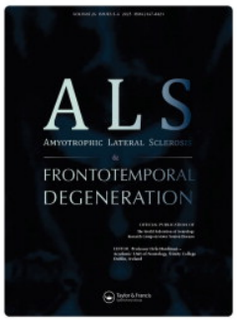

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RESEARCH ARTICLE

Nutritional care practices in ALS: perspectives of healthcare professionals and people with ALS

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Abstract

Objective: To map nutritional care provided to people with ALS, PMA and PLS (pwALS) and identify barriers encountered by healthcare professionals and pwALS. *Methods:* Two online questionnaires, addressing current nutritional management of ALS in the Netherlands, were sent to healthcare professionals of the 36 certified ALS care teams and pwALS drawn from a population-based registry. Topics were: 1) contact between pwALS and their ALS care team, 2) monitoring nutritional status, 3) nutritional advice provided or received, and 4) satisfaction with current nutritional care and barriers encountered. *Results*: In total, 100 healthcare professionals and 372 pwALS completed the questionnaires. Dietitian responses (n = 36/100) showed that 28% utilized malnutrition screening tools and 17% measured body composition. Dietitians used different predictive equations to estimate energy and protein requirements. Patient responses showed that 50% had contact with a dietitian, 7% indicated body composition had been measured and 25% reported never being weighed or weighing themselves. Healthcare professionals and pwALS highlighted the need for comprehensive, up-to-date information on nutrition and ALS, national consensus on nutritional advice and monitoring methods, patient information material, training for healthcare professionals and personalized nutritional advice for pwALS. *Conclusions*: Practice variation was observed in the assessment and monitoring of nutritional status and the provision of nutritional advice. Suboptimal monitoring of nutritional status and estimation of nutritional requirements may result in delayed detection of malnutrition and inaccurate dietary recommendations. Further research and national consensus on monitoring methods and nutritional advice is required.

Keywords: *Amyotrophic lateral sclerosis, motor neurone disease, nutritional support, nutritional status, surveys and questionnaires*

Introduction

Amyotrophic lateral sclerosis (ALS), progressive muscular atrophy (PMA) and primary lateral sclerosis (PLS), further referred to as ALS, are neurodegenerative diseases characterized by symptoms such as dysphagia, muscular atrophy, fatigue and loss of appetite. Therefore, many patients face difficulties in maintaining adequate nutritional intake (1,2). Compounded by hypermetabolism, these difficulties increase the risk of malnutrition and weight loss (3–7). As weight loss further impairs physical functioning, problems with nutrition can have a major impact on quality of life (3). Furthermore, malnutrition is a prognostic factor for survival (8–10).

Although existing guidelines from the ESPEN (11), EAN/EFNS (12,13) and NICE (14) recommend maintaining a good nutritional status in people with ALS (pwALS) and advocate structural

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monitoring of body weight and nutritional intake, they do not offer detailed, practical guidance for healthcare professionals (HCPs). Furthermore, there is a lack of consensus in scientific literature regarding the optimal content of nutrition (carbohydrates, proteins, fats and energy) (3,11), appropriate timing for patient referral to a dietitian (2) and placement of a feeding tube (15).

In the Netherlands, after diagnosis, neurologists refer pwALS to a rehabilitation physician, who coordinates multidisciplinary care within one of the 36 certified ALS care teams (a detailed description of the Dutch ALS care setting can be found in supplementary material 1). These teams manage patient populations of fewer than 20 to 100 pwALS, which may result in varying degrees of experience and expertise in ALS. Organization of nutritional care within the teams remains unclear.

Insufficient guidance for HCPs, lack of consensus in scientific literature and variation in the size and experience of ALS care teams in the Netherlands may cause practice variation, indicating that the provision of high-quality nutritional care may not be guaranteed for all pwALS.

Practice variation has also been reported internationally (2,16–18), including differences in the skills and knowledge of HCPs, organization and delivery of nutritional care (18), and differences in the content of care provided (2,16,17). Various nutritional assessment methods have been applied and several equations used to estimate nutritional requirements.

Since pwALS are the recipients of ALS care, it is crucial to retrieve their experiences with current nutritional care and integrate these with those of HCPs. Incorporating the feedback of pwALS and understanding their perceived barriers will ensure new care strategies are relevant and effective.

A better understanding of current nutritional care and the barriers encountered in the nutritional management of ALS is necessary to facilitate the development of a more standardized approach, ensuring that all pwALS have access to high-quality personalized nutritional care. Therefore, this study aimed to 1) determine whether there is practice variation in the ALS care network in the Netherlands, and 2) provide insight into the barriers encountered by HCPs and pwALS.

Methods

Study design and population

A cross-sectional survey study was performed. Two questionnaires were developed and created in Castor EDC, a secure web-based Electronic Data Capture platform which ensures the anonymity and confidentiality of survey responses (Castor EDC - Login). All dietitians, rehabilitation physicians, speech therapists and nurse specialists of the 36 certified ALS care teams in the Netherlands were invited to participate. PwALS were recruited via the neuromuscular diseases registry of the Dutch ALS Center. Patient characteristics, including diagnosis, date of diagnosis and score on the ALS Functional Rating Scale Revised (ALSFRS-R) were also retrieved from the registry.

The study was deemed exempt from review by the Medical Ethics Committee of the University Medical Center Utrecht. All participants received a personal link to the questionnaire and gave informed consent prior to participation. The study was reported according to the Checklist for Reporting Of Survey Studies (CROSS) (19) (Suppl. 2).

