Dysphagia
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ORIGINAL ARTICLE

European Survey: Dysphagia Management in Patients with Neuromuscular Diseases

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Abstract

Dysphagia is common in patients with neuromuscular diseases (NMDs). Its management differs by country and clinical setting. The purpose of this study was to describe current practices in the management of dysphagia in NMDs across Europe. An online survey of sixteen questions was developed, including basic information on facilities, existence of a management protocol, availability of dedicated therapists, tools used during screening, assessment, treatment stages, and treatment strategies. The survey was rolled out to European healthcare facilities providing care for NMDs. A total of 140 facilities across 25 European countries completed the survey. Substantial discrepancies in dysphagia management were identified among respondents. Seventy-two percent of the facilities reported having a protocol for at least one of the three management stages whereas only 39% had one for all. Speech and language therapists were reported as involved throughout the entire management stage while participation of other members from multidisciplinary teams varied depending on the stage. Clinical swallowing assessment was the most frequently reported tool in the assessment and treatment stages. For screening, questionnaires were the most frequently used while instrumental examinations were mainly reported in the assessment stage. For the treatment stage, adaptation strategies (diet, food, and posture) were the most reported approaches. In conclusion, the survey highlighted the absence of a defined protocol concerning the management of dysphagia in most of the surveyed healthcare facilities. Standardized training strategies and guidelines are necessary in the future to familiarize clinicians with each stage of the management of dysphagia.

Keywords Dysphagia · Neuromuscular diseases · Survey · Deglutition · Swallowing disorders

Introduction

Swallowing impairments, also called dysphagia, are common in patients with neuromuscular diseases (NMDs) [1–3]. NMDs represent a heterogeneous group of approximately 500 pathologies [4]. The hallmark of those diseases is the impairment of a component of the neuromuscular system, which includes the motor neuron, the neuromuscular junction, and the muscle itself [1, 5, 6]. NMDs vary in terms of pattern of inheritance, genetic mutation, incidence, symptoms, age at onset, rate of progression, and prognosis [1, 5, 7]. These can be rapidly progressing adult diseases such as amyotrophic lateral sclerosis (ALS) as well as more slowly progressive or stable conditions that are present in childhood such as muscular dystrophies [8]. The prevalence of dysphagia in NMDs varies from 34 to 80% [3, 9–12]. However, dysphagia is probably underestimated, especially in children [13–16]. Dysphagia can appear early in the course

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of these diseases and may lead to complications such as malnutrition, dehydration, aspiration pneumonia or difficulty in managing secretions [1, 2, 17]. It may also have social and psychological consequences, with a negative impact on the patient's quality of life (QoL) [18, 19]. To minimize related complications, proper management is essential. This involves early detection and referral to appropriate clinical follow-up [1, 19–21]. While recommendations for clinicians involved in the management of dysphagia in NMDs are not numerous, the European Society for Swallowing Disorders (ESSD) provides a consensus on best practice in the management of dysphagia in its statements [1, 9, 16, 22, 23]. They specify that (1) reliable, feasible and validated tools must be used to measure, screen, assess, diagnose and treat dysphagia; (2) dysphagia should be managed by multidisciplinary teams; (3) healthcare practitioners involved in dysphagia should have specific training, good knowledge and experience; and (4) the World Health Organization (WHO) International Code of Diseases and International Classification of Functioning, Disability and Health for dysphagia must be included in the medical report of every patient [23].

A survey was developed to better understand current practices in the evaluation and management of swallowing disorders in patients with NMDs in Europe. As it has been observed in other parts of the world for patients with dysphagia, we hypothesized that practices vary considerably according to clinicians, healthcare facilities, regions, healthcare habits and culture in Europe [24–26]. The information collected will provide a comprehensive view, a benchmark of European practice patterns and guidance for the future direction of dysphagia literature and clinical practice in Europe.

