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Dysphagia

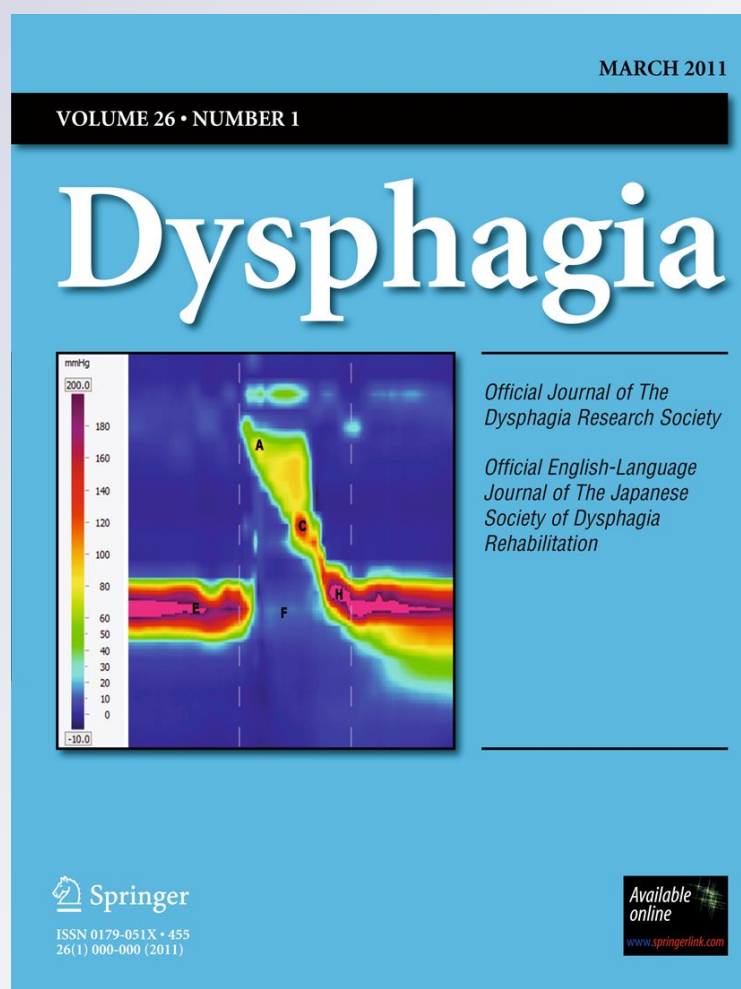
ISSN 0179-051X

Volume 27

Number 1

Dysphagia (2012) 27:46-52

DOI 10.1007/s00455-011-9336-2



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The Dysphagia Handicap Index: Development and Validation

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Received: 19 November 2010 / Accepted: 26 February 2011 / Published online: 20 March 2011
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Abstract Quality-of-life indicators for dysphagia provide invaluable information to the treating clinician regarding the success or failure of swallowing therapy. The purpose of this study was to develop a clinically efficient, statistically robust patient-reported outcomes tool that measures the handicapping effect of dysphagia on emotional, functional, and physical aspects of individual's lives. 60 statements describing the handicapping effect of dysphagia were collected from patient reports and divided into subscales of physical, emotional, and functional problems. The statements were presented to 77 individuals with dysphagia. Respondents replied never, sometimes, or always to each statement and rated their self-perceived dysphagia severity on a 7-point equal-appearing interval scale. Cronbach's α was performed to assess the internal consistency validation of the items within the questionnaire. The final questionnaire was reduced to 25 items and administered to 214 individuals with dysphagia and 74 controls. Test-retest was performed on 63 individuals with dysphagia. Cronbach's α

for the initial and final versions was strong at $r = 0.96$ and $r = 0.94$, respectively. Significant differences occurred between the dysphagia and control groups. Test-retest reliability was strong. We present a new, easy-to-complete, statistically robust, patient-reported outcomes measure for assessing the handicapping effect of dysphagia.

