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ORIGINAL ARTICLE

Defining dysphagia – a modified multi-professional Danish Delphi study

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ABSTRACT

Objective: To establish a generally accepted Danish definition of dysphagia to enhance collaboration across sectors and professions.

Methods: The study was initiated by a multi-professional group of experienced researchers and board members of the Danish Society for Dysphagia. We used a modified Delphi methodology to achieve consensus among experienced health care professionals from different professions and contexts. The initial stage consisted of a literature search leading to the draft of different definitions followed by two Delphi rounds between professionals and a stakeholder consultation round.

Results: We conducted two Delphi rounds until one definition was clearly preferred. A total of 194 participants responded in round one, and 279 in round two. Both rounds had a broad representation of sectors and geography and most participants had worked with dysphagia for more than four years.

Conclusion: The preferred definition was 'Dysphagia is a functional impairment that either prevents or limits the intake of food and fluids, and which makes swallowing unsafe, inefficient, uncomfortable or affects quality of life'. The definition was widely accepted among different health professional groups, patients and across sectors.

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Chewing disorder; deglutition; Delphi Study; dysphagia; mastication; swallowing disorder

Introduction

Dysphagia is a common symptom in many patients and elderly with a prevalence ranging from <5% in healthy individuals [1] to 50–87% in geriatric patients and nursing home residents [2,3]. The word dysphagia comes from Greek: dys- = difficulty and fagi = eating, and dysphagia is often referred to as difficulty in swallowing [4] but there is no clear definition of dysphagia. In the previous mentioned papers, definition of dysphagia ranged from self-reported answer to the question 'In the last year, how often have you had difficulty swallowing' to performing screening tests for dysphagia. Dysphagia has significant consequences for both the individual, and for society. Individuals experiencing dysphagia are at risk of e.g. malnutrition, social isolation, reduced quality of life, aspiration pneumonia and death leading to several contacts with both the healthcare system, and municipal healthcare each year [4,5]. The complexity of dysphagia, which has many different expressions, causes and consequences, combined with poor communication and misunderstandings among health professionals may negatively affect the individual's likelihood of receiving the appropriate assessments and treatments [4,5]. For example, if an elderly otherwise healthy individual adjusts intake of food and water based on a functional decline, disagreements or unawareness whether this is dysphagia may prolong the referral to appropriate assessment and treatment. A national standardized definition of dysphagia will allow for a common language and understanding of dysphagia among health professionals, care providers and researchers which is pivotal to facilitate and improve quality of care and patient safety.

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The aim of this study was to establish a generally accepted Danish definition of dysphagia for application across different specialties, sectors and professions working with dysphagia to enhance the collaboration between sectors and professions.

Methods

In this study we used a modified Delphi methodology [6–9] to achieve consensus among experienced health care professionals from different professions and contexts. The study was initiated by a multi-professional group of experienced researchers and board members of the Danish Society for Dysphagia and was led by a work group of four authors (SJE, JD, HM, and DM). A Danish protocol for the process was drafted a priori and can be retrieved upon request.

The modified Delphi process

A multi-professional panel of experts advised the work group throughout the Delphi process [6,8–10]. Members of the expert panel were identified by the board of the Danish Society of Dysphagia. In addition to the use of snowball recruitment to achieve maximum variation in professions and medical fields, members of the expert panel suggested additional members for the expert panel e.g. if a relevant expert in an area was not already represented. The final expert panel consisted of six physicians, a dietitian, a nurse, three occupational therapists, a physical therapist and a speech therapist. The expert panel represented a broad range of specialities (intensive care, oto-rhino-laryngology, gastroenterology, neurology, oncology, geriatrics, paediatrics) and sectors (universities, university hospitals, regional hospitals, general practice and municipal healthcare).

Literature search

The initial stage consisted of a literature search for definitions of dysphagia in the electronic bibliographic databases: PubMed, Embase, Cochrane Library. Selected key words were: 'dysphagia'; 'deglutition disorder'; 'swallowing disorder'; 'mastication'; 'chewing disorder'; and 'definition'; 'define'; 'defines'; 'defined'. The search was limited to records in English, German, Danish, Norwegian, or Swedish. A total of 104 records were identified and imported into Covidence, which is an electronic tool supporting the workflow of screening, and independently assessing papers for inclusion. All records were in English, German or Danish.

