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RESEARCH ARTICLE

Current practices and barriers in gastrostomy indication in amyotrophic lateral sclerosis: a survey of ALS care teams in The Netherlands

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Abstract

To describe current practices and barriers and support needs in gastrostomy indication and decision-making amongst rehabilitation physicians of ALS care teams in the Netherlands. *Methods:* Cross-sectional online survey of rehabilitation physicians of ALS care teams in the Netherlands. Survey items covered current practices in *timing of indication* (i.e. indicators and criteria), *goals*, *initiating discussion about gastrostomy*, and criteria for preferred *method of placement*; and *barriers* and *support needs* in indication and decision-making. Descriptive analysis was used for quantitative responses, thematic, and content analysis for qualitative data. *Results:* Twenty-nine physicians (41%) of 27 ALS care teams (71%) responded. *Timing of indication:* physicians agreed on important indicators but not cutoff values/criteria. *Goals:* optimizing nutritional status (100%), ensuring safe food-intake (72%), and reducing effort of meals (59%). *Initiating discussion about gastrostomy:* 52% introduces the topic early after diagnosis, 48% at indication. Criteria for *method of placement* included physician preference (69%), availability of service (21%), lower complication risk (17%), contraindication (59%), and patient preference (24%). Reported *barriers* (69% of respondents) were: patient readiness (52%), timing of indication (31%), and organizational barriers (18%). *Support needs* (62%): evidence-based timing of indication (35%) and tailored patient education (31%). *Conclusions:* There is practice variation in the timing of first introduction of gastrostomy and preferred method of placement, but agreement on goals and indicators. More evidence on optimal timing of gastrostomy placement is needed. However, until then early and regular discussion of the topic of gastrostomy and better patient information may promote patient readiness and support patient choice.

Keywords: Amyotrophic lateral sclerosis, motor neurone disease, gastrostomy, gastrostomy indication, patient readiness

Introduction

Patients with amyotrophic lateral sclerosis (ALS) often experience poor nutritional status and weight loss due to loss of muscle mass and a reduction in body fat mass, which is undesirable as these are independent prognostic factors for survival (1). The etiology of weight loss in ALS is complex and multifactorial and includes increasing problems

with chewing and swallowing, and the ability to bring food to the mouth due to reduced upper limb function (2). Prolonged, effortful meals can also negatively influence quality of life and cause distress to patients and their caregivers (3). ALS guidelines recommend to consider gastrostomy to support patients with ALS to meet their nutritional requirements (4–8). However, healthcare

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professionals find the timing of indication, discussion with the patient, and placement of gastrostomy difficult and challenging (9).

A uniform approach to placement of gastrostomy is complicated by heterogeneous speed of disease progression and difference in clinical presentation (10). There is a lack of conclusive evidence on effectiveness of gastrostomy in promoting survival, weight, and quality of life (11–15). Additionally, clear cutoff values for dysphagia, weight loss, and respiratory impairment to support optimal timing of gastrostomy placement are also largely absent (2, 11). This is reflected in the Dutch and international ALS guidelines which offer limited help with regard to optimal timing of gastrostomy indication (4–8). The two most commonly used methods of gastrostomy in ALS are percutaneous endoscopic gastrostomy (PEG), which has long been the golden standard and most commonly used method, and percutaneous radiological gastrostomy (PRG), also known as radiologically inserted gastrostomy. Studies show no difference between PEG and PRG in the effect on survival or weight stabilization (11, 13, 16) and both come with advantages and drawbacks (4, 17). Finally, a lack of patient readiness, i.e. the inability or unwillingness to make a decision, can also complicate the decision-making process (18,19). Uncertainty on optimal timing and method of placement, and complexity of the decision-making process may lead to practice variation.

In the Netherlands, 38 multidisciplinary ALS care teams coordinated by rehabilitation physicians are responsible for the care of patients with ALS. It is unclear what current practices with regard to gastrostomy are in ALS care teams. In order to improve the clinical pathway, information provision, and decision-making on gastrostomy, we investigated (1) current practices in timing of indication, goals, initiating discussion about gastrostomy, and method of placement (PEG or PRG) in gastrostomy amongst rehabilitation physicians of ALS care teams in the Netherlands, and (2) barriers and support needs in the indication and decision-making process.

Method

Setting

In the Netherlands, care for patients diagnosed with ALS is covered by 38 multidisciplinary ALS care teams associated with the ALS Care Network. The ALS Care Network is a nation-wide healthcare network aimed at providing optimal care for people with ALS in the Netherlands. The ALS care teams vary in number of patients and organizational structure, but also in setting from small regional hospitals, large university medical centers, to rehabilitation centers. Care in these teams is

multidisciplinary and coordinated by a rehabilitation physician.