Keywords Dysphagia · Handicap · Quality of life · Patient-reported outcomes · Deglutition · Deglutition disorders

Introduction

It has been reported that dysphagia has a negative affect on all aspects of a person's life, including work, leisure, and social situations [1]. It is widely accepted that videofluorography (VFG) provides the most objective evaluation tool available to assess the oropharyngeal stages of swallowing and that many treatment modalities exist which have proved beneficial to individuals with dysphagia [2–4]. When investigating the effect of dysphagia on an individual's quality of life, most patient-reported outcomes tools are disease-specific. For example, the MD Anderson Dysphagia Inventory [5] was developed to assess quality of life in individuals with head and neck cancer. Carrau et al. [6] developed a tool that focuses upon the disabling effects of laryngopharyngeal reflux. In 1991, Gustafsson and Tibbling [1] created the Dysphagia Goal Handicap (DGH). They administered this questionnaire to 19 individuals with esophageal dysphagia and determined that dysphagia negatively affected work, social, and leisure situations. Dakkak and Bennett [7] created a scoring system for the viscosity and solidity of food eaten and the amount of time it took to complete a meal in 49 individuals with esophageal strictures.

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The SWAL-QOL [8] is an existing and widely used patient-reported outcomes tool that focuses on dysphagia in the general population and also includes general health indicators such as fatigue and sleep patterns. The probe statements in this tool tend to be abstract. The complex wording of the statements and column headings and the many response choices per statement may be difficult for some patients to comprehend. This may create the need for increased clinician cueing to assist an individual completing the SWAL-QOL and may increase the overall clinical time required for patients to complete the tool.

The goal of this study was to develop a patient-reported outcomes (PRO) tool that is clinically efficient, easy for most patient populations to complete, uses concrete statements supplied from patient complaints, and has daily-use practicality to measure the emotional, physical, and functional effects of dysphagia on quality of life in individuals with a variety of medical diagnoses affecting swallowing.

Methods and Data Analysis

Item Reduction

The study authors in the field of speech-language pathology compiled a series of dysphagia complaints made by patients during a 1-month time period. These representative statements of the effect of dysphagia on individuals' lives represented the preliminary, or alpha, version of the Dysphagia Handicap Index (DHI). These statements were 60 in number and used to ensure that the scale had both content and face validity. The 60 statements were sorted into three subscales based on their content. The emotional subscale consisted of 16 statements representing a person's affective response to their dysphagia. Examples of statements on the emotional subscale included the following: "I feel embarrassed to eat in public," "I feel depressed because I can't eat what I want" and "I feel handicapped because of my swallowing problem." There were 27 statements representing a person's self-perception of physical discomfort due to dysphagia. Examples of statements on the physical subscale included "I cough when I drink liquids," "I choke when I take my medication," and "I've lost weight because of my swallowing problem." The functional subscale consisted of 17 statements describing the impact of a person's dysphagia on their daily activities. These included the following statements: "I avoid some foods because of my swallowing problem," "It takes me longer to eat a meal than it used to," and "I've changed my diet due to my swallowing problem." Each probe statement had an accompanying response choice of "never" (a score of zero), "sometimes" (a score of 2) or "always" (a score of 4). Three levels of response were chosen in order to

facilitate patient understanding of response requirements. In order to evaluate an overall picture of the patient's perception of their dysphagia, all subscales were combined to provide an overall total DHI score.

At the completion of the test, subjects were asked to self-rate the severity of their dysphagia on a 7-point equal-appearing interval scale anchored by the number 1 and the word "normal" on one end, the number 7 and the word "severe problem" at the other end and the number 4 in the middle indicating a moderate swallowing problem.

A Cronbach's α coefficient was used to test the internal consistency reliability of the preliminary version of the DHI. The Cronbach's α differentiated how well each item on the test correlated with all of the other items. Items within a scale that have high item-total correlations contribute to the scale's overall reliability and are more representative of scale content than items with low item-total correlations. Nunally [9] suggests that the Cronbach's α coefficient should be at least $r = 0.50$ in order for a single item to demonstrate acceptable internal consistency.