Four authors (SJE, JD, HM, and DM) independently screened title and abstracts of all retrieved citations for eligibility, all citations were screened by two authors. Eligibility was based on whether the paper had a delimitation of dysphagia, even if vague. Disagreements were solved through discussion until consensus was reached. Subsequently, eight eligible articles were reviewed in full-text [11–18]. No limits for year of publication were set, and as only eight articles were identified, they were all included for further review. All full-text articles were discussed in the work group until consensus was achieved. None of the articles contained an exact definition of dysphagia. In addition to the retrieved literature, definitions from the International Classification of Disease (ICD-10), World Health Organization (WHO) and European Society for Swallowing Disorders (ESSD) white paper in Geriatrics [19] were included. All articles and definitions were presented in a consensus meeting aimed at drafting proposals for the Danish definition of dysphagia by the work group.

In the first meeting, the expert panel was presented with the drafts of seven definitions from the working group and these were discussed in depth and subsequently refined.

The two survey rounds

For the first round, a survey consisting of the seven definitions (Table 1) was set up in the Research Electronic Data Capture system (REDCap) [20]. In the survey, participants were asked to rate each definition on a visual analogue scale (VAS) from 0 (not suitable) to 100 (perfect) and to point out key words contained in that definition. Participants were encouraged to propose changes to the initial proposed definitions. No level of consensus was specified a priori.

Before distribution, the functionality of the survey was piloted by the members of the expert panel. The first round was distributed by e-mail to all members of the Danish Society for Dysphagia on 8 June 2021. Members were encouraged to forward the survey through other relevant channels, networks, forums, work place and colleagues. The survey was also shared on social media and on the webpage of the society. A reminder to respond to the survey was issued after 45 days; the survey was closed on 9 October 2021.

The expert panel reviewed and discussed findings from round one of the survey and planned round two of the survey. All comments on aspects of the definitions were discussed and considered, this resulted in minor refinements that were made for round two. On 13 October 2021 a second survey containing the four highest ranking definitions were distributed to the participants who responded to the first round via e-mail and all members of the Danish Society for Dysphagia, as well as other identified relevant forums and members were encouraged to distribute the survey throughout their network. As a result of the skewness of professions responding to the survey in round one, special attention was paid to elicit responses from a broader range of professionals. After round two, the expert panel identified the definition, which consistently ranked highest among all professionals across both rounds as the final definition.

Analysis of data from round 1 and 2 was led by JRJ, who was not a board member of the Danish Society for Dysphagia. Prior to publication, all proposed definitions were translated into English by SJE and AHN and back-translated to Danish by a Danish speech language therapist residing in the United Kingdom and compared for accuracy. Original Danish definitions are available as online supplement (Supplementary Table 1).

Table 1. Definitions of dysphagia.

Definition 1: Dysphagia is understood as a problem with or disturbances of functions that is necessary for transporting food and drinks from the oral cavity through the pharynx and esophagus to the stomach with appropriate frequency and speed.
Definition 2: Dysfunction that prevents processing and efficient and safe swallowing of saliva, food and liquid from the oral cavity to the stomach.
Definition 3: Dysphagia is characterized by difficulty with swallowing saliva, food and drinks.
Definition 4 (final definition): Dysphagia is a functional impairment that either prevents or limits the intake of food and fluids, and which makes swallowing unsafe, inefficient, uncomfortable or affects quality of life.
Definition 5: Dysphagia is an experience of problems with eating and drinking to the extent or in a way that is unsatisfactory and/or affects quality of life.
Definition 6: Dysphagia is a disturbance of the ability to swallow one's saliva, eat and drink safely, efficiently and with well-being.
Definition 7: Dysphagia is a problem with or disturbances of functions, which is necessary for bringing food and drinks from the oral cavity through the pharynx and esophagus to the stomach with appropriate frequency and speed and which is identified either by objective assessment or the patient's subjective experience.

Patient and public involvement

A final stakeholder round was attempted to capture patients' perceptions of the final definition. A total of 10 patient organizations and patient networks were contacted for identification of patient representatives willing to participate in the stakeholder round. A short electronic questionnaire was issued to patients by e-mail asking them to reflect on the suitability of the final definition.

Ethical considerations

Participation in the Delphi study was voluntary. All data were anonymised before being shared with the expert panel. Patients received written information about the study and gave written consent to participation before completing the questionnaire of the stakeholder round. Patients were allowed to save a copy of their responses and withdraw their data afterwards if so desired although no one chose to. The study was conducted in accordance with the Helsinki Declaration [21] and reported using the CREDES guideline for reporting Delphi studies [22].