Design and participants

We conducted a cross-sectional online survey on gastrostomy indication and decision-making in ALS amongst rehabilitation physicians of ALS care teams in the Netherlands. A total of 71 rehabilitation physicians of 38 ALS care teams were identified through the registry of the ALS Center Netherlands; rehabilitation physicians were informed about the study and invited to participate via email. After two months a reminder was sent out to all physicians who had not yet completed the survey. Physicians' anonymity was ensured by using codes instead of names.

Survey

The online survey was developed using Castor's Electronic Data Capture software (www.castoredc.com). The topics of the survey were based on literature and expert opinion of rehabilitation physicians (WK, EK, AV) of our ALS care team at UMC Utrecht, the Netherlands. All items were a combination of multiple choice, dichotomous, and open questions. The survey started with questions on years of experience in ALS, the number of patients currently in care and the number of those with gastrostomy (PEG, PRG, or other) or nasogastric tube.

Current practices regarding gastrostomy. To determine current practices regarding gastrostomy in the Netherlands, we asked participants to answer items on four topics. *Timing of indication:* clinical indicators (malnutrition/weight loss, dysphagia, sufficient intake of liquids, vital capacity (VC), prolonged and difficult meals, decreased appetite, dependency on others, hypermetabolism, recurrent chest infections due to aspiration, oral hygiene) and criteria/cutoff values for these indicators; guidelines used in coming to a gastrostomy indication. Additionally, what guidelines are used in to come to a gastrostomy indication? *Goals:* the three most important goals of gastrostomy placement. *Initiating discussion about gastrostomy:* timing of first introduction of the topic of gastrostomy; involvement in decision-making of family, ALS care team members, other and healthcare professionals (HCP) outside the ALS care team; information sources about gastrostomy provided to patients. *Method of placement:* criteria for preferred method of gastrostomy placement (PEG, PRG, other) or nasogastric tube.

Barriers and support needs in indication and decision-making. We included items on barriers and support needs in the indication and decision-making process. *Barriers:* difficulties or barriers in

the process of gastrostomy indication and discussion of the topic. *Support needs*: support needed to enhance the process of gastrostomy indication.

Analysis

We used descriptive statistics to summarize responses to multiple choice and dichotomous questions. Responses to open questions were coded by one researcher (RvE) using open coding and discussed with two researchers (AB, WK). For questions on current practices, the instances of codes were analyzed (content analysis). Generated codes for barriers and support needs were analyzed for themes (thematic analysis).

Results

The survey was completed by 29 of 71 physicians (41%) of 27 out of 38 ALS care teams (71%). At the time of survey, respondents had a median experience of 7 years (interquartile range = 3–15) working with ALS and mean of 20 patients in care. Together they were responsible for 590 patients; 32% of these patients had a gastrostomy, of whom 50% had a PEG ($n=93$), 49% a PRG ($n=91$). Three patients had a nasogastric tube, one of which was temporary, and one a jejunal endoscopic probe.

Current practices regarding gastrostomy

Timing of indication. *Clinical indicators.* All respondents agreed on the importance of malnutrition/weight loss, dysphagia, and prolonged and effortful meals as indicators for gastrostomy (Table 1). Further important indicators, reported by 80% or more of respondents, were recurrent chest infections, insufficient or unsafe intake of liquids, and low vital capacity. Many respondents did report that they viewed the indicators, including malnutrition/weight loss, as very subjective and interrelated.

Criteria/cutoff values. With regards to malnutrition/weight loss, 76% of respondents uses a loss of 10% or more during the last three to six months as a cutoff value. Other than that, respondents' answers showed uncertainty and a lack of agreement on cutoff values/criteria for indicators. Twelve respondents (41%) mentioned patient's wishes with regard to one or more of the indicators, most commonly in connection to effortful meals (11 of 12) and less often to appetite (4 of 12) and dependency on others (3 of 12).

Goals. All respondents reported optimization of nutritional status as a goal of gastrostomy placement (Table 2). Other frequently reported goals were safe food-intake (72%) and reduction of effortful meals (59%). Only 24% mentioned optimization of quality of life and 7% prolonging survival.

Table 1. Timing of gastrostomy indication.