Questionnaires

A questionnaire for dietitians, created by White et al. (2), served as inspiration for the HCP questionnaire (Suppl. 3a). Questions were adapted to the context of ALS care in the Netherlands, which is organized within rehabilitation facilities (e.g. questions related to the commissioning and funding of MND services, as well as the section on multidisciplinary team (MDT) working were omitted). Also new questions were added to assess contact (e.q. frequency) between ALS care teams and patients and to identify challenges and needs in nutritional care for pwALS. The HCP questionnaire consisted of a maximum of 68 questions, the total number depending on previous responses. No questions were tailored to specific disciplines, because the organization of nutritional care within different ALS care teams may vary.

Questions for the patient questionnaire (Suppl. 3b) were based on the HCP questionnaire and expert opinion (from a project team consisting of two dietitians, two researchers, two pwALS, a caregiver and a rehabilitation physician). The questionnaires were reviewed for face validity to confirm that the included items were appropriate. The draft questionnaire was sent to the patients and caregiver of the project team for feedback. After incorporating their feedback (e.g. inclusion of additional questions to assess whether dietary advice offered new information and whether it was followed), the revised questionnaire was pretested by the project team and two patient representatives of the Dutch ALS patient association. The final patient questionnaire consisted of a maximum of 84 questions, the total number depending on previous responses.

The first part of both questionnaires focused on nutritional care organization for pwALS in the Netherlands; the second part on barriers and needs for improvement. Questions were divided into four topics: 1) Contact between pwALS and their ALS care team, 2) monitoring nutritional status, 3) nutritional advice provided or received, and 4) satisfaction with current nutritional care, and barriers

encountered. The questionnaires contained both multiple choice and open-ended questions.

Each questionnaire was available for a period of approximately four weeks between December 2023 and April 2024 and took 20-25 minutes to complete. Two weeks after the invitation, an automated reminder was sent from Castor EDC. A manual reminder was also sent to participants who had started the questionnaire but had not yet submitted it. Questionnaires completed for at least 50% were included in the analysis.

Analysis

Quantitative data were analyzed in RStudio (version 2023.12.1 + 402) for Windows. Responses to multiple choice questions were summarized using descriptive statistics (frequency counts, percentages, medians and interquartile ranges). Analysis of both questionnaires was conducted in two phases: 1) analysis of all participant responses and 2) subgroup analyses to determine whether the subgroup responses differed from the overall group responses. For the HCP questionnaire, subgroups were defined based on number of pwALS managed by the team: small (<20), middle (20–50) and large (>50). For the patient questionnaire, subgroups were stratified according to the swallowing item score of the ALSFRS-R. For the HCP questionnaire, dietitian responses related to current practices for monitoring nutritional status were analyzed separately. Missing data (item nonresponse) were not imputed. Responses to open-ended questions (qualitative data) were organized into categories (coded) and key findings were summarized.

Results

Population characteristics

A total of 100/242 HCPs (41%) and 372/714 pwALS (52%) from 36/36 (100%) certified ALS care teams completed the questionnaires. A median of two-and-a-half HCPs (IQR = 2-4) and eight pwALS (IQR = 4-14) per ALS care team participated. The population characteristics are shown in Tables 1 and 2. Dietitians, rehabilitation physicians and speech therapists from teams managing fewer than 20, 20-50 and more than 50 pwALS responded to the questionnaires, whereas nurse specialists were only represented in teams caring for more than 50 patients (Suppl. Table 1).

Current nutritional care practices reported by HCPs

Timing of, and criteria for patient referral to a dietitian and monitoring nutritional status. Fifty-six percent ($n = 56/100$) of HCPs reported that all pwALS were referred to a dietitian at time of diagnosis (18 of 36 teams). The other half ($n = 44/100$) reported referring pwALS on medical grounds (18 of 36 teams), most commonly weight loss (100%, $n = 44/44$), decreased nutritional intake (91%, $n = 40/44$) and dysphagia (86%, $n = 38/44$). Responses to an open-ended question regarding the amount of weight loss leading to a referral varied from cutoffs of 2-3 kg, 5%, 10% to no specific cutoff values used. Methods used to measure nutritional status did not differ between HCPs who referred pwALS to a dietitian at diagnosis and those who referred on medical grounds (e.g. measuring body weight (at diagnosis: 91%, $n = 51/56$; medical grounds: 93%, $n = 41/44$; $p = 1$), body composition (at diagnosis: 14%, $n = 8/56$; medical grounds: 7% $n = 3/44$; $p = 0.3$) or calculating BMI (at diagnosis: 68%, $n = 38/56$; medical grounds: 61% $n = 27/44$; $p = 0.6$)).

Analysis of the results revealed that HCPs with professions other than dietitians frequently answered "I don't know" to questions regarding nutritional assessment of pwALS. Forty-seven percent ($n = 15/32$) of the speech therapists did not know how nutritional status is measured in their ALS care team. Additionally, 63% ($n = 20/32$) of the speech therapists and 35% ($n = 8/23$) of the rehabilitation physicians did not know whether screening tools are used to assess the risk of malnutrition and 59% ($n = 19/32$) of the speech therapists, 35% ($n = 8/23$) of the rehabilitation physicians, and 60% ($n = 3/5$) of the nurse specialists reported uncertainty in how energy requirements for pwALS are estimated. Therefore, a post-hoc analysis was performed with only dietitian responses to this section of the questionnaire.

