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ORIGINAL ARTICLE

Dysphagia in amyotrophic lateral sclerosis (ALS)—The role of the ALS team to facilitate patient participation in dysphagia interventions

Ann-Sofie Eriksson[1]*, Kerstin Johansson[2]

[1]Division of Speech Language Pathology, Rehabilitation Clinic, Västerås Hospital, Sweden; [2]Division of Speech Language Pathology, Department of Clinical Science, Intervention and Technology, Karolinska Institutet, Stockholm, Sweden

*Corresponding author: Ann-Sofie Eriksson, Division of Speech Language Pathology, Rehabilitation Clinic, Västerås Hospital, Sweden. Email: ann-sofie.eriksson@regionvastmanland.se

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Abstract

Around 80% of patients with amyotrophic lateral sclerosis (ALS) suffer from dysphagia, which increases the risk of malnutrition and pneumonia, and correlates with death. To diminish that risk, it is important to involve patients in their dysphagia care in order to introduce interventions in time. To explore how ALS teams manage dysphagia, a 27-item survey was distributed to professionals in Swedish ALS teams. Less than half of the respondents (46%) reported a routine regular dysphagia screening. Dysphagia screening, early information, and training of swallowing functions occurred more frequently in bulbar onset than in the spinal. In this study, nurses were reported to be responsible for delivering dysphagia information. At the same time, it was revealed that they felt uncertain about dysphagia management. The results provide information for an initial team checklist with defined interventions to support the team management of dysphagia in ALS.

Keywords: amyotrophic lateral sclerosis; dysphagia management; interprofessional team

Abstract

Cirka 80% av patienter med amyotrofisk lateralskleros (ALS) lider av dysfagi, vilket ökar risken för undernäring och lunginflammation samt associeras med för tidig död. Denna risk kan minskas om patienten involveras i sin dysfagivård och åtgärder introduceras i tid. För att undersöka hur ALS-team hanterar dysfagi skapades en enkät med 27 frågor som riktade sig till ALS-team i Sverige. Mindre än hälften av respondenterna (46%) rapporterade att de hade en rutin för regelbunden screening av dysfagi. Screening av dysfagi, tidig information och träning av sväljfunktioner förekom oftare vid bulbär ALS

än vid spinal ALS. I denna studie rapporterades sjuksköterskor vara en av de yrkesgrupper som hade ansvar för att ge information om dysfagi. Samtidigt framkom det att de kände sig osäkra på hanteringen av dysfagi. Resultaten i studien ligger till grund för ett utkast av en checklista med definierade åtgärder som kan stödja teamets hantering av dysfagi vid ALS.

Keywords: amyotrofisk lateralskleros; insatser vid dysfagi; interprofessionellt team

Introduction

Amyotrophic lateral sclerosis (ALS) is a fatal progressive disease that causes degeneration of both upper and lower motor neurons, which leads to muscle weakness. The incidence rate of ALS in Sweden is 4.1 per 100,000 persons per year. Incidence rates increase with advancing age, and the mean age at diagnosis is 68 years (Imrell *et al.*, 2024). The onset of symptoms is bulbar in approximately 30%, with dysphagia and dysarthria as the first symptoms, and spinal in 70%, with weakness in a limb as the first symptom (Millul *et al.*, 2005). The disease progresses over time with increasing weakness causing paralysis in the body, swallowing difficulties, and problems with communication and breathing. Since there is yet no effective drug treatment for ALS, treatment is mostly symptomatic. The disease progresses in average over 4 years and only 20% patients live for longer than 5 years post-diagnosis, with faster progression and shorter survival in patients with bulbar onset (Chiò *et al.*, 2009). Most commonly, death is caused by respiratory failure, cardiovascular disease, pneumonia, and pneumonitis (Larson *et al.*, 2023). More than 40% of the ALS patients also demonstrate cognitive impairment (Montuschi *et al.*, 2015; Phukan *et al.*, 2012). Frontotemporal dysfunction and behavioral changes are common and might affect the patient's ability to stay involved in healthcare decisions (Strong *et al.*, 2009).

Regardless of bulbar or spinal onset more than 80% suffer from dysphagia. When the symptom progress is slow, swallowing difficulties are often underestimated due to adaptation, and swallowing difficulties have been visualized in patients before reporting any changes in eating habits (Higo, Tayama, & Nito, 2004; Onesti *et al.*, 2017). Oral muscle weakness is an early symptom that leads to difficulties to control both solid and fluid boluses orally. Dyscoordination and weakness in the pharyngeal muscles lead to delayed and reduced elevation of the larynx with risk of aspiration during or after swallowing. The symptoms progress over time with increased risk of aspiration (Ertekin *et al.*, 2000; Higo *et al.*, 2004). Thirty-three percent of ALS patients have been found to have laryngeal sensory deficits, and among those with dysphagia, 20% have an impaired cough reflex. This indicates that, in event of aspiration, there is a risk of compromised airway protection (Ruoppolo *et al.*, 2013, 2016).

Weight loss is a common feature in ALS and a strong and independent negative prognostic factor (Ludolph *et al.*, 2023). Reduced weight and lowered body mass index (BMI) are known risk factors for premature death in ALS. Conversely, a higher fat mass can lead to longer survival (Janse van Mantgem *et al.*, 2020; Marin *et al.*, 2011). However, dysphagia is not the only cause of weight loss in ALS, and factors, such as decreased appetite, loss of muscles and hypermetabolism, are also significant (Janse van Mantgem *et al.*, 2020; Ludolph *et al.*, 2023; Ngo *et al.*, 2019).

Therefore, it is important to investigate the underlying cause of weight loss to introduce appropriate interventions.

A common intervention to secure nutritional intake is percutaneous endoscopic gastrostomy (PEG). It is recommended in the presence of bulbar symptoms and weight loss of more than 10% and increases survival with at least 6 months both in spinal and bulbar ALS (Andersen *et al.*, 2012; Spataro, Ficano, Piccoli, & La Bella, 2011). However, PEG placement comes with a surgical procedure, and in patients with a forced vital capacity (FVC) less than 50%, there is an increased risk of respiratory failure and death. Therefore, it is important to introduce interventions, such as PEG before respiratory function becomes too impaired (Andersen *et al.*, 2012; Russ, Phillips, Mel Wilcox, & Peter, 2015).

To facilitate that interventions are introduced in time, contact with a multidisciplinary team is recommended in the presence of ALS diagnosis. The team should offer a regular contact with follow-up every 2–3 months for patients with ALS, and swallowing function is to be assessed at every follow-up (Andersen *et al.*, 2012; National Institute for Health and Care Excellence, 2019).