Clinical indicators	Respondents, n (%)
Malnutrition/weight loss	29 (100)
Dysphagia	29 (100)
Prolonged and effortful meals	29 (100)
Recurrent chest infections	27 (93)
Insufficient intake of liquids	24 (83)
Low vital capacity	24 (83)
Decreased appetite	19 (65)
Dependency on others	10 (34)
Hypermetabolism	2 (7)
Oral hygiene	2 (7)
Criteria/cutoff values^a	
<i>Cutoff values for malnutrition/weight loss^b</i>	
≥ 10% weight loss in last 3-6 months	22 (76)
≥ 5% weight loss in last 3-6 months	11 (37)
≥ 10% premorbid weight loss	10 (34)
BMI ≤ 18,5	7 (24)
≥ 5% premorbid weight loss	5 (17)
BMI ≤ 20	4 (14)
No explicit cutoff value	2 (7)
Guidelines	Respondents, n(%)
Dutch guideline PEG placement for patients with ALS (ALS Center Netherlands 2010)	29 (100)
Motor neurone disease: assessment and management (NICE NG42)	2 (7)
Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition (NICE CG32)	1 (3)
EFNS guidelines on the clinical management of ALS (EFNS 2012)	0
The care of the patient with ALS: Drug, nutritional, and respiratory therapies (AAN 2009)	0
<i>Other</i>	
Guideline of ALS care team or affiliated hospital/rehabilitation center	15 (55)

$n=29$. ^a All questions on criteria/cutoff values for the clinical indicators were open questions, except for malnutrition/weight loss for which we provided a choice between seven options based on existing guidelines and relevant literature.

^bMultiple answers were possible. BMI: body mass index.

Initiating discussion about gastrostomy. Half of respondents (52%) reported the topic of gastrostomy is first introduced by them, or another member of the ALS care team, early after diagnosis, i.e. during first or second consultation, before an indication for gastrostomy and the need to make a decision (Table 3). The other half (48%) introduces the topic later when there is an indication for gastrostomy.

Method of placement. Independent of other criteria, 15 physicians (52%) referred to PEG as “first choice”, “standard”, or “preferred” method of placement versus five respondents (17%) for

Table 2. Physician goals of gastrostomy placement.

Goals	Description	Respondents, n (%)
Optimize nutritional status	... to prevent weight loss and unnecessary muscle loss, and ensure adequate intake of energy, food, liquids, and medication.	29 (100)
Ensure safe food-intake	... to prevent choking, pneumonia, and other respiratory infections due to aspiration.	21 (72)
Reduce effort of meals	... to decrease energy cost, time loss, strain on patient and caregiver, and anxiety over food intake, and provide more time to enjoy what can be eaten and social aspects of eating.	16 (59)
Optimize quality of life		7 (24)
Prolong survival		2 (7)

n = 29. Multiple answers were possible.

Table 3. Initiating discussion about gastrostomy.

Decision-making	Respondents, n (%)
First introduction	
Early after diagnosis	15 (52)
At indication	14 (48)
Involvement in decision-making process	
Family	29 (100)
<i>ALS care team members</i> ^a	
Speech therapist	29 (100)
Dietician	29 (100)
Social worker	9 (31)
Occupational therapist	8 (28)
Physiotherapist	7 (24)
Psychologist	3 (10)
ALS care team during team meeting	3 (10)
<i>Other healthcare professionals</i> ^a	
Gastroenterologist	15 (52)
Pulmonologist	13 (45)
General practitioner	7 (24)
Radiologist	6 (21)
Others (i.e. neurologist or nurse specialist, otorhinolaryngologist, anesthetist, case-manager palliative care team, homecare team)	8 (28)
Information provided to support decision-making on gastrostomy	
Website of ALS Center Netherlands	25 (86)
Brochures from ALS care team	17 (59)

n = 29.

^aMultiple answers were possible.

PRG; nine physicians (31%) did not state a preference for one method over the other (Table 4). Availability of service was also mentioned as a factor partly determining the preference for PEG (14%) or PRG (7%); however, it is frequently mentioned that the alternative is available to the patient at a different hospital in the region. Procedure-related criteria were reported for both PEG (17%) and PRG (59%); and seven respondents (24%) stated that patient preference also plays a role in deciding on the preferred method of placement.

Other methods. Physicians only rarely considered placement of nasogastric tubes or surgical

jejunal probes. Nasogastric tubes are only considered in case of acute emergency, temporarily pending PEG/PRG placement, or in the terminal phase of the disease. Jejunal probes were only considered if both PEG and PRG were not possible, for example due to unfavorable anatomy.

Barriers and support needs in indication and decision-making

Barriers. Two-thirds of respondents (69%) experienced barriers during the indication and decision-making process (Table 5). Five respondents (17%) reported organizational barriers, nine (31%) reported uncertainties over the timing of indication

Table 4. Selection criteria for preferred method of gastrostomy placement: PEG or PRG.