Screening for risk of malnutrition and nutritional assessment performed by dietitians. Twenty-eight percent ($n = 10/36$) of the dietitians indicated that nutritional screening tools were used in their ALS care team. None were part of a small ALS care team (<20 patients). Some dietitians used multiple tools, most frequently the Short Nutritional Assessment Questionnaire (SNAQ) (70%; $n = 7/10$), and the Malnutrition Universal Screening Tool (MUST) (40%; $n = 4/10$) (Table 3).

Dietitians assessed nutritional status most frequently by measuring body weight (97%; $n = 35/36$) or calculating BMI (78%, $n = 28/36$) (Table 3). Seventeen percent ($n = 6/36$) indicated using Bioelectrical Impedance Analysis (BIA) to measure body composition. Almost all dietitians reported estimating protein- (100%; $n = 36/36$) and energy requirements (94%; $n = 34/36$), however, equations used varied (Table 3).

Dietary advice. Topics most frequently discussed by dietitians were body weight (100%; $n = 35/35$), and the use of enteral nutrition (100%; $n = 35/35$) (Table 4). Open-ended questions revealed that approximately one-third of the dietitians recommended protein intake based on nutritional status.

Table 1. Healthcare professional characteristics.

		HCPs N = 100
Profession, *n (%)*		
	Rehabilitation physician	23 (23)
	Dietitian	36 (36)
	Speech therapist	32 (32)
	Nurse specialist	5 (5)
	Other	4(4)
Experience (yrs), *median (IQR)*		
	In profession	15 (8-23)
	In ALS care	8 (5-15)
Hours of work per week, *median (IQR)*		28 (23-34)
Case load ALS (%)[a], *median (IQR)*		20 (10-36)
Number of ALS patients supported by team, N = 36 teams, *n (%)*		
	<20	11 (30)
	20-50	15 (42)
	>50	10 (28)
Permanent dietitian in team, *n (%)*		34 (94)

[a]Percentage of total work load dedicated to ALS.

Abbreviations: ALS, Amyotrophic Lateral Sclerosis; HCPs, HealthCare Professionals; N, Number of HCPs – total; n, number of HCPs – proportion; yrs, years.

Table 2. Patient characteristics.

		Patients N = 372
Diagnosis, *n (%)*	ALS	264 (71)
	PMA	66 (18)
	PLS	42 (11)
Site of onset, *n (%)*	Spinal	294 (79)
	Bulbar	63 (17)
	Thoracic/Respiratory	6 (2)
	Generalised	5 (1)
	Unknown	4 (1)
Disease duration, months, *median (IQR)*		32 (18-70)
ALSFRS-R, N = 277, *median (IQR)*	Total score	31 (23-39)
	Bulbar score[c]	10 (8-12)
	Swallowing score[d]	4 (3-4)
Receives nutritional care[a], *n (%)*		188 (51)
Ever received dietary advice[b], *n (%)*		211 (57)

[a]Currently or in the past year.

[b]From the dietitian of the ALS care team.

[c]Bulbar score is an item of the ALSFRS-R and indicates function of speech, salivation and swallowing. Each item can be scored from 4 (normal function) to 0 (complete loss of function), with a maximum bulbar score of 12. A lower score indicates greater impairment.

[d]Swallowing score is part of the bulbar score of the ALSFRS-R and indicates swallowing problems. A higher swallowing score means fewer swallowing problems. The maximum score is 4, which indicates normal eating habits, a score of 3 indicates early eating problems, 2 dietary consistency changes, 1 supplementary tube feeding needs and 0 nothing by mouth; exclusively enteral feeding.

Abbreviations: ALS, Amyotrophic Lateral Sclerosis; ALSFRS-R, Amyotrophic Lateral Sclerosis Functional Rating Scale – revised; N, number of patients – total; n, number of patients – proportion; PMA, Progressive Muscular Atrophy; PLS, Primary Lateral Sclerosis.

For malnourished pwALS, the majority of the dietitians recommended 1.2-1.5 g/kg, whereas for well-nourished pwALS, the recommended intake varied between 0.8 and 1.2 g/kg.

Other HCPs most frequently discussed pleasure experienced when eating (83%; $n = 48/58$), consistency of liquid nutrition (78%; $n = 45/58$) and meal duration (74%; $n = 43/58$) (Table 4).

Guidance used by HCPs. Seventy-six percent ($n = 71/93$) of HCPs indicated that dietary advice is based on guidelines. A Dutch guideline, in which the GRADE system for evidence synthesis was not applied, was most frequently used (Table 5). Dietary advice was based on the ESPEN guidelines by 20% ($n = 14/71$) of the HCPs (mostly dietitians ($n = 12$)).

Table 3. Malnutrition screening tools and nutritional assessment methods used by dietitians.

	n (%) N = 36
Screening tools malnutrition	
SNAQ	7 (19)
MUST	4 (11)
SGA	1 (3)
I don't know which tool is used	1 (3)
Malnutrition is not screened with screening tools	26 (72)
Body weight/composition assessment	
Body weight	35 (97)
BMI	28 (78)
TSF	0 (0)
MUAMC	1 (3)
BIA	6 (17)
DEXA	0 (0)
MRI	0 (0)
CT	0 (0)
Ultrasound	0 (0)
BODPOD	0 (0)
Micronutrients in blood	0 (0)
Method evaluation nutritional intake	
Dietary history method[a]	29 (81)
24-h recall[b]	3 (8)
Food diary[c]	2 (6)
Food diary and dietary history method combined	2 (6)
Nutritional intake is not evaluated	1 (3)
Equations to estimate energy requirement	
WHO	14 (39)
ALSFRS-equation/Kasarskis	17 (47)
Harris and Benedict	6 (17)
Energy requirements are not estimated	2 (6)

[a]With the dietary history method patients are asked about their habitual dietary intake.