Final Version Validation Scale Reliability

To assess the reliability of the total DHI and the three subscales, Cronbach's α was computed for each score. The test-retest reliability was assessed using Pearson's correlation coefficients and intraclass correlation coefficients.

Features of the Score Distribution and Scale-Scale Correlations

To describe the possible and observed values for each scale, the following statistics were computed: the number of items per scale; the possible range; the observed range; the observed number of distinct levels, the observed mean, median, and standard deviation; and the percent achieving the lowest (floor effect) and highest (ceiling effect) possible scores. Pearson's correlation coefficients were computed to assess the relationships between the three different subscales.

Clinical Validity

Wilcoxon two-sample tests were performed to compare the scores between the dysphagia and control groups. This method was chosen over the two-sample *t*-test because of the unequal variability between the two groups.

Self-reported Severity

Analysis of variance (ANOVA) methods were used to compare the DHI scores among the self-reported severity groups. If an overall difference was observed, post hoc

analyses were done to assess the pairwise comparisons of the severity groups. In addition, Spearman's correlation coefficients were computed to assess the relationship between the DHI scores and the self-reported severity score (measure from 1 to 7).

Clinical Severity

ANOVA methods were also used to compare the scores among the clinical severity groups. Post hoc analyses were also done to assess pairwise group comparisons.

Study Populations

The alpha, or preliminary, version of the DHI was administered to 77 consecutive patients with dysphagia at Henry Ford Hospital. The group consisted of 33 females (age range = 25–89 years, mean age = 60.3 years) and 44 males (age range = 24–94 years, mean age = 62.6 years). The subjects represented a broad range of individuals with swallowing problems from a variety of medical diagnoses such as head and neck cancer, stroke, amyotrophic lateral sclerosis (ALS), Parkinson's disease, esophageal achalasia, gastroesophageal reflux disorder (GERD), and globus. The subjects were grouped into five categories based on their medical diagnoses, including 40 (52%) with neurological disorders, 10 (13%) with head and neck disorders, 6 (7.8%) with esophageal abnormalities, 3 (3.9%) with GERD, and 18 (23.4%) with other or unknown etiology.

The beta, or final, version of the DHI was administered to a new set of 214 consecutive individuals with dysphagia at Henry Ford Hospitals in southeast Michigan. The subjects were grouped into six categories based upon their medical diagnosis, including 76 (35.5%) with head and neck disorders, 72 (33.6%) with neurological impairment, 23 (10.7%) with GERD, 6 (2.8%) with esophageal abnormalities, 9 (4.2%) with respiratory disorders, and 28 (13.1%) with other etiologies such as diabetes, post bariatric surgery, globus sensation, or unknown causes. The group with head and neck disorders included etiologies such as vocal fold paralysis, head and neck cancer, thyroidectomy, or phonosurgery. The group with neurological disorders included etiologies such as stroke, Parkinson's disease, ALS, myasthenia gravis, meningioma, and oculopharyngeal dystrophy. The respiratory disorders group included postintubation, chronic obstructive pulmonary disease (COPD), pneumonia, and other respiratory disorders. The esophageal group included individuals with esophageal achalasia or stenosis and other esophageal abnormalities.

The experimental group consisted of 110 females [age range = 20–92 years, mean age = 60.3 years (SD = 16.5)]

and 104 males [age range = 19–96 years, mean age = 65.5 years (SD = 12.8)].

A 74-member control group was randomly selected from individuals within the community. The control group consisted of adults without dysphagia, history of head and neck cancer, head or neck surgery (with the exception of tonsillectomy), history of neurological problems, or feeding tube placement. The control group consisted of 40 females [age range = 30–86 years, mean age = 55.8 years (SD = 12.9)] and 34 males (age range = 30–80 years, mean age = 53.5 years (SD = 13.7)).