Materials and Methods

Survey Development

The Checklist for Reporting Results of Internet E-Surveys (CHERRIES) was followed during the different stages of the study design [27]. Based on a literature overview including two systematic reviews and the results of the "ESSD World Swallowing Day Survey on screening for dysphagia", a multidisciplinary expert committee developed a 16-question survey (Supplement 1) [16, 22, 28].

The first set of questions focused on the size and type of healthcare facility, team members, and number of NMD patients followed in the responding institution [28]. The next questions concerned the different areas of dysphagia management in the surveyed facilities, i.e., the existence of a management protocol, availability of dedicated therapists, tools or questionnaires used to evaluate swallowing function (during screening, assessment and treatment stages), and therapeutic options proposed. The last two questions were related to the desire to improve management of dysphagia and potential obstacles to this improvement. Each question needed to be answered before moving on to the next one and completing the survey. An initial French version of the survey was translated by perfectly bilingual people into English, German, Spanish, Italian and Dutch following the Translation, Review, Adjudication, Pretesting and Documentation (TRAPD) model [29].

Participants

Recruitment of the participating facilities took place in the fifty European countries defined by the European Union and the United Nations [30, 31]. Inclusion criteria was to be a healthcare facility providing pediatric and/or adult care for NMD patients. We first made an extensive Internet search of all European centers caring for NMD patients and of local, national, and European associations dedicated to NMD patients. Then, we established an exhaustive list of all centers and hospital units caring for NMDs in Europe and we searched for the personal email of each center or referent therapist. The searches identified 974 email addresses. Sixty-four of these were invalid. A final sample of 910 professionals received an invitation by email to complete the survey (professionals who did not respond were contacted twice). The email included a cover letter from the principal investigator explaining the purpose and the rationale behind the study and a link to the different language versions of the survey. Participants were advised that all data would remain anonymous, kept confidential and stored safely. Consent was implied by the respondents' decision to return the completed survey. Respondents did not receive any compensation for their participation.

Data Collection

The survey was disseminated as an online Google form (Google LLC, USA) between 1 March 2019 and 1 January 2020. Each participant was asked to identify the name of the facility and the team leader**,** to be able to identify duplicates. Multiple answers from the same facility were permitted if they came from different teams/units within the same facility, thereby constituting different answers. In addition, the survey was shared via professional networks and social media (Facebook, Twitter, and LinkedIn).

Data Interpretation and Analysis

Survey responses were downloaded from the Google forms interface. Data were analyzed using IBM SPSS 27 for Windows and Microsoft Excel 2011. Descriptive statistics (counts and percentages) were used to report findings. The

Chi-square test or Fisher's exact test, where appropriate, was used to test associations between categorical variables. A p value lower than 0.05 was considered significant.

Results

A total of 153 individual responses were collected. Twelve responses were eliminated as they were duplicates and another one because the respondent did not meet the inclusion criteria. Responses from 140 healthcare facilities across 25 European countries were included in the final analysis (Fig. 1). The overall penetration rate (number of answers collected/number of emails sent) was 17%. The most represented countries were France (37), the UK (21), Italy (12), Switzerland (9) and Belgium (9). Table 1 reports the characteristics of the included facilities. The respondents were doctors, physiotherapists, speech and language pathologists (SLP), nurses, or coordinators part of specialized units or teams in NMDs in a hospital/clinic (69%). Others were part of NMD rehabilitation centers and non-specialized units in a hospital/clinic. Eighty-six facilities cared specifically for adult patients, 26 for pediatric patients and 28 for both adults and children.