[b]With a 24-h recall, patients are asked about their food intake in the past 24 hours.

[c]With a food diary, patients are asked to record their food intake over several days.

Abbreviations: ALSFRS, Amyotrophic Lateral Sclerosis Functional Rating Scale; BIA, Bioelectrical Impedance Analysis; BMI, Body Mass Index; BODPOD, instrument used for whole body air-displacement plethysmography; CT, Computed Tomography; DEXA, Dual Energy X-ray Absorptiometry; MRI, Magnetic Resonance Imaging; MUAMC, Mid Upper Arm Circumference; MUST, Malnutrition Universal Screening Tool; N, Number of dietitians – total; n, number of dietitians – proportion; SNAQ, Short Nutritional Assessment Questionnaire; SGA, Subjective Global Assessment; TSF, Triceps Skinfold; WHO, World Health Organization.

Current nutritional care practices reported by pwALS

Monitoring nutritional status. About half of the pwALS (53%; $n = 197/372$) reported weighing themselves or being weighed at least once per month, while 25% ($n = 90/372$) reported never being weighed. Among those weighed, approximately 25% ($n = 79/282$) were weighed by a HCP of their ALS care team. Seven percent ($n = 26/372$) indicated their body composition had been measured, of whom 69% ($n = 18/26$) indicated measurements were performed by a HCP of their ALS care team.

Dietary adjustments. Forty percent ($n = 147/372$) of the pwALS reported dietary adjustments since the onset of the disease. Adjustments most frequently included smaller portions, pureeing or cutting food into smaller pieces, increasing the number of meals per day and using oral nutritional supplementation or enteral nutrition. Twenty-three percent ($n = 87/372$) of the pwALS indicated adhering to a specific dietary pattern, with 60% ($n = 52/87$) following a protein-rich diet. Eighty percent ($n = 70/87$) started adhering to this diet because of their illness. Eight percent ($n = 29/372$) reported having a feeding tube (PRG/PEG).

Approximately 50% ($n = 181/372$) reported using dietary supplements (mostly vitamin D, C, B12 and magnesium), thirty-seven percent ($n = 68/181$) as advised by a HCP. A small proportion (8%; $n = 29/372$) indicated using complementary and alternative medicine, including homeopathy.

Dietary advice. About half of the pwALS (56%; $n = 211/372$) reported having received dietary advice from their ALS care team's dietitian. Of these, about half ($n = 114/211$) reported guidance on energy requirements and 65% ($n = 137/211$) on protein requirements. Approximately 75% indicated this information was new (Suppl. Table 2). Additionally, pwALS reported receiving dietary advice from other HCPs. Topics most often discussed were body weight (56%; $n = 165/372$), adjusted cutlery (35%; $n = 132/372$) and (excessive) saliva (34%; $n = 125/372$) (Table 4).

Approximately half of the pwALS whose recent ALSFRS-R scores were available ($n = 135/277$) reported being in contact with a dietitian (Table 6). Of these pwALS, 67% ($n = 91/135$) had a swallowing score below 4, indicating nutritional issues. However, 11% ($n = 6/142$) of those not in contact with a dietitian had swallowing difficulties (score below 3).

Barriers encountered and needs for improvement in current nutritional care practices reported by HCPs

Barriers when monitoring nutritional status of pwALS. Fifty-four percent ($n = 51/95$) of the HCPs reported encountering barriers when monitoring the nutritional status of pwALS (Table 7). Twenty-one percent ($n = 20/95$) indicated a lack of measuring equipment, 18% ($n = 17/95$) a lack of guidelines and 18% ($n = 17/95$) a lack of time. HCPs in smaller ALS care teams (<20 patients) experienced challenges in monitoring nutritional status more often (67%; $n = 14/21$) compared to HCPs in large teams (>50 patients) (50%; $n = 18/36$).

Barriers in providing dietary advice to pwALS. With regard to providing dietary advice to pwALS, 59% of the HCPs reported barriers (Table 7) including a lack of guidelines (24%;

Table 4. Dietary advice provided by HCPs and received by patients.

	Dietitians, n (%) N = 35	Other HCPs, n (%) N = 58	Patients, n (%) N = 372
Topics			
Body weight (maintenance, loss, gain)	35 (100)	42 (72)	165 (56)
Use of enteral nutrition	35 (100)	35 (60)	65 (17)
Protein intake*	34 (97)	21 (36)	137 (65)
Improving defecation	34 (97)	30 (51)	84 (23)
Use of oral nutritional supplementation	33 (94)	29 (50)	98 (26)
Texture of food	32 (91)	37 (64)	72 (19)
Appetite	32 (91)	34 (59)	105 (28)
Fluid intake	32 (91)	34 (59)	82 (22)
Meal duration	31 (89)	43 (74)	57 (15)
Pleasure experienced when eating	31 (89)	48 (83)	72 (19)
Caloric intake*	30 (86)	16 (28)	114 (54)
Consistency of liquid nutrition	30 (86)	45 (78)	73 (20)
Fibre intake	27 (77)	13 (22)	33 (9)
Use of dietary supplements (e.g. protein supplements)	27 (77)	4 (7)	65 (17)
Dutch dietary guidelines for healthy nutrition	25 (71)	5 (9)	42 (11)
Vitamin intake	21 (60)	6 (10)	33 (9)
Mineral intake	16 (46)	4 (7)	33 (9)
Adjusted cutlery/tableware	12 (34)	40 (69)	132 (35)
Fat intake	8 (23)	2 (3)	21 (6)
Swallowing techniques/anxiety	8 (23)	40 (69)	95 (26)
(Excessive) saliva	–	–	125 (34)
Other	2 (6)	3 (5)	–