The final version of the DHI was administered on two occasions to 63 individuals with dysphagia (40 females, mean age = 60.3 years, and 23 males, mean age = 65.5 years). These subjects either had scheduled return appointments within the health system, mailed back the DHI 1 week after their initial response, or responded to the DHI statements via a telephone call at least 1 week after completion of their initial DHI. Within this group, 22 (35%) had a diagnosis of head/neck disorder, 26 (41.3%) with a neurological disorder, 7 (11.1%) with GERD, 1 (1.6%) with an esophageal abnormality, and 7 (11.1%) with other diagnoses. During this time the dysphagia group did not undergo any intervening medical or surgical intervention or behavioral treatment for swallowing. The amount of time between administrations of the DHI to the dysphagia group was 7–116 days (mean = 36, SD = 32.2, median = 21).

Results

Preliminary Version Scale Development and Item Reduction

The item total correlations of the initial version of the DHI ranged from $r = 0.03$ to $r = 0.74$, with an overall Cronbach's α coefficient of $r = 0.96$. Items with item total correlations of $r < 0.50$ were eliminated from the preliminary version of the DHI with the exception of four items that were judged by the authors to have high content validity or provided pertinent clinical information. These items were "My mouth is dry," "I need to drink fluids to wash food down," "It takes me longer to eat a meal than it used to," and "I choke when I take my medication." Fourteen items with item total correlation scores of $r > 0.50$ were eliminated as they had similar wording to other selected items. Examples of these items included: "I'm embarrassed to eat in front of my family" and "I'm embarrassed because of my drooling." The final version was subsequently reduced to a 25-item test consisting of a 9-item physical scale, a 7-item emotional scale, and a 9-item functional scale ([Appendix](#)).

Final Version Validation

Scale Reliability

The overall Cronbach's α of the final version of the DHI was 0.94. The Cronbach's α values were also high for the DHI subscales (Table 1). The test–retest reliability for the total score and subscales was found to be strong for the total DHI and for the DHI subscales, with both the Pearson's and the intraclass correlation coefficients ranging from 0.75 to 0.86.

Scale Distributions

Table 2 contains the features of the total DHI and DHI subscales. These features include the number of questions per subscale and the number of distinct values observed. The minimum and maximum possible values for each scale and the observed minimum and maximum values are also represented. The maximum value (ceiling effect) was reached by only two patients in the emotional subscale. Floor effects ranged from 1.4% for the total DHI to 32.7% for the emotional subscale.

Scale–Scale Correlations

The correlation between the subscales was highest between the emotional and functional subscales (Pearson's correlation coefficient = 0.77) and the lowest between the physical and emotional subscales (Pearson's correlation coefficient = 0.66). The correlation between the physical and functional subscales was between these two values (Pearson's correlation coefficient = 0.72).

Control Group Clinical Validity

The control group was compared to the dysphagia group for the total DHI and DHI subscales using Wilcoxon two-sample tests. The control group had significantly lower scores for all scales when compared to the dysphagia group [total $W(74,214) = 3,621, p < 0.001$; physical $W(74,214) = 4,032, p < 0.001$; functional $W(74,214) = 4,926, p < 0.001$; and emotional $W(74,214) = 5,512, p < 0.001$]. In the control group, almost all of the participants responded with a score of zero, or never, on the subscales and viewed themselves as having a normal swallow on the severity rating scale (Table 3).

Self-reported Severity of Dysphagia

The self-reported severity ratings were grouped into four categories using the following definitions: 1 = normal, 2 and 3 = mild, 4 and 5 = moderate, and 6 and 7 = severe. Of the 214 dysphagia patients, 35 (16%) reported no dysphagia (normal), 65 (31%) reported mild, 93 (44%) reported moderate, and 20 (9%) reported severe dysphagia. Self-reported severity was missing for one patient. Mean DHI subscales and total score were computed for the four severity groups (Table 4). The severity group differences were significant for total DHI and all DHI subscales [total $F(3,212) = 87.7, p < 0.001$; physical $F(3,212) = 60.4, p < 0.001$; functional $F(3,212) = 56.7, p < 0.001$; and emotional $F(3,212) = 63.5, p < 0.001$]. Post hoc analyses of the severity groups showed that all pairwise comparisons were significant ($p < 0.05$). Spearman's correlation coefficients were also computed to assess the relationship between the dysphagia group's DHI scores and their