Table 1 Characteristics of the included healthcare facilities ($n=140$)

	%
Type of healthcare facilities	
NMD specialized team/unit in a hospital/clinic	69.3
NMD rehabilitation center	10.7
Non specialized unit	20.0
Number of patients followed	
0–50 patients	22.9
50–100 patients	13.6
100–500 patients	33.6
500–1000 patients	12.1
> 1000 patients	17.9
Type of patients followed	
Adult patients	61.4
Pediatric patients	18.6
Adult & pediatric patients	20.0

NMD Neuromuscular diseases

Seventy-two percent of the facilities reported having a protocol for at least one of the three stages of the management of dysphagia (screening, assessment and treatment). However, only 39% had one for each of the three stages. The results regarding the therapists reported as involved or the tools used are presented in Table 2 and Table 3, respectively. No association was found between the presence of a management protocol and the type of

Fig. 1 Number of responses across European countries

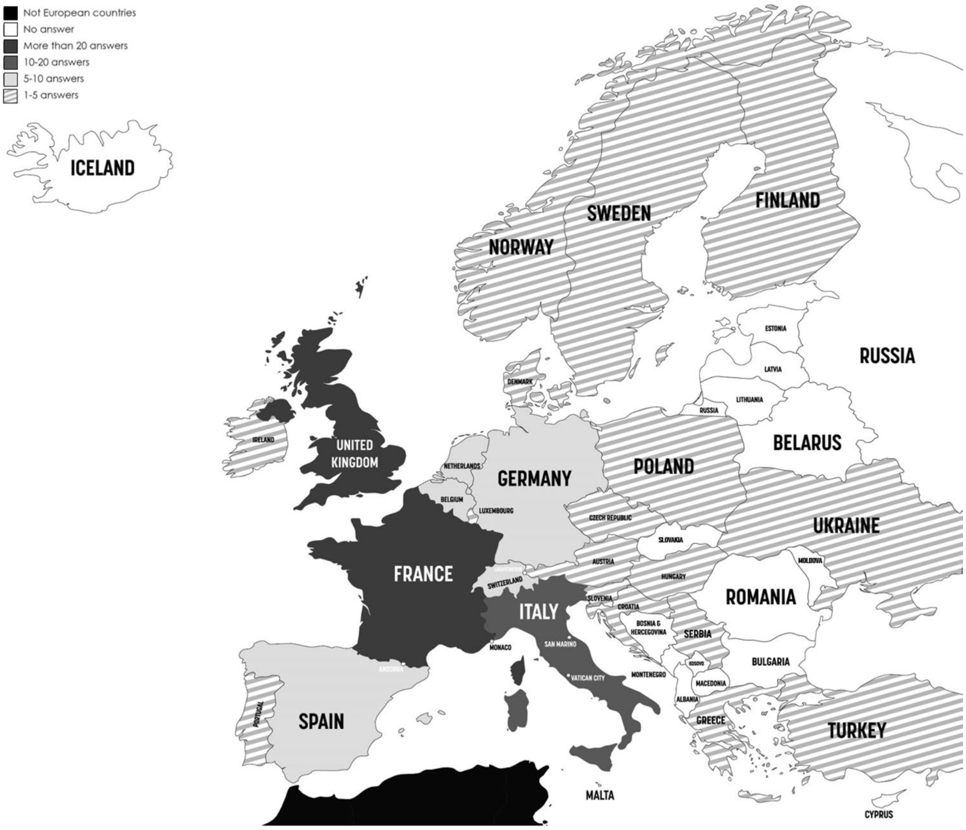

Table 2 Health professionals reported as involved in the management of dysphagia for NMD patients

	Screening (%)	Assessment (%)	Treatment (%)	All stages (%)	Not available (%)
Protocols for dysphagia management	56.4	60.7	49.3	39.3	30.0
Professionals involved					
Dietitian	45.7	60.7	63.6	28.6	15.0
ENT specialist	28.6	65.0	43.6	15.0	22.1
Gastroenterologist	25.7	47.1	32.1	10.0	27.9
General practitioner	16.4	5.7	7.1	2.9	78.6
Neurologist	67.1	63.6	47.9	36.4	13.6
Nurse	60.0	54.3	48.6	25.7	12.9
Occupational therapist	37.9	44.3	48.6	22.1	31.4
Pediatrician	35.0	30.0	27.9	16.4	53.6
Physiotherapist	50.0	57.9	60.7	23.6	10.0
Pulmonologist	43.6	56.4	43.6	21.4	20.7
Radiologist	30.0	52.9	16.4	7.1	31.4
SLP	53.6	77.1	75.7	45.7	12.1

