech/voice) | 12 (21) |
| Buccofacial/verbal apraxia (speech) | 5 (9) |
| Unclassified diagnosis (speech/language) | 4 (7) |
| Cognitive problems (neuropsychological symptoms) ^a | 12 (21) |
| Amnesia | 6 (11) |
| Neglect/hemianopia | 6 (11) |
| None | 16 (28) |

^a Patients can experience several problems in communication and/or cognition

Test–retest reliability

The average time between the two interviews was 14.9 (\pm SD 3.1) days with a minimum of 7 and maximum of 24 (range = 17) days. Due to missing data, the sample size per subscale varied between 48 and 56 patients (Table 2). The weighted kappa was excellent ($k > 0.75$) for the overall score and seven subscales of the total group ($n = 56$), the group with ($n = 40$) and without communicative and/or cognitive problems ($n = 16$). It was good for subscale ‘fear’ ($k = 0.675/0.677/0.660$) and ‘fatigue’ ($k = 0.713/0.736/0.631$). A further comparison between communicative and cognitive problems showed that all scales were excellent for the group with communicative problems ($n = 30$). The sample size of the cognitive impaired group was considered too small for analysis. There were no major differences in test–retest reliability between the use of the weighted kappa, the Spearman’s rho and ICC (Table 2).

Discussion

This study showed that using a structured, and at the same time, flexible interview format tailored to the individual needs of patients enhances the feasibility and does not compromise the reliability for dysphagic stroke patients with problems in communication and cognition.

In general, an interview format is more time-consuming and requires more resources and training, but we demonstrated that our adaptations led to a scale applicable within

Table 2 Test–retest reliability of the Swal-Qol subscales ($n = 56$)

| Subscale (# items) | <i>n</i> | Total group (weighed kappa) | Total group (Spearman’s rho/ICC) | Subgroups (weighed kappa) | |
|----------------------------------|----------|-----------------------------|----------------------------------|---|---|
| | | | | Problems with communication and/or cognition ($n = 40$) | No problems with communication/cognition ($n = 16$) |
| 1 Burden (2) | 56 | 0.849 | 0.854/0.850 | 0.862 | 0.815 |
| 2 Eating duration and desire (5) | 54 | 0.822 | 0.828/0.817 | 0.811 ^a | 0.856 |
| 3 Dysphagia symptoms (14) | 54 | 0.940 | 0.934/0.941 | 0.960 ^a | 0.779 |
| 4 Food selection (2) | 53 | 0.823 | 0.834/0.818 | 0.836 ^a | 0.804 ^a |
| 5 Communication (2) | 56 | 0.786 | 0.777/0.789 | 0.790 | 0.761 |
| 6 Fear (4) | 53 | 0.675 | 0.715/0.678 | 0.677 ^a | 0.660 ^a |
| 7 Mental health (5) | 55 | 0.898 | 0.877/0.891 | 0.879 | 0.946 ^a |
| 8 Social functioning (5) | 48 | 0.908 | 0.909/0.909 | 0.931 ^a | 0.785 ^a |
| 9 Fatigue and sleep (5) | 55 | 0.713 | 0.710/0.714 | 0.736 | 0.631 ^a |
| Overall score (44) | 48 | 0.953 | 0.951/0.952 | 0.960 ^a | 0.924 ^a |

^a n is smaller than the group size given at the top of each subgroup

30 min in half of the cases. In comparison with previous Swal-Qol studies, with an average fill-out time between 14 and 30 min [11, 13, 15], time to complete our interviews was much longer, mostly due to storytelling. However, the length of the Swal-Qol interview is considered feasible, since the majority of patients did not experience a heavy burden and were satisfied with the time to complete and the attention given by the interviewer.

Caution is needed when comparing our test–retest reliability results with previous studies, since these studies used the self-report version and excluded patients with communicative and cognitive problems. Their population was not limited to stroke, the sample sizes were small ($n < 40$), and most patients were not living in nursing homes. Despite these differences, the results of our test–retest reliability analysis are largely comparable with previous studies.

The absence of recent objective test results to estimate the communicative and/or cognitive problems might have influenced the group composition for the subgroup analysis. Since our population consisted of a group of very frail elderly, it was not considered ethical or practical to use additional standardized tests; instead, the diagnosis was derived from medical records. As group comparisons showed no major differences between feasibility aspects and test–retest reliability, it is not likely that this had a large impact. Moreover, by allowing a group of patients to participate who are usually excluded from research, we believe our data are based upon a more representative group of dysphagic stroke patients than reported thus far.

By tailoring measurement instruments for specific patient groups without compromising the clinimetric properties, data on subjective health status can be collected in a larger and more representative population, which benefits both research and clinical purposes. We think that more specific instruments in different domains can be adapted for use in this specific group of patients.

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