Criteria	Description	PEG, n (%)	PRG, n (%)
Physician preference	... for one method (PEG or PRG) because this is the “first choice”, “standard”, or “preferred” method of placement of the physician and/or hospital affiliated with the ALS care team.	15 (52)	5 (17)
Availability of service	... may play a role, in the case of PEG because it is the only available method at the local hospital affiliated with the ALS care team, with PRG available at the regional university medical center; or because there is only collaboration with a radiologist in the case of PRG.	4 (14)	2 (7)
Lower risk of complications	... due to the procedure and less frequent probe changes.	5 (17)	
Contraindication PEG	... due to impaired respiratory capacity or health, or previously failed PEG placement.		17 (59)
Patient preference ^a	... for PEG over PRG because probe changes are needed less frequently; or PRG over PEG because conscious sedation is not needed during the procedure making the procedure less threatening, anxiety inducing, and uncomfortable in their perception, and this also enables patients to postpone decision-making on gastrostomy.	2 (7)	7 (24)

n = 29. PEG: Percutaneous endoscopic gastrostomy; PRG: Percutaneous radiological gastrostomy. Multiple answers were possible.

^a Two respondents mentioned patient preferences for both PEG and PRG; thus seven physicians mentioned in total mentioned patient preferences in relation to method of placement.

and intervention, and the most frequently reported barrier was promoting patient readiness to make a decision on gastrostomy (48%). Postponement of decision-making was most frequently mentioned in relation to patient readiness, but also rejection of gastrostomy in the face of clinical need. In both situations, physicians said they sometimes find it difficult to decide when and how to discuss the topic in a manner that would support the decision-making process. Finally, one respondent mentioned frontotemporal dementia as a potential barrier hindering decision-making.

Support needs. Participants reported that more clarity on and evidence for (timing of) indication (35%) and better tools to tailor information to the patient (31%) can support the decision-making on gastrostomy (Table 6).

Discussion

Our study shows practice variation in the timing of first introduction in the topic of gastrostomy and method of placement amongst rehabilitation physicians of ALS care teams in the Netherlands. There is agreement on the most important goals and clinical indicators for gastrostomy indication, but not on the cutoff values/criteria for these indicators. The majority of rehabilitation physicians reported support needs related to evidence-based timing of indication and placement, tailored patient information, and promoting patient readiness.

In line with international guidelines for ALS (4,5), the most frequently reported goals for gastrostomy in our survey were optimizing nutrition, ensuring safe food intake, and reducing the effort of meals. Although gastrostomy may help preserve health-related quality of life in ALS (12), this was only infrequently mentioned by our respondents and should be considered a secondary goal of gastrostomy together with prolonging survival. A lack of conclusive evidence may explain why prolonging survival was not mentioned as a goal. Although a recent meta-analysis reported a positive effect of PEG on survival (20), another meta-analysis was inconclusive (14) and the most recent study by Vergonjeanne et al. 2021 showed that gastrostomy placement did not have any impact on survival (21). Studies have suggested that earlier placement might enhance survival (21) and prevent further weight loss (13); however, it is debatable whether earlier placement will be acceptable to patients with ALS (3, 19).

Respondents agree on the most important, primary clinical indicators for gastrostomy (i.e. malnutrition/weight loss, dysphagia, prolonged and effortful meals, recurrent chest infections, insufficient intake of liquids, low vital capacity). Decreased appetite, increased dependency on others, and hypermetabolism were mentioned less frequently despite research showing their association with weight loss, altered nutritional state through lower energy intake or increased energy needs, or decision-making on gastrostomy (3,

Table 5. Barriers in indication and decision-making.