*$n = 211$ instead of 372, as only patients who responded "yes" to the initial question "Have you ever received advice from the dietitian of the ALS care team?" received follow-up questions regarding whether they had received dietary advice specifically related to caloric intake and protein intake. In contrast, the other dietary topics were included in a multiple response (select all that apply) question that was presented to all patient respondents.

Note: Multiple answers could be given.

Abbreviations: HCPs, HealthCare Professionals; N, Number of participants – total; n, number of participants – proportion.

Table 5. Guidance used by HCPs.

	n (%)
Guidelines (N = 71)	
ESPEN	14 (20)
NICE	3 (4)
EFNS	0 (0)
MNDA	2 (3)
AAN	1 (1)
DvS	46 (65)
Local guidelines	15 (21)
Dutch guideline Speech Therapy in ALS, PMA and PLS	11 (15)
Other sources (N = 93)	
Scientific literature	26 (28)
Visiting conferences	73 (78)
Performing scientific research	4 (4)
Websites	50 (54)
Professional books[a]	3 (3)
Nutritional education[b]	12 (13)
Dietitian of our MDT	13 (14)
No other sources	3 (3)

[a]about dysphagia.

[b]followed courses or training on nutrition.

Note: Multiple answers could be given.

Abbreviations: AAN, American Academy of Neurology; DvS, Dutch association for dietitians working in the field of neuromuscular diseases; EFNS, European Federation of Neurological Societies; ESPEN, European Society for Clinical Nutrition and Metabolism; HCPs, HealthCare Professionals; MDT, Multidisciplinary Team; MNDA, Motor Neurone Disease Association; N, Number of HCPs – total; n, number of HCPs – proportion; NICE, National Institute for Health and Care Excellence.

Table 6. Dietitian engagement based on ALSFRS-R swallowing item scores.

		Contact with dietitian, n(%)		
		Yes	No	N
Swallowing score	0,1,2	50 (89)	6 (11)	56
	3	41 (53)	37 (47)	78
	4	44 (31)	99 (69)	143
	Total	135 (49)	142 (51)	277

The swallowing score is an item of the ALSFRS-R and indicates swallowing problems. A higher swallowing score means fewer swallowing problems. A swallowing score of 4 indicates normal eating habits, 3 early eating problems, 2 dietary consistency changes, 1 supplementary tube feeding needs and 0 nothing by mouth; exclusively parental or enteral feeding.

Abbreviations: N, Number of patients – total; n, number of patients – proportion.

$n = 23/95$), a lack of information material (24%; $n = 23/95$) and a lack of evidence-based dietary interventions (23%; $n = 22/95$). HCPs in smaller ALS care teams reported challenges in providing dietary advice more often (62%; $n = 13/21$) compared to HCPs in large teams (47%; $n = 17/36$).

Needs for improvement. HCPs indicated a need for reliable patient information, targeted education and accessible evidence-based resources for HCPs, specifically focusing on nutrition in ALS in response to open-ended questions (Table 8). HCPs in smaller teams indicated a need for training more often (52%; $n = 11/21$) than HCPs in large teams (39%; $n = 14/36$). Qualitative analysis revealed the need for uniformity and consensus in dietary recommendations and monitoring practices, particularly regarding the estimation of protein- and energy requirements.

Barriers encountered and needs for improvement in current nutritional care practices reported by pwALS

PwALS were generally satisfied, with more than 70% expressing satisfaction with the knowledge and dietary advices from both dietitians and other HCPs (Table 9). Responses to open-ended questions showed that many did not indicate barriers or needs for improvement. Some pwALS suggested nutritional care could be initiated earlier, more comprehensive and personalized to individual needs. Additionally, pwALS expressed a wish to receive regular updates on developments in nutrition and ALS, as well as more proactive inquiries from HCPs regarding their nutritional needs, rather than having to request information or assistance themselves.

Discussion

This study revealed practice variation in nutritional care provided to pwALS between different ALS care teams in the Netherlands. Variability was found in timing of and criteria for patient referral to a dietitian, assessment of nutritional status and recommendations for nutritional requirements. About half of the pwALS had no contact with a dietitian, despite some (11%) were experiencing swallowing difficulties. HCPs expressed the need for targeted education on nutrition in ALS and standardized monitoring practices and dietary recommendations. While pwALS were generally satisfied, some felt nutritional care could be initiated earlier and more personalized.

HCPs in this study suggested that practice variation may be attributed to a lack of evidence-based guidelines containing practical guidance on nutritional screening, assessment and advice. Consequently, HCPs rely on personal clinical experience and local guidelines to inform nutritional care practices. ALS-specific clinical experience varies among ALS care teams in the Netherlands, as some teams support fewer than 20 pwALS, while others manage more than 50. As already suggested by international studies (2,17,18,20), this study found evidence to suggest that HCPs with limited exposure to pwALS (those with a small number of pwALS managed by their ALS care team or having pwALS as small portion of their overall caseload) tend to have lower levels of expertise in ALS care.