Results

A total of 194 participants responded in round one and 279 in round two. A wide range of different health care professions were represented, though most participants were occupational therapists (Table 2). This probably reflects that in Denmark health care occupational therapists are the main profession in diagnosing and rehabilitating patients with dysphagia. Nurses were not well-represented in round one and special efforts were made to recruit nurses for round two. Both rounds had a broad representation of sectors and geography and most participants had worked with patients with dysphagia for more than four years (Table 2).

Table 2. Characteristics of respondents.

Respondent characteristics	Round 1 $N = 194$	Round 2 $N = 279$
Profession		
Dietitian	30 (15.5%)	42 (15.1%)
Occupational therapist	114 (58.8%)	116 (41.6%)
Physical therapist	8 (4.1%)	10 (3.6%)
Physician	19 (9.8%)	24 (8.6%)
Residential social worker	9 (4.6%)	0 (0.0%)
Nurse	1 (0.5%)	67 (24.0%)
Other health professions	13 (6.7%)	20 (7.2%)
Primary workplace		
Hospital	77 (39.7%)	142 (50.9%)
Municipal health care	92 (47.4%)	114 (40.9%)
Private practice	12 (6.2%)	9 (3.2%)
Other	13 (6.7%)	14 (5.0%)
Region		
Capital Region of Denmark	47 (24.2%)	67 (24.0%)
Central Denmark Region	55 (28.4%)	93 (33.3%)
North Denmark Region	18 (9.3%)	14 (5.0%)
Region Zealand	26 (13.4%)	39 (14.0%)
Region of Southern Denmark	47 (24.2%)	65 (23.3%)
Outside of Denmark	1 (0.5%)	1 (0.4%)
Years of experience with dysphagia management		
<0.5 years	9 (4.6%)	8 (2.9%)
$0.5-2$ years	26 (13.4%)	41 (14.7%)
2–4 years	22 (11.3%)	30 (10.8%)
4–6 years	31 (16.0%)	28 (10.0%)
6–8 years	15 (7.7%)	26 (9.3%)
>8 years	91 (46.9%)	146 (52.3%)

Results of round one

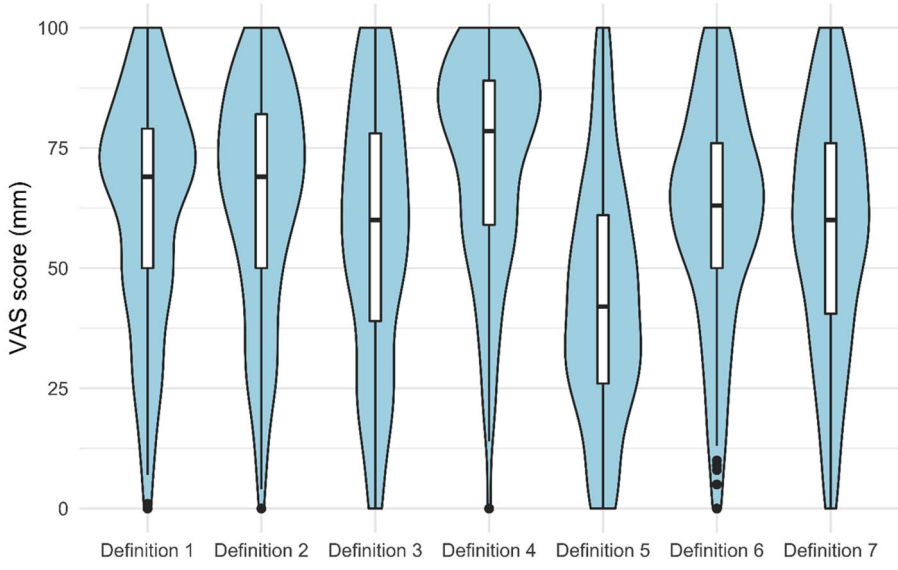
Figure 1 shows the distribution of rating for each of the seven definitions in round one as boxplots with surrounding violin plots (blue area). Six of the seven definitions received a median score above 50 mm on the VAS (except definition 5) (Figure 1). For an overview of definitions, see Table 1. Definition four received the highest rating in round one. Most professions favored definition four, however physicians favored definition three (Figure 2).

There was no systematic pattern in free text comments and selections of keywords that gave rise to changes in the definitions. The expert panel decided that a second round was required, as there was no definition clearly outperforming any of the others. The four best performing definitions (1–4) were retained for round two. Definitions one, two, and four were chosen due to their overall score, while definition three was chosen as it was the most favored definition among physicians.