Barriers	Description	Respondent quotes	Respondents, n (%)
Experienced barriers			23 (69)
<i>Organization</i>			
Organizational barriers	... because of the high number of HCP's and departments involved, lack of expertise with ALS in regional hospitals, and time-consuming referral processes when method of placement is not available locally	“Many patients prefer to do this nearby. I would prefer the ALS Center because of their experience, care and good aftercare. Away from the ALS Center, I often find there aren't enough opportunities to have a short, fast and clear discussion about what the problems are, how these can best be dealt with and how the aftercare can best be arranged. I get bogged down with assistants, secretaries, insufficient communication etc.” (Respondent 12) “First of all, the patient must be registered in the right place and then the dietician must provide proper guidance with the correct information from the hospital where the procedure is to be performed. PEG is done in our hospital, but PRG is not and that requires more energy and time investment on our part to get it right”. (Respondent 26)	5 (17)
<i>Procedure</i>			
Uncertainty over timing of indication and intervention	... complicating discussion with patient and family, and placement (i.e. not too early or too late), because of lack of clear cutoff values, interrelated indicators, and unpredictable disease progression	“What does pose a problem is timing. Sometimes there are apparent indications for PEG/PRG whereby it doesn't have to be used for feeding up until death, on the other hand there is sometimes a fairly sudden progression of swallowing problems/weight loss or breathing problems that require intervention at short notice”. (Respondent 3) “It is sometimes difficult to discuss at the right time when you do not know how quick the progress will be”. (Respondent 28) “It is a combination of 'relative' indicators”. (Respondent 36)	9 (31)
Uncertainty over risk of complications depending on method of placement (PEG or PRG)		“At other times, there are also complaints/problems after placement of PEG/PRG which (temporarily) reduce functioning/well-being. It is unclear how often this occurs in ALS patients and whether there is a difference between PEG/PRG”. (Respondent 3)	1 (3)
<i>Patient</i>			
Promoting patient readiness to make a decision on gastrostomy	... was most frequently reported as a barrier in relation to postponement of decision-making, i.e. unwillingness or inability of some patients to discuss the topic and make a decision on gastrostomy, which could result in placement that was too late when the patient eventually accepted the necessity of gastrostomy. But some physicians also reported struggling to accept patients' choice when they rejected gastrostomy in the face of, according to their physician, obvious clinical need	“Discussing this is not difficult, but getting people motivated in time is difficult. Many people are reluctant for (too long) a time and keep waiting and then suddenly turn out to want a tube at a much too late stage (where it previously had been firmly rejected time and time again). How to get more people motivated for this procedure at an earlier stage is a real question for me”.. (Respondent 12) “People are not always open to it, but I do discuss it with them. However, it remains their choice, which can sometimes lead to unpleasant scenes”. (Respondent 46) “The patient also has a major say in their situation and sometimes wants something other than what is recommended”. (Respondent 64)	14 (48)
Frontotemporal dementia hindering process of decision-making		“It can be difficult when there is also FTD [frontotemporal dementia]”. (Respondent 45)	1 (3)
No barriers			9 (31)

n = 29. Multiple answers were possible.

Table 6. Physician support needs in indication gastrostomy.

Support needs	Description	Respondent quotes	Respondents, n (%)
Experienced support needs			17 (62)
<i>Organization</i>			
Overcoming organizational hurdles	... to facilitate communication between different teams and healthcare professionals.	"I would like a broader network of places where the choice of PRG/PEG can be considered and discussed. I would like to see shorter lines of communication with the specialized home care provider dealing with the feeding tube (working on it). I think there could and should be a clearer network here, managed nationally but spread across the various regions". (Respondent 12)	3 (10)
<i>Procedure</i>			
More evidence-based indication	... resulting in more clarity on cutoff values, timing, and interrelationship of criteria, a decision tool, and an update of the current guideline including PRG.	"More specific interpretation of indications: when can one still wait (certainly with the increasing range of energy/protein-enriched foods), when is PEG/PRG appropriate, and at what time". (Respondent 3) "An update of the [national] guideline would be appreciated". (Respondent 20) "I would like to see a decision model that can predict when the patient will need a PEG tube based on e.g. type of ALS, survival, swallow score, BMI (or BMI difference score), duration of meals etc., so that the patient can be told: based on how things are now, you will need a PEG tube in 9 months". (Respondent 35)	10 (35)
<i>Patient</i>			
Tailored patient information	... that includes advantages and disadvantages of gastrostomy, stories of other patients, and more information on the intervention and taking care of the feeding tube.	"What are the advantages and disadvantages (quality of life gain seems to be mainly in subjective indicators such as stressful meal duration/exhaustion, in the case of swallowing problems there is often a clear advantage but weight preservation, for example, is not immediately noticeable for the patient at that moment)". (Respondent 3) "Stories from experts - explanation of procedure, material, care". (Respondent 28) "For the patient, I would like to see stories from people with similar problems, who can tell the patient about their own experiences and dilemmas related to the placement of a feeding tube". (Respondent 31) "More opportunities to inform the patient before tube feeding is necessary, for example about the various possibilities for administering tube feeding". (Respondent 64)	9 (31)
More attention for psychological factors		"More insight into the psychological factors that may play a role". (Respondent 65)	1 (3)
No support needs			11 (38)

n = 29. Multiple answers possible.

22,23). The lack of consensus on cutoff values/criteria for clinical indicators of gastrostomy found in our survey is in agreement with findings from earlier surveys in England and Canada (11, 24) and is reflected in ALS guidelines (4–8). This stresses the need for a more evidence-based indication.