Medical care should also focus on facilitating decisions for the patient. In patient-centred healthcare, the individual's own values and preferences should be a guide in decision-making (Brummel-Smith *et al.*, 2016). Decision-making can be seen as a cyclic process, including stages of participant engagement, establishing choices, decisions of how to proceed, and decision implementation (Hogden, Greenfield, Nugus, & Kiernan, 2015). The National Institute for Health and Care Excellence (2021) recommends that decision-making should be supported by offering interventions at different stages during the process of the disease, both before, during, and after discussion with the patient. It is also suggested that healthcare professionals should ask patients whether they want significant others to be included to facilitate decision-making.

The role of SLP includes educating and supporting individuals with ALS to facilitate eating and handling dysphagia in the best ways. Information should include risks of malnutrition and dehydration as complications of dysphagia. An important part of the SLP's role is to inform about compensatory strategies, such as postural swallowing techniques, diet modifications, and optimised eating behaviours to minimize the risks of aspiration and to facilitate swallowing and meals. The aim of the SLP intervention is to maintain safe and efficient oral intake for as long as possible. It is also important to inform about PEG and notice when the need of PEG appears (Plowman, 2015; Strand, Miller, Yorkston, & Hillel, 1996).

To prolong oral intake during progression of the disease, a shift from reactive to proactive and patient-centred approach is suggested. This includes early involvement of SLP management to evaluate and introduce training of swallowing functions before dysphagia symptoms appear (Rogus-Pulia & Plowman, 2020). For example, there are findings indicating that expiratory muscle strength training (EMST) at a mild-to-moderate intensity has a positive effect on expiratory force and suprahyoid muscle strength in patients with ALS in early stages, which affect upper oesophageal sphincter opening and allow for a more efficient bolus transit from the pharynx to the oesophagus (Plowman *et al.*, 2016b, 2019).

Taken together, both recommendations and experiences of clinical practice emphasise that the patient must be informed early in the disease process, and that

the swallowing function must be assessed on a regular basis by the ALS team. These routines are important, since there is a risk that patients will adapt to slowly progressing swallowing difficulties, and, as a result, miss to report dysphagia. Regular follow-ups can potentially result in patients gaining a better understanding of their own care, and thus increased patient compliance, which can improve the possibility to offer interventions in time. Contrarily, neglecting the management of dysphagia increases the risk of related complications, which might impact survival of the patient. Absence of standardised clinical guidelines, or low compliance with clinical recommendations can lead to both discrete symptoms and new symptoms being missed. To address this, understanding the experiences of Swedish ALS teams is essential, as it facilitates the development of recommendations that enable the ALS team to support greater patient compliance.

The aim of this study was to explore how ALS teams inform their patients about dysphagia, to identify factors of success and barriers for patient participation, and to facilitate for the healthcare to offer relevant interventions in time.

The following research questions were asked:

- How do Swedish ALS teams manage dysphagia care?
- What is the ALS team's experience of the patient's possibility of being involved in the dysphagia care?
- What does the ALS team consider important to inform about in order to increase the patient's possibility to be involved in decision-making and dysphagia care?
- When and at what intervals during the process of the disease does the ALS team experience they have to inform about dysphagia?
- What tools or methods are used to simplify informed decision-making for the ALS patient?
- Which factors of success and which obstacles can the ALS team identify as significant for patient's compliance and decision-making?

Methods

Procedure

To explore how dysphagia in ALS is managed, a digital survey was created using Google Forms. The target group of the survey was professionals in ALS teams in the specialised healthcare in Swedish hospitals. The survey was revised after having been evaluated by a test panel. The answers were analysed quantitatively, and the free-form text responses were summarised narratively. Findings are presented in text and graphs to show what items were reported to be important in the dysphagia care in ALS.

Participants

Of the 25 respondents, 24 were included in the study. One respondent was excluded due to their comment indicating they did not work within an ALS team. This individual also selected the "Do not know" option more frequently than other participants, particularly for questions concerning team-based management of dysphagia in ALS. There was no specific question verifying whether participants worked in

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an ALS team. However, information about the target group (professionals in ALS teams located in specialised healthcare in Swedish hospitals) was provided in the survey instructions. Information about the participants' self-perceived experience of working in an ALS team is shown in Table 1. There are specialised ALS teams located in the university hospitals and several regional hospitals in the 20 regions of Sweden (Longinetti *et al.*, 2018), and the objective was to include as many of the ALS teams as possible with a goal of 20–40 participants to ensure representation from multiple teams. To reach out to as many ALS teams as possible, the survey was spread through Facebook groups and e-mail to known Swedish ALS networks. When requested, the survey was also sent by e-mail to enable participants to forward the survey to other colleagues in their teams.

The survey was open for 2 months during the spring of 2022. After the first month a reminder was sent out. The survey was anonymous, and it was voluntary to participate. No compensations were offered to the respondents. Participants were informed that they consented to participating by submitting their responses to the survey questions but could cancel their participation at any time before submitting.

Survey

Based on the literature and clinical experience, questions were formed to answer the research questions of the study. To maintain the respondents' interest but still be able to answer all the research questions, the number of questions and answer options were considered. To obtain face validity and content validity, the survey's content, form, and extent were evaluated in a pilot test (Patel & Davidson, 2019) by two SLPs and one social counsellor at the same hospital as that of the first author. All three had experience of multidisciplinary teams and some experience of ALS patients. The SLPs had extensive experience in dysphagia management.

In the first version of the survey, there was a mix of open- and close-ended questions. The test panel provided feedback on how easy the questions were to answer, and on the questions' clinical relevance. Based on their feedback, the questions were

Table 1. Participant characteristics, and self-reported experience of working in an ALS team.

		Experience n (%)				
Participants	**n (%)**	**Very large**	**Large**	**Average**	**Small**	**Very small**
Women	20 (83%)	5 (25%)	6 (30%)	8 (40%)	1 (5%)	
Men	4 (17%)	1 (25%)		3 (75%)		
All	24 (100%)	6 (25%)	6 (25%)	11 (46%)	1 (4%)	
Occupational therapist	3 (12%)	1 (33%)	1 (33%)	1 (33%)		
Physiotherapist	2 (8%)	1 (50%)		1 (50%)		
Social counsellor	2 (8%)		1 (50%)	1 (50%)		
Speech-language pathologist	9 (38%)	2 (22%)	2 (22%)	4 (44%)	1 (11%)	
Neurologist	4 (17%)	2 (50%)		2 (50%)		
Nurse	4 (17%)		2 (50%)	2 (50%)		

rephrased from open-ended to close-ended to reduce the risk of non-valid responses. A central concern of the test panel was to ensure that the questions were easy to understand and respond to. Another consideration was making the survey accessible on smartphones. Consequently, the number of response options was narrowed down. For rating scales, 3–5 options were provided, such as "less than half," "half," and "more than half," depending on the content of the question. Throughout the process, the survey questions were frequently compared to the research questions to ensure that they would collect relevant answers. Questions and answer options were designed with the intention of minimising the risk of respondents feeling offended (Trost & Hultåker, 2016).