Table 1 Reliability estimates for dysphagia group

| DHI Scale | Cronbach's α | Test–retest | |
|------------|---------------------|-----------------------------------|------------------------------------|
| | | Pearson's correlation coefficient | Intraclass correlation coefficient |
| Total | 0.94 | 0.83 | 0.83 |
| Physical | 0.78 | 0.77 | 0.77 |
| Functional | 0.91 | 0.86 | 0.86 |
| Emotional | 0.86 | 0.75 | 0.75 |

Table 2 Features of scale distributions

| DHI scale | No. items | No. observed levels | Possible range | Observed range | Mean | Median | SD | % Floor | % Ceiling |
|------------|-----------|---------------------|----------------|----------------|------|--------|------|---------|-----------|
| Total | 25 | 30 | 0–100 | 0–96 | 27.3 | 22 | 21.2 | 1.4 | 0 |
| Physical | 9 | 14 | 0–36 | 0–34 | 11.5 | 11 | 6.9 | 2.3 | 0 |
| Functional | 9 | 16 | 0–36 | 0–34 | 10.0 | 8 | 9.8 | 24.8 | 0 |
| Emotional | 7 | 13 | 0–28 | 0–28 | 5.8 | 4 | 6.8 | 32.7 | 2.3 |

Table 3 Comparing dysphagia and control groups

| Subscale | Dysphagia | Controls |
|------------|---------------|-------------|
| Total | 27.33 ± 21.18 | 2.32 ± 2.71 |
| Physical | 11.52 ± 6.86 | 2.11 ± 2.45 |
| Functional | 10.04 ± 9.79 | 0.14 ± 0.51 |
| Emotional | 5.76 ± 6.78 | 0.08 ± 0.40 |

Values are given as mean ± SD

Dysphagia group, $n = 214$

Control group, $n = 74$

judgment of the severity of their swallowing problem. Results indicated a moderate–high relationship between the two measures for the total score, $r = 0.77$, and the subscales as follows: physical, $r = 0.69$; functional, $r = 0.67$; and emotional, $r = 0.68$.

Clinical Severity

In 60 of the 214 dysphagia patients, a videofluorographic (VFG) swallowing study of the oropharynx was performed at the same time that the DHI was administered. Experienced speech-language pathologists who had completed the dysphagia competency program at Henry Ford Hospital and who were unfamiliar with the patients' DHI scores interpreted the VFG swallowing studies. Of the 60, 19 (32%) were evaluated as normal on the VFG swallowing study, 29 (48%) as mild, 4 (7%) as moderate, and 8 (13%) as having severe dysphagia. Because of the small numbers, the moderate and severe patients were grouped together for the following analyses. Mean total DHI and DHI subscales were computed for the three clinical severity groups (Table 5). The overall difference between the clinical severity groups was significant for total DHI [$F(2,59) = 6.23$, $p = 0.003$], functional subscale [$F(2,59) = 7.33$, $p = 0.001$], emotional subscale [$F(2,59) = 5.07$, $p = 0.009$], and physical subscale [$F(2,59) = 3.18$, $p = 0.049$]. Post hoc pairwise group comparisons showed that the moderate–severe group was different from the other two groups for total DHI [normal $t(29) = 2.92$, $p = 0.006$ and mild $t(39) = 3.11$, $p = 0.003$], functional subscale [normal

Table 5 Subscales by clinical severity for dysphagia group

| Subscale | Normal | Mild | Moderate/Severe |
|------------|---------------|---------------|-----------------|
| Total | 24.21 ± 21.26 | 27.72 ± 17.40 | 49.83 ± 27.43 |
| Physical | 10.32 ± 6.16 | 13.03 ± 6.71 | 16.50 ± 7.34 |
| Functional | 7.58 ± 10.10 | 9.52 ± 8.03 | 20.33 ± 11.81 |
| Emotional | 6.32 ± 7.25 | 5.17 ± 5.72 | 13.00 ± 10.25 |

Values are given as mean ± SD

Normal, $n = 19$; mild, $n = 29$; moderate/severe, $n = 12$

$t(29) = 3.21$, $p = 0.003$, and mild $t(39) = 3.41$, $p = 0.001$], and emotional subscale [normal $t(29) = 2.13$, $p = 0.041$ and mild $t(39) = 3.13$, $p = 0.003$]. For the physical subscale, the difference between the moderate–severe and normal groups was significant [$t(29) = 2.53$, $p = 0.017$].