In our survey, half of the respondents reported lack of patient readiness as a barrier to decision-making on gastrostomy, whereas physicians may prefer a more proactive approach to symptom-management, patients and their caregivers may prefer a more reactive, wait-and-see approach (9, 18). Decision-making on gastrostomy, another

milestone in the disease, can be a difficult and emotional process for patients and their caregivers (2, 25) for whom psychosocial factors like coping, illness cognitions, and the need for control may trump medical arguments (3, 9, 19, 26,27). Underlying this may also be a more fundamental paradigm difference by physicians and patients of disease versus illness, i.e. an objective, clinical manifestation versus a subjective, experiential, psychosocial experience (28). This may also be why clinical goals like optimizing nutritional status and ensuring safe food-intake were more frequently

mentioned by our respondents compared to enhancing quality of life as a goal of gastrostomy.

Stimulating patient choice in gastrostomy may help to promote patient readiness to make a decision. Patients may desire to postpone decision-making or even decline gastrostomy and this should be respected by physicians while exploring the patient's choice and pointing out the benefits of (timely) placement (2). Meanwhile, dietary changes and supplementation can be explored to provide nutritional support before and after gastrostomy indication (5, 15, 29). However, physicians in our survey would have preferred patients not to postpone decision-making because this can lead to emergency placements, more complications, and possibly a negative effect on survival. Some respondents also reported finding it difficult to accept patients' autonomy when they declined gastrostomy. There is a delicate balance between patient choice and higher risk of complications and it is recommended that physicians discuss this dilemma with the patient (5). Additionally, cognitive impairments and especially frontotemporal dementia can impair decision-making capacity in ALS (30) and affect patient readiness; however, this was only mentioned by one respondent as a potential barrier.

Similar to studies in England and Canada (11, 24), our survey shows that in addition to clinical factors and patient preference, availability of options at the institution, and especially physician preference can play a role when considering the method of placement i.e. PEG or PRG. It has been argued that local availability and expertise should be the deciding factor since these influences the success rate of placement both in terms of mortality, complications, and aftercare (17). PEG-placement is associated with less tube-related complications compared to PRG, but is not always possible when conscious sedation is deemed unfeasible due to respiratory impairment (4, 17). PRG has a higher procedural success rate (17) and can take place later in the disease which may be attractive to patients wishing to postpone the procedure. Additionally, the tube needs to be replaced every three months in PRG but not in PEG. However, since there is no difference in survival between both methods of placement in ALS (13), without contraindication for one of the options, both should be discussed including advantages, drawbacks, and safety especially in relation to respiratory failure. Discussing decline of pulmonary function in relation to both timing and preferred method of placement is crucial given the concerns about the safety of PEG tube placement in patients with severely restricted pulmonary function (2). If the patient prefers a different method than locally available they can be referred to another nearby hospital; a number of respondents

in our survey report this option. Of course, this is easier in a small, densely populated country like the Netherlands compared to for example Canada.

In such a difficult, emotionally charged decision like gastrostomy (25, 31), early and regular discussion of gastrostomy is recommended (5), and gives patients time to think things over and become accustomed to the idea and prevents emergency decision-making (26, 32). Additionally, it seems important to explore motivations and emotions underpinning patient preferences, but also possible cognitive deficits (30) and low health literacy which can negatively influence patient decision-making. Decision aids have been proven effective in supporting decision-making (33) and can combine patient information with questions prompting patients to reflect on their preferences to better prepare them to discuss the decision with HCP's (34). Finally, all respondents in our survey included the family of the patient in the decision-making process and provided patients and their families with relevant information. Timely introduction of the topic, providing relevant information, and including the family are all important aspects of shared decision-making which supports patient autonomy in a preference-sensitive decision like gastrostomy (35).

Clinical and research recommendations

First, introduce the topic of gastrostomy early and, depending on the disease progression, continue discussing regularly. This enables patients to reflect on their preferences and get accustomed to the idea that they may have to make a decision on this topic in the future and prevent emergency decision-making. Second, provide relevant information to all patients on gastrostomy and method of placement (both PEG and PRG), preferably while (a) pointing out the advantages and disadvantages of gastrostomy and method of placement, (b) exploring dietary solutions to support nutritional status, (c) possible underlying preferences, emotions, and reasons, and (d) promoting patient choice. Third, ideally, decision aids and other information should be developed together with patients to provide patient information and support patients in exploring their preferences, which can help physicians to better explore patient readiness and tailor decision-making to individual patient needs. This is not an easy process, but the research group of Hogden and colleagues in Australia provide a useful development pathway that could provide guidance (18, 26, 34, 36). Fourth, prospective studies on gastrostomy in ALS should be conducted aimed at providing conclusive evidence on efficacy on survival, weight, and quality of life, and on optimal timing. Fifth, clinical implementation studies should explore how

ALS care teams can incorporate decreased appetite, fear of dependency on others for feeding, and hypermetabolism in gastrostomy indication and decision-making.