The final version of the survey consisted of 27 questions divided into four parts: demographic information about the respondents (five questions), the ALS team composition (five questions), management of dysphagia in ALS (10 questions), and team experience of the patients' participation in their own dysphagia care (seven questions) (Appendix A).

Data analysis

Descriptive data from the survey was compiled and presented in graphs and text. Excel was used to analyse frequency counts, mean, mode and range of the collected data, and to form frequency diagrams and tables to provide a descriptive representation of the data. Qualitative data from the free-text answers was analysed and then presented in text.

Ethical considerations

Since the collection of data was anonymous and no personal data was requested, this was not an errand for review by the board of ethics and no ethical approval was required according to the Declaration of Helsinki. However, an anonymous participation can still result in feelings of guilt and inadequacy. To control this, feedback on survey questions and answer options was requested from a test panel; since this was not fed back as a problem, the risk for feelings of guilt was considered low. To further diminish risk of guilt, as well as the risk of influencing the participants' choice of answers, the questions and response alternatives were formed in a non-judgmental way. To offer the answer "Do not know" as a ready-made option was also a way to make answering the survey more unprejudiced.

Increased knowledge about clinical routines gathered from ALS teams provides a valuable perspective and helps to identify the factors of success as well as barriers to patient participation. This can help reduce patient stress and positively impact socioeconomic factors, as untreated dysphagia leads to increased healthcare utilisation and costs (Attrill, White, Murray, Hammond, & Doeltgen, 2018; Patel *et al.*, 2018).

Results

The results are presented in three areas based on the structure of the survey: the ALS team, dysphagia management, and experience of patient participation. Demographic information is presented in the "Methods" section.

Multidisciplinary ALS team

Most of the 24 participants spent only part of their working hours with ALS patients: 17 respondents (71%) reported that less than half of the time was spent on this patient group, only two respondents (8%) estimated that half time is spent, and five respondents (21%) claimed that more than half the time was spent on ALS patients. Time spent distributed on occupations is shown in Figure 1.

Two respondents reported their team lacked routines for establishing contact with the patient. The remaining 22 respondents reported a first team contact within 4 weeks from ALS diagnosis; of these, 10 (42%) established a team contact with the patient already during the investigation before the diagnosis was set.

Apart from the initial contact with a neurologist, the follow-up team contact usually took place with parts of the team based on the patient's need, according to 18 (75%) of the respondents. The remaining six respondents (25%) reported that the patient was seeing either the whole team at one appointment or during a coherent period, such as a day or a week, and one person reported the first contact to be with only neurologist and nurse.

Dysphagia management in the ALS team

Almost half of the respondents (n = 11; 46%) answered that swallowing function was screened on a regular basis, seven respondents (29%) reported lacking a routine for regular dysphagia screening, and six respondents (25%) did not know whether any dysphagia screening was performed. Management differed depending on the symptom onset, as shown in Figure 2. Screening is more common in patients with a bulbar onset (n = 17; 71%) than a spinal (n = 3; 13%). Also, information and introduction to training of swallowing functions were more common in bulbar ALS.

According to 20 respondents (83%), oral dysphagia information was delivered when visiting the hospital, eight respondents (33%) reported written information was handed out during a physical contact, three respondents (13%) also delivered information via telephone, and only two respondents (8%) to significant others.

Figure 1. Part of working time spent on the patient group distributed on participating professionals (number of responses and percentage values).

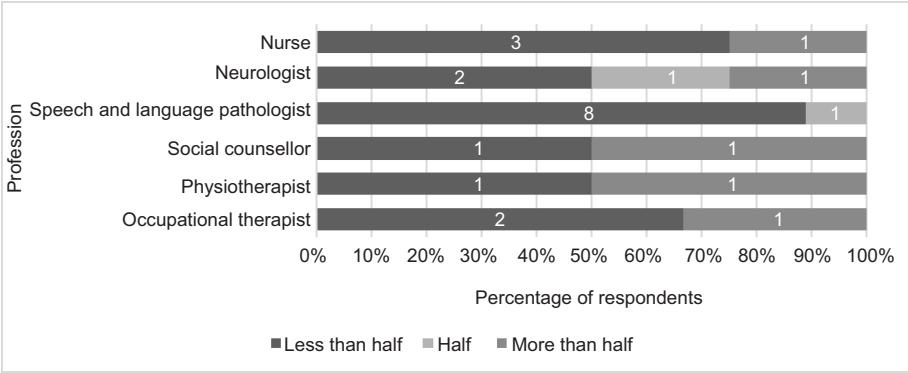

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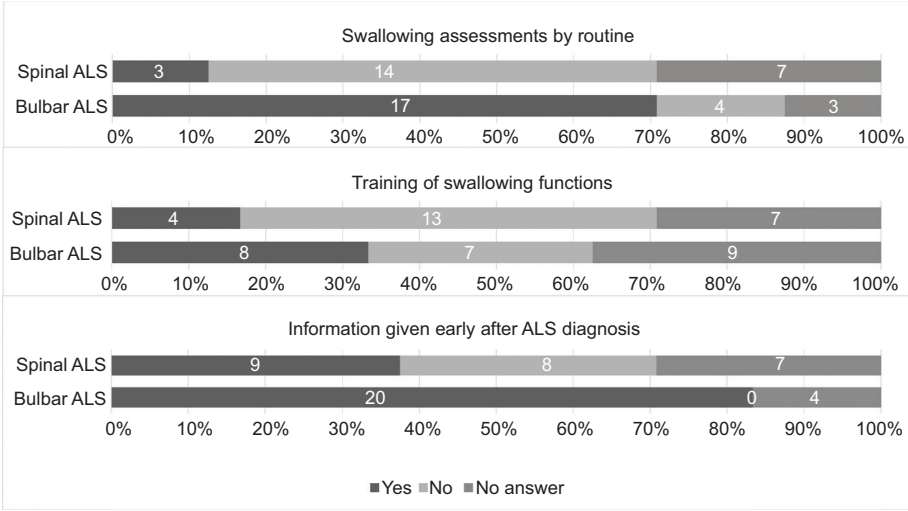
Figure 2. Prevalence of dysphagia management—assessment, training, and information—for patients with bulbar and spinal ALS, respectively (number of responses and percentage values).



Four respondents (17%) reported that they did not know how information about dysphagia was delivered.

The dysphagia interventions offered were essentially about diet modifications, nutritional treatments, and PEG according to 20 (83%) of respondents; 18 (75%) offered instructions of postural swallowing techniques, and 7 (29%) provided training of swallowing functions. Five respondents (21%) answered that they did not know what interventions were provided in dysphagia. The information considered most important varies depending on whether symptoms of swallowing difficulties were present (Figure 3).