Early structural monitoring of the nutritional status of pwALS is crucial, as weight loss at diagnosis significantly increases risk of death (21,22). Despite this, previous studies (2,18) report that only 19-31% of pwALS are referred to a dietitian in early disease stages. Encouragingly, this study found that in the Netherlands, 50% of the HCPs refer pwALS to a dietitian at diagnosis and approximately half of the pwALS reported an introduction to the dietitian. However, this still suggests that nutritional intake and requirements are not accurately monitored in all pwALS, with the risk of malnutrition remaining undetected and hence untreated (9,10).

Although screening tools are highly valued for assessing the risk of malnutrition (23), this study found that they are rarely used for pwALS. Consistent with a previous study (2), a small proportion of dietitians used screening tools; those who did, used a variety of tools, likely due to the lack of validation studies in ALS and the absence of guidelines recommending a screening tool. Similarly, international studies (2,17,18) show that body composition is seldom measured in pwALS, body weight or BMI being used most often to assess nutritional status. This study found that only 17% of the dietitians measured body composition, suggesting that changes in fat mass and fat-free mass are not being captured. This is particularly interesting in pwALS, as weight can either

Table 7. Barriers experienced by HCPs in current nutritional care for patients with ALS.

Barriers	Description	Quotes HCPs	n(%) N = 95
Monitoring nutritional status			
	Lack of measuring equipment	"Unfortunately we do not have equipment to measure indirect calorimetry or BIA." (HCP 51) "We only use body weight and BMI to assess nutritional status. No other measurement equipment." (HCP 27) "There is a lack of equipment, but if equipment were available, this would in turn lead to time constraints." (HCP 85)	20 (21)
	Lack of time	"I need more hours than are officially allocated for this." (HCP 23) "I only have 5.5 hours per week available for NMD patients, including patients with diseases other than ALS. To be able to measure body composition I would need more hours." (HCP 86) "We do not yet use a BIA. This could provide more information. A lack of time sometimes means contact with patients is not very regular." (HCP 81)	17 (18)
	Lack of guidelines	"There is a lack of clarity about which measurement equipment to use; there is a lack of uniformity regarding cut-off values and what advice we can provide based on these cut-off values." (HCP 5) "There is no uniformity on how and what to measure." (HCP 39)	17 (18)
	Unclear division of roles	"For specific questions regarding nutrition, I refer to the dietitian. I would like to have a clearer division of roles in terms of measuring body weight etc. within our team." (HCP 37)	1 (1)
	Other barriers regarding monitoring of the nutritional status	"If body weight can no longer be safely measured at home, then it is not clear what the best way to monitor nutritional status would be." (HCP 87) "Which measurement instruments are valid for evaluating nutritional status in ALS patients? ." (HCP 95)	17 (18)
	No barriers experienced in monitoring nutritional status		44 (46)

(*Continued*)

Table 7. (*Continued*).

Barriers	Description	Quotes HCPs	n(%) N = 95
Providing dietary advice			
	Lack of guidelines	"We could be more proactive, we need to coordinate more with the various teams across the country (everyone is doing something different), availability of information is limited (the dietary treatment guidelines from the Dutch association for dietitians working in the field of neuromuscular diseases is only available to members and not to other professions), there is a lack of knowledge about what currently the best advice is and how to monitor the nutritional status of these patients." (HCP 5) "There is a lack of good evidence-based treatment guidelines and information; for example, regarding the estimation of protein- and energy requirements." (HCP 87) "There are guidelines, but they are not up to date. I miss uniform guidelines on treatment specifically for ALS, similar to those available for physical therapy or speech therapy." (HCP 39)	23 (24)
	Lack of information material	"I am not aware of any information material specifically for ALS patients; therefore I tend to use "general guidelines." (HCP 51) "I utilize information material designed for gastroenterology patients." (HCP 16)	23 (24)
	Lack of unambiguous (scientific) literature	"There is a lot we do not know about nutritional requirements, supplements or disease progression of patients with ALS." (HCP 79) "There is no consensus in scientific literature on, for example, the estimation of protein- and energy requirements." (HCP 23)	22 (23)
	Lack of time	"Staying up to date with the latest research and translating it into practice is challenging. In addition, there is never enough time to do this thoroughly, such as performing an extra calculation when needed." (HCP 45) "I often have too little time	19 (20)

(*Continued*)

Table 7. (*Continued*).

Barriers	Description	Quotes HCPs	n(%) N = 95
		to dive into the literature or websites myself." (HCP 73)	
	Unclear division of roles	"I notice that there is much overlap between professions. This results in giving advice from each other's area of expertise." (HCP 72)	5 (5)
	Other barriers regarding the provision of dietary advice	"It remains unclear what the best way is to calculate protein requirement (based on kilogram body weight or on FFMI). Can BIA have added value in assessing the FFM or phase angle? Is a two-point measurement sufficient? ." (HCP 72) "There is no central place where all guidelines, information material, unified literature are easily accessible. I also really notice the lack of training and e-learning courses specifically on ALS. When I started working for [rehabilitation center], I really had to extend my knowledge, but I am not sure this has been enough." (HCP 95)	10 (11)
	No barriers experienced in providing dietary advice		39 (41)
Other barriers			
	Introduction and placement feeding tube	"It is unclear what the appropriate moment is to introduce the PRG/PEG. Should this be when someone experiences swallowing problems or at the time of diagnosis, for example at the intake meeting with the rehabilitation physician?" (HCP 72)	5 (5)
	Patient attitude/willingness	"Sometimes it is difficult to motivate patients; some of them really do not want to change much, even though their dietary pattern is inadequate." (HCP 92) "It is difficult to explain to patients with ALS why nutrition is important. Muscle atrophy can't be brought to a halt by improving nutrition, and so patients question why we need to place so much focus on it. Furthermore, the limited evidence of the role of nutrition in ALS makes this even more difficult." (HCP 39) "I have the feeling that not much is known about nutrition and ALS.	6 (6)

(*Continued*)

Table 7. (*Continued*).