Methodological limitations

At 41% the response rate of rehabilitation physicians was low; however, over two thirds of ALS care teams in the Netherlands were represented in the survey. However, some of the respondents stated that their responses represented the opinion of all rehabilitation physicians within their ALS care team and we assume there to be a large degree of concordance within these teams.

Conclusion

There is evidence of practice variation in the timing of first introduction on the topic of gastrostomy and method of placement amongst rehabilitation physicians in the Netherlands. There is agreement on the goals and most relevant clinical indicators for gastrostomy, but not on the cut-off values/criteria to come to an indication. More evidence on the efficacy and optimal timing of gastrostomy placement is needed. However, until then early and regular discussion of the topic of gastrostomy based on adequate patient information may promote patient readiness and support patient choice.

Declaration of interest

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References

1. Janse Van Mantgem MR, Van Eijk RPA, Van Der Burgh HK, Tan HHG, Westeneng HJ, Van Es MA, et al. Prognostic value of weight loss in patients with amyotrophic lateral sclerosis: a population-based study. *J Neurol Neurosurg Psychiatry*. 2020;91:867–75.
2. Hobson EV, McDermott CJ. Supportive and symptomatic management of amyotrophic lateral sclerosis. *Nat Rev Neurol*. 2016;12:526–38.
3. Stavroulakis T, Baird WO, Baxter SK, Walsh T, Shaw PJ, McDermott CJ. Factors influencing decision-making in relation to timing of gastrostomy insertion in patients with motor neurone disease. *BMJ Support Palliat Care*. 2014;4:57–63.
4. Burgos R, Bretón I, Cereda E, Desport JC, Dziewas R, Genton L, et al. ESPEN guideline clinical nutrition in neurology. *Clin Nutr*. 2018;37:354–96.
5. National Institute for Health and Clinical Excellence (2016). Motor neurone disease: assessment and management (NICE guideline).
6. Miller RG, Jackson CE, Kasarskis EJ, England JD, Forshew D, Johnston W, et al. Practice Parameter update: the care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies (an evidence-based review): report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. 2009;73:1218–26.
7. van den Berg JP, De Goeijen JC, Kruitwagen-Van Reenen ET, Piepers S, Van Der Kooij AJ, Westermann EJA. Dutch Guideline Percutaneous Endoscopic Gastrostomy (PEG) placement for patients with Amyotrophic Lateral Sclerosis (ALS). 2010. <https://www.als-centrum.nl/kennisplatform/richtlijn-peg-plaatsing-bij-als/>
8. Andersen PM, Abrahams S, Borasio GD, de Carvalho M, Chio A, Van Damme P, et al. EFNS guidelines on the Clinical Management of Amyotrophic Lateral Sclerosis (MALS)-revised report of an EFNS task force. *Eur J Neurol*. 2012;19:360–75.
9. Martin NH, Lawrence V, Murray J, Janssen A, Higginson I, Lyall R, et al. Decision making about gastrostomy and noninvasive ventilation in amyotrophic lateral sclerosis. *Qual Health Res*. 2016;26:1366–81.
10. van Es MA, Hardiman O, Chio A, Al-Chalabi A, Pasterkamp RJ, Veldink JH, et al. Amyotrophic lateral sclerosis. *Lancet*. 2017;390:2084–98.
11. Stavroulakis T, Walsh T, Shaw PJ, McDermott CJ, Progas Study. Gastrostomy use in motor neurone disease (MND): a review, meta-analysis and survey of current practice. *Amyotroph Lateral Scler Frontotemporal Degener*. 2013;14:96–104.
12. Kurien M, Andrews RE, Tattersall R, McAlindon ME, Wong EF, Johnston AJ, et al. Gastrostomies preserve but do not increase quality of life for patients and caregivers. *Clin Gastroenterol Hepatol*. 2017;15:1047–54.
13. Group PS. Gastrostomy in patients with amyotrophic lateral sclerosis (ProGas): a prospective cohort study. *Lancet Neurol* 2015;14:702–9.
14. Cui F, Sun L, Xiong J, Li J, Zhao Y, Huang X. Therapeutic effects of percutaneous endoscopic gastrostomy on survival in patients with amyotrophic lateral sclerosis: a meta-analysis. *PLoS One*. 2018;13:e0192243.
15. Stavroulakis T, McDermott CJ. Nutritional support in amyotrophic lateral sclerosis. In Arsava EM, editor. *Nutrition in neurologic disorders*: Springer; 2017. p. 91–104.
16. Yang B, Shi X. Percutaneous endoscopic gastrostomy versus fluoroscopic gastrostomy in amyotrophic lateral sclerosis (ALS) sufferers with nutritional impairment: a meta-analysis of current studies. *Oncotarget* 2017;8:102244–53.
17. Strijbos D, Keszthelyi D, Gilissen LPL, Lacko M, Hoeijmakers JGJ, van der Leij C, et al. Percutaneous endoscopic versus radiologic gastrostomy for enteral feeding: a retrospective analysis on outcomes and complications. *Endosc Int Open*. 2019;7:E1487–95.
18. Hogden A, Greenfield D, Nugus P, Kiernan MC. s. Development of a model to guide decision making in amyotrophic lateral sclerosis multidisciplinary care. *Health Expect*. 2015;18:1769–82.
19. Greenaway LP, Martin NH, Lawrence V, Janssen A, Al-Chalabi A, Leigh PN, et al. Accepting or declining non-