Seventeen of the survey's 27 items included the response alternative "Do not know." For the entire survey, this "Do not know" option was most frequently used by social workers (43%), followed by physiotherapists (19%) and nurses (18%).

The responsibility to inform about dysphagia is usually distributed across the entire team. However, certain professional groups are reported to have a greater responsibility to provide information about dysphagia: SLPs (n = 20; 83%), neurologists (n = 15; 63%), nurses (n = 12; 50%) and dieticians (n = 10; 42%). The time point when it is considered relevant to deliver information about dysphagia differs. In free-text answers, it is reported to depend on whether it is urgent and if the patient wishes to receive information about symptoms that have not yet occurred.

Free-text responses also included suggestions for interventions, such as optimising sitting position, using assistive eating devices, employing a self-assessment form before doctor's visits, and assessing nutritional status. The SLP is contacted if dysphagia is detected, but the entire team is responsible for detecting swallowing difficulties and to address the need of PEG at an early stage.

Figure 3. Type of information delivered before the onset of dysphagia (light grey) and after dysphagia (dark grey).

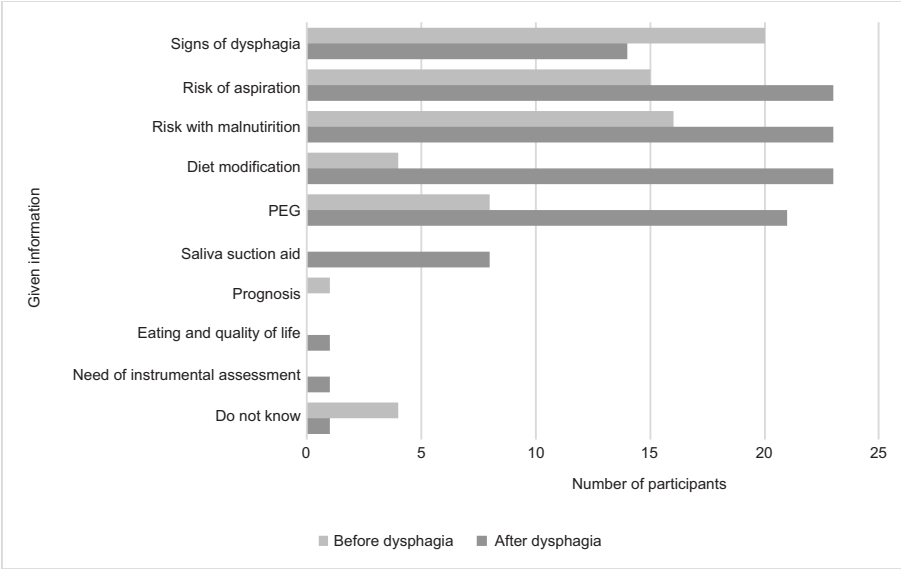
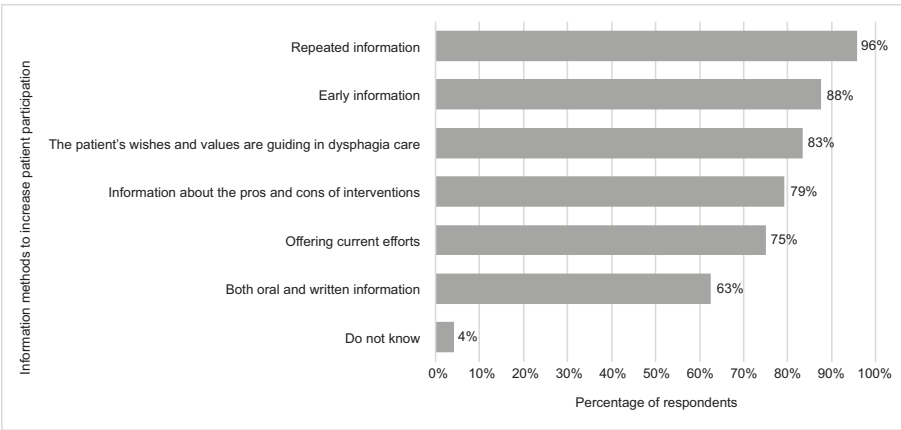


Figure 4. Various actions offered by the ALS team to enable the patients to participate in their dysphagia care.



Experience of patient participation

According to 20 respondents (83%), less than half of the patients requested information about dysphagia. To encourage patients to be involved in their dysphagia care, the teams provided information and interventions both before and after the onset of symptoms. Furthermore, they continued to provide support and guidance throughout the progression of ALS, as depicted in Figure 4.

The respondents were asked to identify success factors and barriers that they had experienced to affect participation of patients. Success factors mentioned were, for example, patients' insight into their difficulties, information about dysphagia delivered in time, and the ALS team offering interventions before dysphagia becomes too severe. Also, a committed network around the patient is reported to be an important success factor. Identified barriers, on the other hand, were a negative attitude of the patient, the patient lacking insight in its dysphagia, no existing network around the patient, and whether the patient was not asking for information. Long waiting period and difficulties accessing medical appointments were not considered affecting the patient's ability to participate in its dysphagia care. Neither was information delivered too early.

To improve dysphagia management, respondents reported in free-text answers that it is important how to deliver information about dysphagia. Factors such as providing information as early as possible after diagnosed with ALS, synchronised information delivered by different professionals, and written information were identified. Other suggestions for improved dysphagia care were offering training, routine for assessing dysphagia, and better involvement of significant others to increase understanding of early interventions. Increased knowledge of dysphagia among all professionals in the ALS team was also highlighted as important.

Discussion

In this study, information about dysphagia management for patients with ALS was collected to facilitate the patients' participation in dysphagia care. The results were based on 24 ALS team professionals' responses to a 27-item digital survey covering four areas: respondents' demographic information, ALS team composition, management of dysphagia in ALS, and team experiences of patients' participation in their own dysphagia care.

Dysphagia management

When investigating dysphagia management offered by the ALS teams, it appears that contact with a multidisciplinary team is established early during the progress of ALS, as recommended in international guidelines (Andersen *et al.*, 2012; National Institute for Health and Care Excellence, 2019). However, interventions and routines for evaluating dysphagia differ. Nurses are often considered an important contact in healthcare, and they were one of the professionals responsible for delivering information about dysphagia, together with SLPs, neurologists, and dietitians. At the same time, the responding nurses in this study reported uncertainty regarding what to inform about dysphagia and what the dysphagia management in the team looked like. Hence, there is a risk that nurses who feel insecure about dysphagia and how and when to inform about dysphagia interventions, would miss providing important information to the patient. This finding supports a need for a standardised checklist and indicates the importance of education and need for increased knowledge about dysphagia within the ALS team.