Discussion

The goal of the development of the DHI was to provide an efficient, clinically relevant, statistically robust, patient-reported outcomes tool for dysphagia. Focusing on the patient experience of having a swallowing problem, combined with their medical diagnosis, provides a broad, meaningful picture of the health of an individual and can assist health-care workers in the decision-making process of care. According to The World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF), the term “disability” is an umbrella term for impairment, activity limitations, or participation restrictions [10]. We maintained the use of the term “handicap” in the DHI as that was a consistently reported, self-describing term used by patients when referring to the effect of their dysphagia on quality of life.

The DHI was found to differentiate between controls and individuals with dysphagia, has high internal validity and test–retest reliability, and is sensitive to significant differences in scores based upon the clinical severity of dysphagia.

Table 4 Subscales by self-perceived dysphagia severity for dysphagia group

| Subscale | Normal | Mild | Moderate | Severe |
|------------|-------------|--------------|---------------|---------------|
| Total | 7.89 ± 7.75 | 15.69 ± 9.77 | 34.86 ± 16.02 | 63.20 ± 23.38 |
| Physical | 4.74 ± 3.66 | 8.68 ± 3.80 | 13.85 ± 5.55 | 21.50 ± 7.70 |
| Functional | 2.34 ± 4.27 | 4.58 ± 5.28 | 13.68 ± 8.51 | 24.00 ± 10.68 |
| Emotional | 0.80 ± 2.53 | 2.43 ± 2.90 | 7.33 ± 5.74 | 17.70 ± 8.37 |

Values are given as mean ± SD

Normal, $n = 35$; mild, $n = 65$; moderate, $n = 93$; severe, $n = 20$

The literacy level of the SWAL-QOL and the DHI was analyzed using the SMOG grading reliability formula [11]. The SMOG grade is the reading-grade level that a person must have reached if they are to fully understand the text provided to them. Completion of the SMOG formula revealed that the reading-grade levels for the SWAL-QOL and DHI are tenth grade and eighth grade, respectively. Therefore, the DHI may be more accessible to and promote more accurate responses from individuals with lower literacy levels. According to Doak et al. [12], individuals with lower literacy levels are not easily identifiable by appearance or casual conversation (pp. 1–2). They further explain that low literacy is not equated with low intelligence. Health-care providers have a responsibility to ensure that instructions to patients and assessment tools are easy to understand in order to make our interpretation of results more reliable. The response choices provided in the DHI are limited to only three possibilities to further promote understanding of the instructions and efficiency in a busy clinical setting.

Patient-reported outcomes tools have been used within the communication disorders field for many years to compare patient perceptions of changes in voice [13] and hearing and tinnitus [14–16]. Patient-reported outcomes measures provide a quantitative means of judging whether a difference was made in a patient's life with respect to treatment, and assist in the decision-making process of treatment efficacy [17]. As previously noted, many existing quality-of-life tools focusing on dysphagia exist but are mostly disease-specific. Individuals with a variety of etiologies of dysphagia participated in the current study, thus allowing for wide-spread application of the DHI.

A potential limitation of this study is that most of the patients who participated reported mild or moderate dysphagia and few reported severe symptoms. Administration of the DHI to a larger sample size may provide greater variability of responses for dysphagia severity. Limiting patient responses to three choices, while being conducive to a busy clinical practice, may have also contributed to a reduced variability in patient responses. However, it should be noted that there still appears to be wide variability (large standard deviations) in patient responses which may be a reflection of the diversity of the underlying medical disorders contributing to dysphagia in this patient population.