ENT Ear, Nose and Throat, *SLP* Speech and language pathologist

Table 3 Tools used in the management of dysphagia for NMD patients

	Screening (%)	Assessment (%)	Treatment (%)	Not used (%)
Auscultation	14.3	22.9	6.4	71.4
CSE	50.7	70.0	23.6	20.7
Scales	40.7	46.4	10.7	36.6
FEES	20.7	62.1	6.4	32.1
Manometry	9.3	19.3	3.6	75.0
MTP	5.7	7.9	3.6	90.0
Questionnaire	58.6	52.1	15.7	22.9
sEMG	8.6	13.6	3.6	80.0
Functional test	38.6	55.0	19.3	33.6
Ultrasound	7.1	10.7	2.9	85.0
VFSS	20.7	61.4	6.4	29.3
3oST	33.6	32.1	5.7	50.7

CSE Clinical Swallowing Evaluation, *FEES* Fiberoptic endoscopic evaluation of swallowing, *MTP* Maximum tongue pressure measurement, *sEMG* Surface electromyography, *VFSS* Videofluoroscopic swallowing study, *3ost* 3-oz water swallow test

facility ($p = 0.816$), the number of patients ($p = 0.294$) or the type of patients followed ($p = 0.089$). The use of the fiberoptic endoscopic evaluation of swallowing (FEES), auscultation, or questionnaires in the management of dysphagia was associated with the type of patient followed ($p < 0.01$). The use of the Clinical Swallowing Evaluation (CSE) and auscultation were also associated with the type of facility ($p < 0.01$). This association was not observed for the other tools ($p > 0.05$) (Supplement 2).

Screening

Seventy-nine respondents (56%) reported having a specific protocol for screening. The most common tools identified in this stage were questionnaires (59%), CSE (51%) and scales (41%) (Table 3). Only few used often, regularly, or systematically the questionnaires suggested in the survey (Table 4). The Eating Assessment Tool (EAT-10), the SWAL-QOL and the Sydney Swallow Questionnaire (SSQ) were the most

Table 4 Frequencies of questionnaire use in the management of dysphagia for NMD patients

	Never (%)	Rarely (%)	Often (%)	Systematically (%)
EAT-10	67.9	12.9	13.6	5.7
MDADI	85.7	9.3	2.1	2.9
MDQ	81.4	12.1	5.0	1.4
SSQ	79.3	12.1	4.3	4.3
SWAL-QOL	72.1	18.6	4.3	5.0

EAT-10 The Eating Assessment Tool, *MDADI* M. D. Anderson Dysphagia Inventory, *MDQ* Mayo Dysphagia Questionnaire, *SSQ* Sydney Swallow Questionnaire

frequently used with 32%, 28% and 21%, respectively. Neurologists and nurses were the most reported as involved in the screening of dysphagia with 67% and 60%, respectively. Dedicated SLPs and physiotherapists were present in half of the facilities and were associated with increased use of CSE and questionnaire ($p < 0.05$). Our results showed a statistically significant positive association between the presence of specialists and the use of techniques such as neurologist with 3-oz water swallow test (3oST) for screening ($p < 0.01$), pediatrician with manometry ($p < 0.01$) and pulmonologist with FEES ($p < 0.05$).

Assessment

A dedicated protocol for the assessment of dysphagia was present in 85 facilities (61%). The tools cited were CSE (70%), FEES (62%) and videofluoroscopic swallowing study (VFSS) (61%). The most frequently reported professionals as involved in the assessment were SLPs, Ear, Nose and Throat (ENT) specialists, neurologists and dietitians (Table 2). The use of VFSS was associated with the presence of ENT specialists ($p < 0.01$), gastroenterologists ($p < 0.01$) and dietitians ($p < 0.001$) during the assessment. Similarly, the reported involvement of gastroenterologists and ENT specialists was associated with manometry ($p = 0.001$ and $p < 0.01$, respectively). The facilities that included SLPs and dietitians used more frequently the CSE during the assessment ($p < 0.001$).