The results showed that swallowing assessment occurred to a much larger extent in bulbar ALS than in spinal. Similarly, training swallowing functions often are

introduced for patients with bulbar dysphagia, and in case dysphagia is already present. In a proactive approach, training in degenerative diseases, such as ALS, should be introduced before symptoms occur (Rogus-Pulia & Plowman, 2020). Since dysphagia affects close to 80% of the ALS patients, regardless of spinal or bulbar onset of symptoms (Onesti *et al.*, 2017), training should be considered at a greater extent in spinal ALS as well. Therefore, it is important for patients with spinal ALS as well to be screened for dysphagia on a regular basis, not only to reduce the risk of missing out on symptoms but also to be able to introduce early rehabilitative treatment. Possibly, patients who are candidates for early rehabilitative swallowing intervention can strengthen their swallowing function, thereby increasing their possibilities to swallow safely and efficiently for a longer period despite disease progress.

How to deliver information that facilitates patient participation

When it comes to the patient's possibility of being involved in its dysphagia care, 83% reported that the patients did not ask for information about dysphagia. Since the symptoms often progress over time, it is possible that the patient adapts to changes and therefore does not pay attention to dysphagia before it is more severe. Dysphagia has been observed in patients even though they report normal swallowing and eating habits (Higo *et al.*, 2004; Onesti *et al.*, 2017). Waiting for patients to report swallowing difficulties can risk delaying interventions. To get the patient involved and to facilitate decisions about dysphagia interventions, here it is suggested that information must be delivered repeatedly during the progress of ALS. Dysphagia assessments on a regular and more frequent basis can increase patients' insights into their difficulties. Thereby, patients' participation in their care would increase, and with that their compliance with intervention. Subjective patient-reported dysfunction and problems can add valuable information about factors that enhance or hinder participation in healthcare; for example, a patient-report questionnaire like the Eating Assessment Tool 10 (EAT-10) has been reported to significantly detect dysphagia in ALS (Plowman *et al.*, 2016a).

A routine for informing patients must be established that offers all patients the opportunity to get involved. Early involvement is motivated by, for example, the fact that some interventions, such as training and PEG, are recommended before symptoms are too severe (Rogus-Pulia & Plowman, 2020; Russ *et al.*, 2015). To be able to achieve this, patients need to be involved in the decisions even though symptoms have not yet occurred. However, patients often desire to primarily focus on the current symptoms instead of preparing for the future (Hogden, Greenfield, Nugus, & Kiernan, 2012). Discussing symptom management and proactive planning early, before symptoms have started to show, can therefore be a challenging task and paradoxically an obstacle to the healthcare goal (Hogden *et al.*, 2015).

Identified factors of success and barriers in patient participation

The importance of a committed network around the patient is a factor of success for patient participation when present, and a barrier when lacking. This is also confirmed by other studies where quality of life is increasing when there are significant others committed to support the patient (Ando, Cousins, & Young, 2019). Living in a partnership at the time of ALS diagnosis is associated with better prognosis

than when living alone (Wolf *et al.*, 2015). According to this, it seems important to involve the network around the patient. To encourage the patient to bring significant others to appointments with the ALS team is one way to get the network involved.

The balance between delivering information and the patient's ability to receive information is delicate, as discussed above. The respondents are reporting dysphagia information delivered in time as one factor of success affecting patient's participation. Earlier studies have shown this timing is difficult with patients wish to be informed and at the same time want to focus on the present being uncomfortable to use the information to make decisions about the future (Hogden *et al.*, 2012, 2015). It is therefore important to individualise the information provided.

According to Hogden *et al.* (2012), the patient's insight into its dysphagia is a factor that could lead to successful participation in dysphagia interventions if existing, or a barrier if not existing. Similarly, this was reported by the respondents in this survey, that is, information communicated early after diagnosis is important to get the patient involved in decisions. Also, long wait for medical appointments is not reported as a barrier in patient participation. Because of the often fast disease progress in ALS, and risk of severe complications if swallowing issues are left untreated, patients with ALS is a group that needs to be prioritised and not kept waiting.

Draft of a checklist

When analysing the respondents' answers, some gaps were detected. The most significant ones were how information is delivered about dysphagia and PEG, if training is offered, assessment routines, and how to involve significant others in healthcare. Based on the findings of this study and supported by the literature, a preliminary checklist of recommended interventions at certain time points during the disease progress is proposed to support patient participation in dysphagia care (Appendix B).

Dysphagia increases the risk of malnutrition and pneumonia, and swallowing problems are often underestimated in ALS due to adaption to progressive symptoms (Onesti *et al.*, 2017). This can be assumed to be also true for other progressive diseases, like Parkinson's disease and multiple sclerosis (Kalf *et al.*, 2012; Mirmosayyeb *et al.*, 2023). This first version of the checklist could be modified and be useful for these patient groups as well, where dysphagia and multidisciplinary team management are central.

Discussion of methods

Since ALS teams in Sweden are usually located at regional hospitals, it can be assumed that there are around 20 teams, one per region. If each team has about six members, the participants in this study would represent at most 20% of the target group. While this might not be enough to represent the entire population, it may still provide an indication of what dysphagia management looks like.

To maintain anonymity, it was not possible to ask questions about the specific locations where the respondents were working. For the same reason, it was not possible to control how many respondents represented the same team. The largest professional group participating was SLPs (n = 9; 38%). Since most of the ALS teams in Sweden do not have more than one or two SLPs, this indicates representation from

several teams. This relatively large group of SLP respondents is assumed to be the result of the survey being spread mostly through SLP networks on Facebook; also, dysphagia engages many SLPs.

One of 25 respondents was excluded for commenting that the person did not work in an ALS team. Additionally, that person also used the option "Do not know" more frequently than all the other respondents, especially for the questions of team composition and the interventions offered. This suggests that the survey was successfully designed to be answered by participants representing an ALS team.

Pilot testing of surveys is recommended, for improving inter-rater reliability as well as face and content validity (Patel & Davidson, 2019). In the pilot test of the survey's first version, three professionals evaluated it and provided feedback on the content, form, and extent. As a result, some questions were changed to close-ended questions. For example, the question "Which diagnostic methods are used?," was modified to include specific response options to ensure clarity. Rephrasing questions into close-ended formats with predefined response options was recognised as a potential risk for biasing respondents' answers. However, that risk was considered insignificant, compared to the risk of respondents skipping questions that were too difficult to answer. To reduce this risk, respondents were given the option to add free-text responses. Using close-ended questions was preferred by the test panel to simplify participation in the survey, and thus could increase the number of respondents.

The test panel also recommended adjustments to the format and length of questions and rating scales, given the prevalence of smartphone use puts demands on the layout and readability of questions and response alternatives. For example, it was important to ensure that questions and response options were easy to read and select on a phone. For instance, pre-set response options are generally easier to use on a phone than typing the text.