Barriers	Description	Quotes HCPs	n(%) N = 95
		Therefore it is sometimes hard to know what appropriate dietary advice is. Additionally, patients with ALS also lose weight because of muscle atrophy, so some patients do not think it is necessary to focus on gaining weight or maintaining their weight (because muscle breakdown is inevitable)." (HCP 74)	
	Lack of home care	"The availability of home care to support patients with medical nutrition or tube feeding is becoming increasingly problematic. A possible solution may be to prepare patients early on, even before there are any medical grounds, by teaching them for example how to self-administer tube feeding. Currently there is no available infrastructure on this." (HCP 35) "There is a lack of home care availability." (HCP 71) "The availability of home care is insufficient to ensure tube feeding is administered effectively or that patients receive proper nutrition." (HCP 100)	4 (4)

Note: Multiple answers could be given.

Abbreviations: ALS, Amyotrophic Lateral Sclerosis; BIA, Bioelectrical Impedance Analysis; BMI, Body Mass Index; FFM, Fat Free Mass; FFMI, Fat Free Mass Index; HCP, HealthCare Professional; N, Number of HCPs – total; n, number of HCPs – proportion; NMD, Neuromuscular Disease; PEG, Percutaneous Endoscopic Gastrostomy; PRG, Percutaneous Radiological Gastrostomy.

be lost due to muscular atrophy caused by the disease or due to decreased nutritional intake, which requires dietary action (24,25).

Approximately half of the dietitians in this study reported using predictive equations that inaccurately estimate energy requirements in ALS (26,27). This is likely due to limited availability of indirect calorimetry, the optimal method for measuring energy expenditure in ALS. Furthermore, scientific literature lacks clarity on the use of predictive equations for pwALS. Originally developed for healthy people, predictive equations underestimate energy requirements, especially in hypermetabolic pwALS (7). Previous studies in the UK, US and Canada (2,16,17) also report the use of predictive equations to estimate energy requirements, which are not validated in ALS, suggesting that current dietary advice may not match actual needs, thereby exacerbating nutritional status (2). Differences were also observed in advice regarding dietary supplements (e.g. vitamins and minerals), probably due to a lack of evidence on the effect of dietary supplements on disease progression, quality of life and survival (2). This underscores the need for further research into the role of dietary supplements in ALS.

This study revealed a discrepancy between HCPs' and pwALS' perspectives on nutritional care in ALS. While HCPs recognized the importance of focusing on nutrition and identified barriers and needs for improvement, pwALS reported high satisfaction with current practices. Most pwALS indicated no need for additional nutritional advice and expressed confidence in the knowledge and skills of HCPs. However, no desire for additional advice may stem from insufficient information provision on the importance of nutrition, which probably contributes to pwALS feeling that their needs are already fulfilled. Studies (28,29) show that patient satisfaction does not reflect actual quality of care. Patients do not have a frame of reference; expectations of clinical care are generally low in people with severe, chronic illnesses, resulting in satisfaction with the care

Table 8. Requirements indicated by HCPs to improve nutritional care for patients with ALS.

Description needs	Quotes HCPs	n(%) N = 95
Information material for patients	"Practical information for rehabilitants and their caregivers regarding potential dietary adjustments." (HCP 6) "It would be beneficial if all available knowledge is pooled and consolidated into material that patients can use to allow them to take the initiative in their own care; this will give them a sense of control over their disease." (HCP 90) "Patients are often not ready for all the information you want to provide them with, especially at the time of diagnosis. Therefore, it would be helpful to have some printed material so they can read it later, this would also be useful for caregivers." (HCP 98)	52 (55)
Guidelines/protocols	"We need specific and concrete advice and a review of the current guidelines. In particular the advice on protein requirement in progressive muscle diseases as well as clear recommendations about BMI. For instance, if someone has spent his whole life trying to maintain a BMI of 23, are we now advising him to increase it to 25? ." (HCP 45) "Guidelines based on scientific research." (HCP 8) "Perhaps we need an additional guideline integrating swallowing and nutrition, including a section that presents expert opinions that are not necessarily evidence-based. Clear expert opinions regarding the utility of nutritional supplements would also be beneficial." (HCP 58) "A clear protocol for measuring body composition, frequency etc. ." (HCP 86)	43 (45)
Education for HCPs	"Currently there is little to no training available for dietitians specifically focused on ALS. An annual congress dedicated to this topic, specifically for dietitians, would be valuable." (HCP 26) "Targeted training that includes guidelines on nutrition, nutritional assessment, dealing with issues around communication and cognition are desirable." (HCP 39) "A training course or meeting for dietitians and speech therapists would be beneficial to allow exchange of experience and knowledge." (HCP 94) "Training about the basics of nutrition, including the latest insights regarding nutrition and ALS, and the opportunity to discuss case histories with fellow ALS dietitians to learn from each other." (HCP 95)	42 (44)
Information material for HCPs	"It would be helpful if information regarding nutrition that has national consensus was available, so that we can align our opinions/advice." (HCP 17) "Material for me as a physician, so that	37 (39)

(*Continued*)

Table 8. (*Continued*).