Treatment

While 125 of the respondents (89%) offered a treatment option in cases of dysphagia, only half of them declared having a specific protocol for treatment. Of the ones that proposed treatment options, an overwhelming majority (88%) offered at least five of the options proposed in the survey. The adaptation of food consistency (95%), diet modifications (89%) and positioning adaptations (88%) were the most frequently used options. Next, speech and language therapy, postural, airway clearance and ventilation techniques were also proposed (Table 5). Sensory stimulation was proposed by 43% of the respondents. Only four teams proposed enteral nutrition via percutaneous endoscopic gastrostomy (PEG) catheter as a treatment option. There was no association between the type of facility, the age or number of patients followed and the proposed treatment ($p > 0.05$).

The therapists reported as involved in the treatment stage were mainly SLPs, followed by dietitians and physiotherapists with 75%, 64% and 61%, respectively (Table 2). Clinical swallowing evaluation, functional tests, and questionnaires were the most reported tools for this stage (Table 3). No difference between specialized and non-specialized facilities in the availability of a treatment ($p = 1.00$) was revealed. It was also highlighted that the more patients the facility treated, the more treatments it offered ($p < 0.05$).

Barriers

Ninety-two percent of the respondents considered it necessary to improve dysphagia management for their patients.

Table 5 Treatment options offered in cases of dysphagia

Treatment options	NMD specialized facilities (%) ($n = 86$)	NMD rehabilitation center (%) ($n = 14$)	Non specialized facilities (%) ($n = 25$)	Facilities offering a treatment option (%) ($n = 125$)
Food consistencies adaptation	95.3	92.9	100.0	96.0
Diet modification	89.5	85.7	92.0	89.6
Speech and language therapy	90.7	71.4	88.0	88.0
Ventilation adaptation	66.3	64.3	56.0	64.0
Positioning adaptation	86.0	92.9	96.0	88.8
Sensory stimulation techniques	37.2	42.9	64.0	43.2
Postural techniques	77.9	71.4	96.0	80.8
Airway Clearance techniques	73.3	78.6	76.0	74.4
Others	10.5	7.1	16.0	11.2

NMD Neuromuscular diseases

The main obstacles reported to this improvement were the small number of people on staff (66%), the absence of trained staff (42%), lack of time (52%) and financial reasons (31%). Other reasons mentioned were among others the availability of equipment/validated procedures or problems of collaboration between the different professionals.

Discussion

The aim of the present European survey was to identify current practices in the evaluation and management of swallowing disorders in patients with NMDs. We collected responses from 140 healthcare facilities across 25 European countries. We observed a wide variation in the management of dysphagia across the different facilities. The major concern was the absence of protocol for all the stages of the management of dysphagia (screening, assessment, or treatment).

Interesting key points were highlighted in the different stages. Speech and language therapists are reported to be involved throughout the entire process of managing dysphagia while the participation of other members of multidisciplinary teams varies depending on the stage. In the same way, CSE was used in the three management stages and it was the most reported tool in the assessment and treatment stages. For screening, questionnaires were the most frequently used tools while instrumental examinations were mostly reported in the assessment stage. Finally, for treatment, adaptation strategies (diet, food, and posture) were the most reported approaches while very few centers reported PEG as an option.