Both aspects of validity and reliability influenced the design of the rating scales. For example, a three-point scale ("less than half," "half," and "more than half") was used to rate how many patients seek information about dysphagia, as it was thought to be simpler to answer. Conversely, a more detailed scale was used for self-reported experiences of working in an ALS team, as pilot testing indicated it was more relevant.

The choices of nominal response alternatives, such as in the question about which diagnostic methods were used, was based on the range of methods commonly used in the dysphagia clinic, in order to assess different aspects of swallowing. In some of the questions, it was a challenge to limit the number of nominal response alternatives, but the goal was always to provide enough valid alternatives to cover a certain concept; for example, dysphagia assessment without overwhelming respondents with too many choices.

One advantage of a digital survey is the possibility for the respondent to remain anonymous during the complete process. Participants are also able to answer the questions at their own time and the risk of researcher affecting the answers by interacting with the participant decreases, factors that may increase the desire to participate (Patel & Davidson, 2019; Wenemark, 2023).

An alternative to a survey study could have been to conduct interviews. Interviews can give opportunities to ask follow-up questions if necessary, and that

would possibly lead to more detailed answers to some of the questions. However, an interview format probably would have included a smaller number of participants. Also, the study was planned, and data was collected during the COVID pandemic, and a survey study was therefore preferred.

Future studies

To better understand ALS dysphagia management, a larger study with control for representation of professionals from all ALS teams in Sweden would be desirable. In future studies, it is also important to invite patients and their significant others to gain insight into their experiences of dysphagia management. It would also be valuable to investigate whether a checklist for ALS dysphagia management could lead to more frequent dysphagia care, earlier assessment and intervention, and to evaluate the impact of these factors on complications, healthcare costs, and mortality.

Conclusion

This study helped to investigate dysphagia management in today's Swedish ALS care. Among the respondents, consensus is often lacking regarding dysphagia management. Also, it appears that dysphagia in ALS with a spinal origin is much less identified despite dysphagia being common in both spinal and bulbar form. In this study, nurses are identified to have a significant role in detecting dysphagia symptoms, but at the same time report uncertainty regarding the type of information and interventions available. Given the low number of participants, the results may not be representative of the entire population. However, it highlights the importance of ensuring that the professionals responsible for providing information about dysphagia possess sufficient knowledge to do so effectively. Otherwise, there is a risk that dysphagia symptoms pass unnoticed, which could constitute a health risk for the patient. A checklist that offers a clear structure for necessary clinical routines in dysphagia management, and the one that can be updated in line with new research findings and guidelines, would increase the likelihood that dysphagia is identified and interventions introduced in time. This would reduce the risk of serious problems with aspiration, and poor oral intake can be reduced, thereby strengthening the quality of life.

References

Andersen PM, Abrahams S, Borasio G.D, de Carvalho M, Chio A, Van Damme P, Hardiman O, Kollewe K, Morrison KE, Petri S, Pradat P-F, Silani V, Tomik B, Wasner M. & Weber M 2012. EFNS guidelines on the clinical management of amyotrophic lateral sclerosis (MALS) – Revised report of an EFNS task force. *European Journal of Neurology* **19(3)**, 360–375. https://doi.org/10.1111/j.1468-1331.2011.03501.x

Ando H, Cousins R. & Young CA 2019. Exploring and addressing "concerns" for significant others to extend the understanding of quality of life with amyotrophic lateral sclerosis: A qualitative study. *Journal of Central Nervous System Disease* **11,** 11:1179573519859360. https://doi.org/10.1177/1179573519859360

Attrill S, White S, Murray J, Hammond S. & Doeltgen S 2018. Impact of oropharyngeal dysphagia on healthcare cost and length of stay in hospital: A systematic review. *BMC Health Services Research* **18(1)**, 594–594. https://doi.org/10.1186/s12913-018-3376-3

Brummel-Smith K, Butler D, Frieder M, Gibbs N, Henry M, Koons E, Loggers E, Porock D, Reuben DB, Saliba D, Scanlon WJ, Tabbush V, Tinetti M, Tumlinson A. & Vladeck BC 2016. Person-centered

care: A definition and essential elements. *Journal of the American Geriatrics Society (JAGS)* **64(1)**, 15–18. https://doi.org/10.1111/jgs.13866

Chiò A, Logroscino G, Hardiman O, Swingler R, Mitchell D, Beghi E, Traynor BG & On Behalf of the Eurals Consortium 2009. Prognostic factors in ALS: A critical review. *Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders* **10(5–6)**, 310–323. https://doi.org/10.3109/17482960802566824

Ertekin C, Aydogdu I, Yüceyar N, Kiylioglu N, Tarlaci S & Uludag B 2000. Pathophysiological mechanisms of oropharyngeal dysphagia in amyotrophic lateral sclerosis. *Brain* **123(1)**, 125–140. https://doi.org/10.1093/brain/123.1.125

Higo R, Tayama N & Nito T 2004. Longitudinal analysis of progression of dysphagia in amyotrophic lateral sclerosis. *Auris, Nasus, Larynx* **31(3)**, 247–254. https://doi.org/10.1016/j.anl.2004.05.009

Hogden A, Greenfield D, Nugus P & Kiernan MC 2012. What influences patient decision-making in amyotrophic lateral sclerosis multidisciplinary care? A study of patient perspectives. *Patient Preference and Adherence* **2012(6)**, 829–838. https://doi.org/10.2147/PPA.S37851

Hogden A, Greenfield D, Nugus P & Kiernan MC 2015. Development of a model to guide decision making in amyotrophic lateral sclerosis multidisciplinary care. *Health Expectations : An International Journal of Public Participation in Health Care and Health Policy* **18(5)**, 1769–1782. https://doi.org/10.1111/hex.12169

Imrell S, Fang F, Ingre C & Sennfält S 2024. Increased incidence of motor neuron disease in Sweden: A population-based study during 2002–2021. *Journal of Neurology* **271(5)**, 2730–2735. https://doi.org/10.1007/s00415-024-12219-1

Janse van Mantgem MR, van Eijk RPA, van der Burgh HK, Tan HH G, Westeneng H-J, van Es MA, Veldink JH & van den Berg LH 2020. Prognostic value of weight loss in patients with amyotrophic lateral sclerosis: A population-based study. *Journal of Neurology, Neurosurgery and Psychiatry* **91(8)**, 867–875. https://doi.org/10.1136/jnnp-2020-322909

Kalf JG, de Swart BJM, Bloem BR & Munneke M 2012. Prevalence of oropharyngeal dysphagia in Parkinson's disease: A meta-analysis. *Parkinsonism & Related Disorders* **18(4)**, 311–315. https://doi.org/10.1016/j.parkreldis.2011.11.006

Larson TC, Goutman SA, Davis B, Bove FJ, Thakur N & Mehta P 2023. Causes of death among United States decedents with ALS: An eye toward delaying mortality. *Annals of Clinical and Translational Neurology* **10(5)**, 757–764. https://doi.org/10.1002/acn3.51762