Results of round two

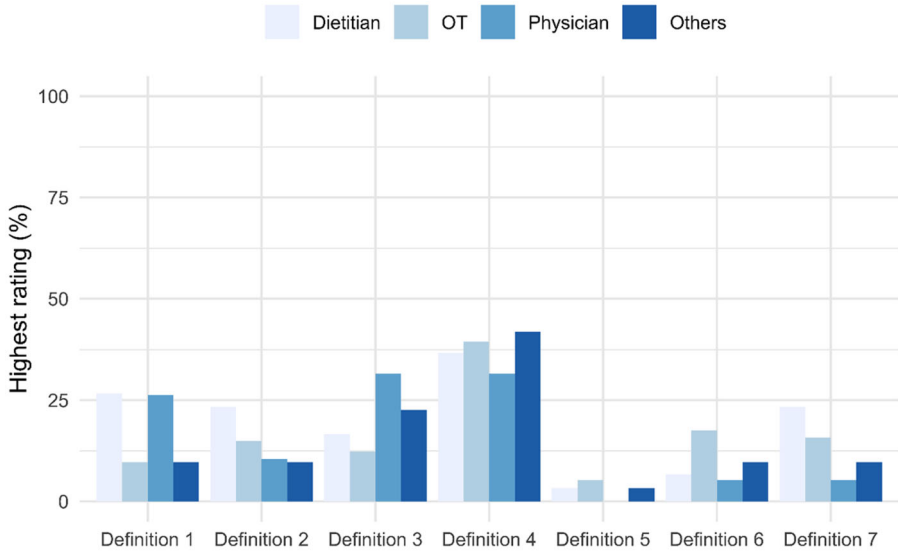
More participants favored definition four as the best definition in round two (46%) (Figure 3) and the median VAS score for this definition was 82 (interquartile range 62–93). All professions favored definition four in round two (data not shown).

The consensus committee decided that there was no need for a third round as definition four (Table 1) was unanimously favored across and between professions in both rounds. Furthermore, there were no systematic pattern in free text comments that gave rise to changes in the definitions or repeated rounds in the Delphi procedure.



VAS Visual analogue scale.

Figure 1. Distribution of rating for each of the seven definitions in round one. VAS: Visual Analogue Scale.



OT: occupational therapist.

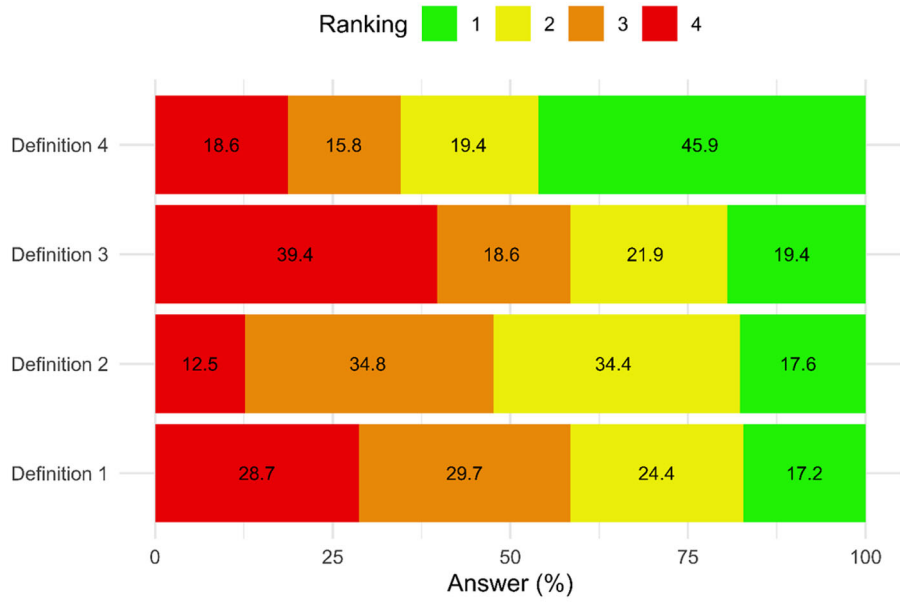
Figure 2. Highest rated definition in round one according to profession. OT: occupational therapist.

Only three patients and two health care professionals from 10 patient organizations replied to the short survey. Most of them found the definition to adequately cover their perception of dysphagia although one patient found it difficult to relate to the question as the patient had not yet experienced problems related to swallowing.