Several points are important to highlight regarding the literature for dysphagic patients and the few specific recommendations for NMD patients. A study about the similarities and differences in dysphagia management in distinct regions of the world (North America, Japan, New Zealand and Australia) described that while the clinical practitioners who perform the screening varies greatly, nurses, physicians and SLPs are the ones who most commonly perform this evaluation [25]. Recently, the guideline of the German Society of Neurology emphasized the importance of a multidisciplinary team in the management of neurogenic dysphagia [32]. In Toussaint et al. health professionals who should be considered as a part of this multidisciplinary team include the patient's primary physician, physiotherapist, SLP and dietitian [9]. Our results highlighted the important involvement of the neurologist in the evaluation and screening of dysphagia that reflects his important and indispensable role within the multidisciplinary team that takes care of NMDs patients. González-Fernández et al. also reported that procedures used for screening combined a short evaluation of a patient's history and a water-swallowing trial. This latter procedure should be approached with caution in NMDs. Instruments involving the rapid and continuous consumption of water, such as the 3oST, may put the patient at risk should they aspirate and introduce a large amount of water in their respiratory tract [33]. In regard to that concern, our results are challenging because one third of the facilities surveyed reported the use of the 3oST. Other tools can be considered but patients with neurological or motor deficits may have limitations in following orders or collaborating on any task requested by the screening instrument [33]. Validated screening tools and the risk of water swallow tests in NMD patients should be explored in future studies. In the same way, the use of quantitative assessment of solid bolus ingestion may be an interesting option in NMDs [34].

Regarding assessment, International consensus (ICON) on assessment of oropharyngeal dysphagia recommended to systematically perform either a FEES or VFSS, FEES being the preferred tool in the assessment stage [20]. Our observations are in line with these recommendations. However, ICON did not mention the involvement of professionals in the assessment, but it seems obvious that the use of FEES and VFSS should include the participation of ENTs. More specifically for NMD patients, the survey findings conform with previous systematic reviews on swallowing and dysphagia management in NMD patients [1, 16, 22]. Nevertheless, Britton et al. emitted reserves on the availability and the expertise required for the use of VFSS and FEES varying by institution and the individual's ability [1]. We can observe that in European countries, more than two thirds of respondents used VFSS and FEES. It will be interesting to compare with other regions.

Few options have been studied specifically for the treatment of dysphagia in NMD populations. According to the systematic review of Jones et al., there is insufficient evidence to determine the effect of therapeutic options for dysphagia on long-term progressive muscle diseases. In our survey, an overwhelming majority of facilities offered at least five treatment options [14]. We observed that the greater the number of patients followed in a facility, the more treatment options it offered. In contrast, we did not observe any relationship between the specialization of a facility and type of treatment. This can be explained by the fact that large facilities were a part of hospital structures that offer more multidisciplinary possibilities and therefore more treatment options. Nevertheless, the number of available therapeutic options was not always linked to a defined protocol. In a recent study attempting to describe practice patterns among 250 SLPs, 47 treatment techniques and ninety different treatment combinations were recommended for the same clinical case [35].

A focus on the use of questionnaires is important. It appears that questionnaires are used almost exclusively in adult facilities. It seems consistent with a previous systematic review which highlighted the lack of validated questionnaires in the pediatric population [16]. However, the number of facilities reporting the use of questionnaires compared with the availability of validated translations is challenging. On one side, EAT-10 is the most frequently used but also the most translated and validated (ten validated translations). On the other, SSQ is used in almost as many facilities as the SWAL-QOL whereas there are only three versions available for the first against nine for the other. This may indicate potential use of non-validated and not culturally adapted translations or questionnaires in another language than the patient's own. It also reveals the need to offer validated and cross-culturally adapted versions for all European patients, and this should be an encouragement to European teams to carry out this important work for the different tools.

Finally, most facilities wished to improve the management of dysphagia for their NMD patients. The main obstacles to this improvement were lack of staff or trained staff, lack of time or financial reasons. Following these observations, dysphagia management remains an area in need of further research in NMD patients. Indeed, even if literature cannot offer more money or staff to the different facilities, it can offer the necessary resources to inform and to train staff and increase the effectiveness of dysphagia management in NMD patients. It emphasizes the importance of developing and tailoring clinical approaches in the management of dysphagia in NMD patients. The White Paper by the European Society for Swallowing Disorders (ESSD) on the screening and non-instrumental assessment for dysphagia in adults (published in 2021) shown that this problem is not only encountered in neuromuscular patients but is also a general concern in the management of dysphagia and highlighted that existing measures in dysphagia are often incomplete or missing evaluations of measurement properties [36].