Longinetti E, Regodón Wallin A, Samuelsson K, Press R, Zachau A, Ronnevi L.-O, Kierkegaard M, Andersen PM, Hillert J, Fang F & Ingre C 2018. The Swedish motor neuron disease quality registry. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration* **19(7–8)**, 528–537. https://doi.org/10.1080/21678421.2018.1497065

Ludolph A, Dupuis L, Kasarskis E, Steyn F, Ngo S & McDermott C 2023. Nutritional and metabolic factors in amyotrophic lateral sclerosis. *Nature Reviews. Neurology* **19(9)**, 511–524. https://doi.org/10.1038/s41582-023-00845-8

Marin B, Desport JC, Kajeu P, Jesus P, Nicolaud B, Nicol M, Preux PM, & Couratier P 2011. Alteration of nutritional status at diagnosis is a prognostic factor for survival of amyotrophic lateral sclerosis patients. *Journal of Neurology, Neurosurgery and Psychiatry* **82(6)**, 628–634. https://doi.org/10.1136/jnnp.2010.211474

Millul A, Beghi E, Logroscino G, Micheli A, Vitelli E & Zardi A 2005. Survival of patients with amyotrophic lateral sclerosis in a population-based registry. *Neuroepidemiology* **25(3)**, 114–119. https://doi.org/10.1159/000086353

Mirmosayyeb O, Ebrahimi N, Shekarian A, Afshari-Safavi A, Shaygannejad V, Barzegar M & Bagherieh S 2023. Prevalence of dysphagia in patients with multiple sclerosis: A systematic review and meta-analysis. *Journal of Clinical Neuroscience* **108**, 84–94. https://doi.org/10.1016/j.jocn.2023.01.006

Montuschi A, Iazzolino B, Calvo A, Moglia C, Lopiano L, Restagno G, Brunetti M, Ossola I, Lo Presti A, Cammarosano S, Canosa A. & Chiò A 2015. Cognitive correlates in amyotrophic lateral sclerosis: A population-based study in Italy. *Journal of Neurology, Neurosurgery and Psychiatry* **86(2)**, 168–173. https://doi.org/10.1136/jnnp-2013-307223

National Institute for Health and Care Excellence. 2019. Motor neurone disease: Assessment and management. Available at https://www.nice.org.uk/guidance/NG42/ (Accessed 17 Oct 2020).

National Institute for Health and Care Excellence. 2021. Shared decision making. Available at https://www.nice.org.uk/guidance/ng197/ (Accessed 21 April 2023)

Ngo ST, van Eijk RPA, Chachay V, van den Berg LH, McCombe PA, Henderson RD & Steyn F. J 2019. Loss of appetite is associated with a loss of weight and fat mass in patients with amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration* **20(7–8)**, 497–505. https://doi.org/10.1080/21678421.2019.1621346

Onesti E, Schettino I, Gori MC, Frasca V, Ceccanti M, Cambieri C, Ruoppolo G & Inghilleri M 2017. Dysphagia in amyotrophic lateral sclerosis: Impact on patient behavior, diet adaptation, and Riluzole management. *Frontiers in Neurology* **8**, 94. https://doi.org/10.3389/fneur.2017.00094

Patel R & Davidson B 2019. *Forskningsmetodikens grunder : att planera, genomföra och rapportera en undersökning* (5th ed.). Lund, Sweden: Studentlitteratur.

Patel DA, Krishnaswami S, Steger E, Conover E, Vaezi MF, Ciucci MR & Francis DO 2018. Economic and survival burden of dysphagia among inpatients in the United States. *Diseases of the Esophagus* **31(1)**, 1–7. https://doi.org/10.1093/dote/dox131

Phukan J, Elamin M, Bede P, Jordan N, Gallagher L, Byrne S, Lynch C, Pender N & Hardiman O 2012. The syndrome of cognitive impairment in amyotrophic lateral sclerosis: A population-based study. *Journal of Neurology, Neurosurgery and Psychiatry* **83(1)**, 102–108. https://doi.org/10.1136/jnnp-2011-300188

Plowman, EK 2015. Is there a role for exercise in the management of bulbar dysfunction in amyotrophic lateral sclerosis? *Journal of Speech, Language, and Hearing Research* **58(4)**, 1151–1166. https://doi.org/10.1044/2015_JSLHR-S-14-0270

Plowman EK, Tabor LC, Robison R, Gaziano J, Dion C, Watts SA, Vu T & Gooch C 2016a. Discriminant ability of the Eating Assessment Tool-10 to detect aspiration in individuals with amyotrophic lateral sclerosis. *Neurogastroenterology & Motility/Neurogastroenterology and Motility* **28(1)**, 85–90. https://doi.org/10.1111/nmo.12700

Plowman EK, Tabor-Gray L, Rosado KM, Vasilopoulos T, Robison R, Chapin JL, Gaziano J, Vu T, & Gooch C (2019). Impact of expiratory strength training in amyotrophic lateral sclerosis: Results of a randomized, sham-controlled trial. *Muscle & Nerve*, **59(1)**, 40–46.

Plowman EK, Watts SA, Tabor L, Robison R, Gaziano J, Domer AS, Richter J, Vu T & Gooch C 2016b. Impact of expiratory strength training in amyotrophic lateral sclerosis. *Muscle & Nerve* **54(1)**, 48–53. https://doi.org/10.1002/mus.24990

Rogus-Pulia NM & Plowman EK 2020. Shifting tides toward a proactive patient-centered approach in dysphagia management of neurodegenerative disease. *American Journal of Speech-Language Pathology* **29(2S)**, 1094–1109. https://doi.org/10.1044/2020_AJSLP-19-00136

Ruoppolo G, Onesti E, Gori MC, Schettino I, Frasca V, Biasiotta A, Giordano C, Ceccanti M, Cambieri C, Greco A, Buonopane CE, Cruccu G, De Vincentiis M. & Inghilleri M 2016. Laryngeal sensitivity in patients with amyotrophic lateral sclerosis. *Frontiers in Neurology* **7**, 212–212. https://doi.org/10.3389/fneur.2016.00212

Ruoppolo G, Schettino I, Frasca V, Giacomelli E, Prosperini L, Cambieri C, Roma R, Greco A, Mancini P, De Vincentiis M, Silani V. & Inghilleri M 2013. Dysphagia in amyotrophic lateral sclerosis: Prevalence and clinical findings. *Acta Neurologica Scandinavica* **128(6)**, 397–401. https://doi.org/10.1111/ane.12136

Russ KBMD, Phillips MCMD, Mel Wilcox CM & Peter SMD 2015. Percutaneous endoscopic gastrostomy in amyotrophic lateral sclerosis. *The American Journal of the Medical Sciences* **350(2)**, 95–97. https://doi.org/10.1097/MAJ.0000000000000517