There are several potential uses of the DHI. The most practical application is daily clinical use to assess a patient's judgment about the relative impact of his or her swallowing problem upon daily activities. The results obtained will help clinicians plan and modify treatment approaches to patient care. Future applications of the DHI also include comparison of an individual's self-perceived dysphagia handicap with a fiber-optic endoscopic examination of swallowing (FEES) procedure [18] or a VFG

swallowing study on a larger group of subjects to further compare and contrast clinical and patient perspectives of dysphagia and its effect on quality-of-life indicators. Clinical and research applications include pre- and post-assessment of changes in a patient's judgment of his or her swallowing handicap for surgical procedures or medical treatments that may impact swallowing capability. It is not unusual in clinical practice to hear opposing perceptions of patient functions between the patients themselves and their family members. One possible offshoot of the DHI is to develop a quality-of-life tool for family members in order to achieve a total picture of the handicapping effects of an individual's dysphagia on themselves, caregivers, and family members.

Conclusions

In summary, we present a psychometrically validated, reliable new tool for assessing the psychosocial handicapping effects of dysphagia. The DHI has general application to a wide variety of individuals with swallowing disorders, may be used with individuals with lower literacy levels, and can be used in clinical and research settings alike. Well-established physiological measures of dysphagia are routinely used in clinical practice. The addition of a quantitative measure of patient self-assessment of dysphagia will strengthen our clinical impressions and provide an objective means of determining the effectiveness and efficiency of dysphagia treatment.

Acknowledgment The authors gratefully acknowledge the staff of the Division of Speech-Language Sciences and Disorders, Department of Neurology, Henry Ford Hospitals and Health Network for their assistance in data collection for this study.

Appendix: Dysphagia Handicap Index (DHI)

Please place a check in the box that describes your swallowing difficulty.

| | Never | Sometimes | Always |
|--|-------|-----------|--------|
| 1P. I cough when I drink liquids. | | | |
| 2P. I cough when I eat solid food. | | | |
| 3P. My mouth is dry. | | | |
| 4P. I need to drink fluids to wash food down. | | | |
| 5P. I've lost weight because of my swallowing problem. | | | |

Appendix continued

| | Never | Sometimes | Always | | | | |
|---|--------|-----------|------------------|---|---|----------------|---|
| 1F. I avoid some foods because of my swallowing problem. | | | | | | | |
| 2F. I have changed the way I swallow to make it easier to eat. | | | | | | | |
| 1E. I'm embarrassed to eat in public. | | | | | | | |
| 3F. It takes me longer to eat a meal than it used to. | | | | | | | |
| 4F. I eat smaller meals more often due to my swallowing problem. | | | | | | | |
| 6P. I have to swallow again before food will go down. | | | | | | | |
| 2E. I feel depressed because I can't eat what I want. | | | | | | | |
| 3E. I don't enjoy eating as much as I used to. | | | | | | | |
| 5F. I don't socialize as much due to my swallowing problem. | | | | | | | |
| 6F. I avoid eating because of my swallowing problem. | | | | | | | |
| 7F. I eat less because of my swallowing problem. | | | | | | | |
| 4E. I am nervous because of my swallowing problem. | | | | | | | |
| 5E. I feel handicapped because of my swallowing problem. | | | | | | | |
| 6E. I get angry at myself because of my swallowing problem. | | | | | | | |
| 7P. I choke when I take my medication. | | | | | | | |
| 7E. I'm afraid that I'll choke and stop breathing because of my swallowing problem. | | | | | | | |
| 8F. I must eat another way (e.g., feeding tube) because of my swallowing problem. | | | | | | | |
| 9F. I've changed my diet due to my swallowing problem. | | | | | | | |
| 8P. I feel a strangling sensation when I swallow. | | | | | | | |
| 9P. I cough up food after I swallow. | | | | | | | |
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | Normal | | Moderate Problem | | | Severe Problem | |

Please circle the number that matches the severity of your swallowing difficulty (1 = no difficulty at all; 4 = somewhat of a problem; 7 = the worse problem you could have)

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