In light of these recommendations and the results of this study, we can adapt these recommendations to provide and suggest to healthcare facilities providing care for NMD patients: (1) to implement screening and assessment of dysphagia using tools that have optimal diagnostic performance in NMD patients; (2) to provide quality training in screening, assessment and treatment of dysphagia to all clinicians involved in the care and management of NMD patients with dysphagia; (3) to define protocol for the management of dysphagia in most of the healthcare facilities providing pediatric and/or adult care for NMD patients.

Several limitations must be considered when interpreting our findings. Nowadays, no database listing neuromuscular centers and teams for all European countries is available. The overall penetration rate was less than 25% and the number of responses varied from country to country. Even if this survey brings valuable information, results should be taken with caution and cannot be generalizable. This low rate may be explained by different hypotheses. First, the survey was available in six languages only. There are twenty-four different official languages in the European Union (EU), and many more if we look to non-EU countries located in Europe [31]. We chose the five most spoken languages in Europe and Dutch, because it is the official language of the country of origin of the study (Dutch is ranked as the seventh language in Europe) [37]. Secondly, contact details and references (website, patient associations and referencing) were more difficult to find in some countries, limiting our local reach. Finally, it makes sense that the number of responses is also associated with the size of the country. These hypotheses may explain the higher number of answers in countries like Belgium, the UK, France, Italy, or Switzerland compared to countries where we obtained only one or no answer, mainly in Eastern Europe. Two considerations concerning the respondents must be addressed. First, the respondents fill out the survey based on specific and pre-determined answers and may lead to over- or under-reporting. Secondly, all responses relied on honor code of the respondents.

Another limitation is that social, economic or geographical specificities could influence responses. Unfortunately, the last official measurement of health system performance by the WHO was published in 2000 and was based on data covering the period 1993–1997. Following these considerations, we did not make comparisons to avoid truncated conclusions. However, we did not observe clear cultural or geographical differences. In this way, Etges et al. explained that assessment, diagnosis, and treatment options depended on their availability and the underlying characteristics of the individual's dysphagia [33]. Consequently, different management strategies can be used depending on practices, staff training and facilities in a same region. The availability of equipment and tools does not always guarantee that they will be used nor that available staff will have the time or training to use it. Surprisingly, most of the facilities stating that they did not have a protocol, described having the necessary multidisciplinary teams and equipment. In this spirit, the results of this survey are in line with the study of Gonzalez-Fernandez et al. about practice patterns in North America, Japan, New Zealand and Australia. They also observed a substantial bias in the guidelines and how evaluation and treatment are carried out. In the non-NMD dysphagic patients, they also noticed that most of the facilities did not have a protocol for all the stages of dysphagia management.

In a future study, it would also be interesting to look at the timing of the assessment and the frequency of the follow-up required in NMD patients. Toussaint et al. proposed various management strategies for dysphagia according to the symptoms identified [9].

Conclusion

This study gives an overview of strategies used to manage swallowing disorders in patients with NMDs in Europe. A major concern is the absence of a defined protocol for the management of dysphagia in most of the healthcare facilities studied. Lack of consensus and recommendations coupled with the lack of trained staff are substantial. Nevertheless, most of the facilities considered it necessary to improve the management of dysphagia. Homogeneous training strategies and guidelines will be necessary in the future to familiarize clinicians with each of the questionnaires and assessment tools.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s00455-021-10392-3.

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Declarations

Conflict of interest The authors have no relevant financial or non-financial conflicts of interest to declare.

Ethical Approval We confirm that we have read the Journal's position on issues involved in ethical issues in publications and affirm that this report is consistent with those guidelines.

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