Spataro R, Ficano L, Piccoli F. & La Bella V 2011. Percutaneous endoscopic gastrostomy in amyotrophic lateral sclerosis: Effect on survival. *Journal of the Neurological Sciences* **304(1)**, 44–48. https://doi.org/10.1016/j.jns.2011.02.016

Strand EA, Miller RM, Yorkston KM & Hillel AD 1996. Management of oral-pharyngeal dysphagia symptoms in amyotrophic lateral sclerosis. *Dysphagia* **11(2)**, 129–139. https://doi.org/10.1007/BF00417903

Strong MJ, Grace GM, Freedman M, Lomen-Hoerth C, Woolley S, Goldstein LH, Murphy J, Shoesmith C, Rosenfeld J, Leigh PN, Bruijn L, Ince P & Figlewicz D 2009. Consensus criteria for the diagnosis of frontotemporal cognitive and behavioural syndromes in amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis* **10(3)**, 131–146. https://doi.org/10.1080/17482960802654364

Trost J & Hultåker O 2016. *Enkätboken* (5th ed.). Lund, Sweden: Studentlitteratur.

Wenemark M (2023). *Enkätmetodik -att planera och genomföra en undersökning*. Stockholm, Sweden: Liber.

Wolf J, Safer A, Wöhrle JC, Palm F, Nix WA, Maschke M & Grau AJ 2015. Factors predicting survival in ALS patients – Data from a population-based registry in Rhineland-Palatinate, Germany. *Neuroepidemiology* **44(3)**, 149–155. https://doi.org/10.1159/000381625

Appendix A

A compilation of the questions included in the survey.

Survey questions

Demographic information about the respondents

1. Gender
2. Age (please specify in years)
3. Occupation
4. How would you rate your level of experience in working with individuals with ALS?
5. On average, what proportion of your current working time is dedicated to ALS patients?

The ALS team composition

6. Which professions are included in your primary ALS team?
   - occupational therapist
   - physiotherapist
   - social counsellor
   - speech-language pathologist
   - neurologist
   - nurse
   - dietitian
   - psychologist
   - other
7. If the following professions are not part of the regular team, which are available at the hospital if needed?
   - occupational therapist
   - physiotherapist
   - social counsellor
   - speech-language pathologist
   - neurologist
   - nurse
   - dietitian
   - psychologist
   - other
8. Is there any profession that is not available at the hospital? If so, which one(s)?
9. After the initial contact with a neurologist, when is the rest of the team usually involved?
   (This can refer to the whole team or parts of the team being involved)
10. At the first team visit, does the patient meet ...
    - the majority of the team simultaneously
    - each profession individually within a limited timeframe (e.g., over a day or a week)
    - parts of the team based on need
    - other

Management of dysphagia in ALS

11. How is information about dysphagia provided?
12. Is there a particular profession responsible for informing and inquiring about dysphagia?
    (If the responsibility is shared between different professions, multiple options can be selected)
13. When is information about dysphagia provided?
14. What do you believe the patient should be informed about before dysphagia is diagnosed?
15. What do you believe the patient should be informed about after dysphagia is diagnosed?
16. Is screening or assessment for swallowing difficulties routinely performed in your practice?
17. a) Which dianostic methods are used?
    b) If multiple diagnostic methods were selected above, please specify which one(s) are most commonly used.
18. What interventions, in addition to swallowing assessment, are offered when dysphagia is confirmed?
19. a) Please check which of the following statements are true regarding bulbar symptom onset (onset with dysarthria and dysphagia).
    - Information about dysphagia is provided early in the disease course
    - We wait to provide dysphagia information until symptoms of dysphagia appear
    - Swallowing assessment is routinely performed
    - Swallowing exercises are initiated

    b) other dysphagia-related routines for bulbar symptom onset...
20. a) Please check which of the following statements are true regarding spinal symptom onset (onset with weakness in hand/arm or leg).
    - Information about dysphagia is provided early in the disease course
    - We wait to provide dysphagia information until symptoms of dysphagia appear
    - Swallowing assessment is routinely performed
    - Swallowing exercises are initiated

    b) Other dysphagia-related routines for spinal symptom onset...

Team experience of the patients' participation in their own dysphagia care

21. What does the team do to ensure that the patient has the opportunity to participate in decisions regarding their dysphagia care?
22. How many of the patients you meet request information about swallowing difficulties/dysphagia?
23. Imagine a patient with mild swallowing difficulties where you felt that the interventions for dysphagia were effective. What facilitated these interventions?
24. Imagine a patient with severe swallowing difficulties where you felt that the interventions for dysphagia were effective. What facilitated these interventions?
25. Imagine a patient with mild swallowing difficulties where you felt that the interventions for dysphagia did not achieve the desired effect. What hindered these interventions?

26. Imagine a patient with severe swallowing difficulties where you felt that the interventions for dysphagia did not achieve the desired effect. What hindered these interventions?
27. Please suggest something that you believe could improve dysphagia care for ALS patients you encounter in your team.

Appendix B

A 7-item checklist for improved dysphagia care and increased patient participation. The checklist is based on the literature, study results, and clinical experience. Documents supporting each item are included.

	Recommended intervention	Aim	When?	Supported by
Information				
1.	Information about signs and risks of dysphagia.	Increase patient awareness.	Every follow-up with neurologist and SLP.	EFNS guidelines (Andersen et al., 2012)
2.	Information about preventive training of swallowing function.	Increased motivation to start training before dysphagia onset.	Close to ALS diagnosis, before subtle signs of dysphagia.	(Rogus-Pulia & Plowman, 2020)
3.	Information about PEG as a complement to oral intake.	Facilitate decision of PEG in time. Diminish risk of aspiration and malnutrition.	Close to ALS diagnosis. Repeatedly after dysphagia onset.	EFNS guidelines (Andersen et al., 2012)
Assessments				
4.	Regular screening/ assessment of swallowing function.	Identify dysphagia. Offer dysphagia interventions in time.	At follow-ups every 3rd month.	EFNS guidelines (Andersen et al., 2012)
5.	Anamnestic questions and self-report questionnaires about dysphagia (e.g., EAT10).	Identify dysphagia. Increase patient's awareness.	Before every follow-up.	(Plowman et al., 2016a), according to free text answers
6.	Regular weight controls.	Identify malnutrition. Offer dysphagia interventions in time.	At follow-ups every 3rd month.	EFNS guidelines (Andersen et al., 2012)
Environmental factors				
7.	Offer patient to bring significant other to healthcare appointments.	Increase patient's and patient network's participation in dysphagia care.	At first healthcare appointment and before follow-ups.	NICE guidelines (National Institute for Health and Care Excellence, 2021)

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