- invasive ventilation or gastrostomy in amyotrophic lateral sclerosis: patients' perspectives. *J Neurol.* 2015;262:1002–13.
20. Bond L, Ganguly P, Khamankar N, Mallet N, Bowen G, Green B, et al. A comprehensive examination of percutaneous endoscopic gastrostomy and its association with amyotrophic lateral sclerosis patient outcomes. *Brain Sci.* 2019;9:223.
 21. Vergonjeanne M, Fayemendy P, Marin B, Penoty M, Lautrette G, Sourisseau H, et al. Predictive factors for gastrostomy at time of diagnosis and impact on survival in patients with amyotrophic lateral sclerosis. *Clin Nutr.* 2020;39:3112–8.
 22. Ngo ST, van Eijk RPA, Chachay V, van den Berg LH, McCombe PA, Henderson RD, et al. Loss of appetite is associated with a loss of weight and fat mass in patients with amyotrophic lateral sclerosis. *Amyotroph Lateral Scler Front Degener* 2019;20:497–505.
 23. Ioannides ZA, Ngo ST, Henderson RD, McCombe PA, Steyn FJ. Altered metabolic homeostasis in amyotrophic lateral sclerosis: mechanisms of energy imbalance and contribution to disease progression. *Neurodegener Dis.* 2016;16:382–97.
 24. Benstead T, Jackson-Tarlton C, Leddin D. Nutrition with gastrostomy feeding tubes for amyotrophic lateral sclerosis in Canada. *Can J Neurol Sci.* 2016;43:796–800.
 25. Oliver DJ, Turner MR. Some difficult decisions in ALS/MND. *Amyotroph Lateral Scler.* 2010;11:339–43.
 26. Labra J, Hogden A, Power E, James N, Flood VM. Gastrostomy uptake in motor neurone disease: a mixed-methods study of patients' decision making. *BMJ Open.* 2020;10:e034751.
 27. Foley G, Timonen V, Hardiman O. Exerting control and adapting to loss in amyotrophic lateral sclerosis. *Soc Sci Med.* 2014;101:113–9.
 28. Helman CG. Disease versus illness in general practice. *J R Coll Gen Pract.* 1981;31:548–52.
 29. (NICE) NI for H and CE. Nutrition support for adults: or oral al nutrition support, enter enteral al tube feeding and parenter parenteral al nutrition. 2016.
 30. Khin EK, Minor D, Holloway A, Pelleg A. Decisional capacity in amyotrophic lateral sclerosis. *J Am Acad Psychiatry Law* 2015;43:210–7.
 31. Voltz R. Assisted nutrition: a difficult decision in patients with amyotrophic lateral sclerosis. *Lancet Neurol.* 2015; 14:671–2.
 32. Seeber AA, Hijdra A, Vermeulen M, Willems DL. Discussions about treatment restrictions in chronic neurologic diseases: a structured review. *Neurology.* 2012; 78:590–7.
 33. Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev.* 2017;4:CD001431.
 34. Hogden A, Crook A. Patient-centered decision making in amyotrophic lateral sclerosis: where are we? *Neurodegener Dis Manag.* 2017; 7:377–86.
 35. Stiggelbout AM, Pieterse AH, De Haes JCJM. Shared decision making: concepts, evidence, and practice. *Patient Educ Couns.* 2015;98:1172–9.
 36. Hogden A, Greenfield D, Caga J, Cai X. Development of patient decision support tools for motor neuron disease using stakeholder consultation: a study protocol. *BMJ Open.* 2016;6:e010532.