Discussion

In this Delphi study, 279 health care professionals favored the definition in which *dysphagia was a functional impairment that either prevents or limits the intake of food and fluids, and which makes swallowing unsafe, inefficient, uncomfortable or affects quality of life*. This definition omits etiologies of dysphagia and focuses primarily on symptoms and experience of dysphagia. Although, in the first round, physicians favored the simplest definition most similar to the ICD-10 diagnostic criteria for unspecified dysphagia, they accepted the broader definition brought by the multi-professional approach in round 2.

As swallowing is a complex process, there are many causes of dysphagia. Reasons for developing dysphagia may depend on the patient's medical history, general constitution and precipitating factors. Within geriatrics, dysphagia is considered a part of the geriatric syndrome, which is closely linked to a functional decline [19]. In other words, development of dysphagia may be related to growing old and frail. Within oncology, dysphagia may be related to the cancer, surgery, chemo-radiation therapy of head and neck, or esophagus. In this case, dysphagia may be related to altered



1 = highest ranking, 4 = lowest ranking.

Figure 3. All participants' ranking of definitions in round two. 1 = highest ranking; 4 = lowest ranking.

anatomical structures or/and xerostomia [23,24], whereas development of dysphagia in patients suffering from stroke or Parkinson's disease is primarily neurological [25]. As such, reasons for developing dysphagia are multiple and diverse and it may be impossible to include a comprehensive list of reasons for dysphagia for a generally accepted definition of dysphagia. Leslie and Smithard [26] addressed this gap between a broad, general definitions of dysphagia and more specific definitions targeting dysphagia of particular etiologies in an online, cross-sectional survey of self-reported dysphagia. Leslie and Smithard [26] used a 10 items questionnaire (EAT-10) to estimate dysphagia, and found a discrepancy between participants' EAT-10 scores suggesting dysphagia and participants stating in free text that they did not experience swallowing problems. According to Leslie and Smithard [26] this may suggest that dysphagia is either under-diagnosed or that normal swallowing is more varied than previously assumed. This shows that since dysphagia is both complex and subtle, there is a need for a clear comprehensive definition of dysphagia but also clearly delineated subtypes of dysphagia to support research purposes [26].

The definition from this study, however, clearly puts experience of dysphagia at the center, which is supported by responses from the involved patient organizations. Moreover, focusing on the clinical presentation of dysphagia could establish some common ground between health care professionals from different professions, specialties and across sectors. A review by Donovan et al. [27] on interprofessional care and teamwork in the intensive care unit distinguishes between (1) multi-professional care where different professional groups work alongside to care for the patient and (2) inter-professional care, where a higher level of integration between the activities of each professional group is established. According to Donovan, inter-professional care is guided by mutual goals for the patient and appreciation for how each team member may contribute to help the patient [27]. Also Hall [28] describes how collaboration between health professionals can provide a positive synergistic influence on patient care when team members are prepared to share skills and acknowledge the contribution from other groups. However, history of professional cultures have often had a hierarchical structure that has limited collaboration between professional groups [28]. On this background, a structured consensus process such as the Delphi process among different healthcare professions, may provide a common ground for discussing dysphagia and for working towards better and more coordinated approaches to provide care for patients with dysphagia across sectors and professions.

Strengths and limitations

A majority of participants in this study were occupational therapists, which reflects clinical practice in Denmark. For the second round a variation and more equal distribution of professions was prioritized, however this limited new participants' opportunity to reflect on previous positions. The first round of the Delphi study did not elicit any responses that could have prompted other definitions or refined phrasings of the definitions and therefore, focus came to be on agreement among participants. However, the chosen definition was supported equally in different professional groups. An *a priori* limit on agreement or preferability of definitions could have been set, however the method of discussion and subsequent consensus in the expert panel was chosen to provide opportunity for analysis beyond a pre-set cut off percentage.

Conclusion

The Delphi study resulted in a Danish definition of dysphagia which translated to English *was* 'A functional impairment

that either prevents or limits the intake of food and fluids, and which makes swallowing unsafe, inefficient, uncomfortable or affects quality of life'. The definition was widely accepted among patients and Danish health professionals from all sectors, and it may be useful when developing multi-professional guidelines or pathways across sectors for patients with dysphagia. For research purposes, more clearly defined subtypes of dysphagia may be necessary to discriminate between subtle symptoms of dysphagia and their causes.

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Ethical approval

Ethical approval for the study was not sought as Danish law does not require ethical approval for questionnaire studies, nor give the option for this.

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