Description needs	Quotes HCPs	n(%) N = 95
	I can provide patients with appropriate information." (HCP 28) "It would be useful if more information was available regarding dietitians and speech therapists working together. Currently, information is primarily offered separately for each profession, despite the overlap between professions." (HCP 75) "Training and information material for rehabilitation physicians and speech therapists to highlight the importance and urgency of proper nutrition in ALS. They play an important role regarding the decision about and timing of PRG/PEG placement." (HCP 66)	
Measuring equipment	"Measuring equipment, such as a BIA/ BIVA instrument, to assess nutritional status and requirements." (HCP 97) "An appropriate (4-point) BIA meter, availability of indirect calorimetry and clear guidelines on protein requirement and the assessment of nutritional status." (HCP 72) "Our dietitians would like to have more comprehensive measurement tools." (HCP 44)	21 (22)
Other needs	"Uniformity in everything: measurements, monitoring, advice, education etc. ." (HCP 5) "Regular updates on what is already known and advice on patient-guidance from the ALS center." (HCP 15)	15 (16)
No needs experienced		9 (9)

Note: Multiple answers could be given.
Abbreviations: ALS, Amyotrophic Lateral Sclerosis; BIA, Bioelectrical Impedance Analysis; BIVA, Bioelectrical Impedance Vector Analysis; BMI, Body Mass Index; HCP, HealthCare Professional; N, Number of HCPs – total; n, number of HCPs – proportion; PEG, Percutaneous Endoscopic Gastrostomy; PRG, Percutaneous Radiological Gastrostomy.

Table 9. Patient satisfaction with current nutritional care.

	n (%)					
	Very satisfied	Satisfied	Neutral	Dissatisfied	Very dissatisfied	NA[b]
Knowledge of the dietitian[a]	63 (30)	116 (55)	29 (14)	3 (1)	0 (0)	161 (43)
Knowledge of other HCPs[a]	78 (27)	135 (47)	65 (23)	4 (1)	3 (1)	87 (23)
Dietary advice provided by the dietitian on:						
Nutritional requirements	55 (32)	97 (56)	21 (12)	1 (1)	0 (0)	198 (53)
Caloric intake	38 (33)	65 (57)	10 (9)	0 (0)	1 (1)	258 (69)
Protein intake	37 (27)	81 (59)	17 (12)	2 (1)	0 (0)	235 (63)
Dietary advice provided by other HCPs	71 (25)	147 (52)	58 (20)	4 (1)	5 (2)	87 (23)

[a]Regarding nutrition and ALS.
[b]The questions presented were dependent on the patient's previous responses; therefore, not all patients answered every question.
Abbreviations: NA, Not Applicable.

available and not being aware that improvement is possible (28). Satisfaction can be influenced by the timing of the questionnaires and phrasing of the questions (29). A questionnaire immediately after care may yield more positive responses, while delayed questionnaires may allow more critical reflection. Similarly, asking "how satisfied are you" tends to elicit more positive responses than asking "did you experience any problems?" Future research should use qualitative methods to further explore experiences of pwALS with current nutritional care.

Strengths and limitations

This study represents a nationwide overview of nutritional care practices for pwALS, as response rates were high, the sample of pwALS was obtained from a population-based registry and all 36 ALS care teams were represented. Compared to previous studies (2,16,17,20), this study is unique, because experiences of pwALS were included and because of the ALS care setting in the Netherlands, organized within rehabilitation facilities. The total sample size was appropriate, but subgroups of professions were small, preventing subgroup comparisons. Lastly, ALSFRS-R scores were missing for 26% of the pwALS, limiting our ability to assess their disease stage.

Clinical implications

This study highlights the need for a clear, evidence-based guideline offering practical guidance to HCPs to reduce practice variation. Improved nutritional screening and monitoring would enable timely, targeted dietitian referrals, optimizing patient care by avoiding unnecessary visits. Future research should examine optimal methods to monitor nutritional status of pwALS, enhancing and supporting development of an evidence-based guideline. Targeted education for HCPs, particularly focusing on nutrition in ALS is necessary for standardizing care and implementing guidelines.

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Data availability statement

Derived data supporting the findings of this study are available from the corresponding author upon reasonable request.

References

1. Essat M, Archer R, Williams I, Zarotti N, Coates E, Clowes M, et al. Interventions to promote oral nutritional behaviours in people living with neurodegenerative disorders of the motor system: a systematic review. Clin Nutr. 2020;39:2547–56.
2. White S, Zarotti N, Beever D, Bradburn M, Norman P, Coates E, et al. The nutritional management of people living with amyotrophic lateral sclerosis: a national survey of dietitians. J Hum Nutr Diet. 2021;34:1064–71.
3. Ludolph AC, Dorst J, Dreyhaupt J, Weishaupt JH, Kassubek J, Weiland U, et al. Effect of high-caloric nutrition on survival in amyotrophic lateral sclerosis. Ann Neurol. 2020;87:206–16.
4. Schmitt F, Hussain G, Dupuis L, Loeffler J-P, Henriques A. A plural role for lipids in motor neuron diseases: energy, signaling and structure. Front Cell Neurosci. 2014;8:25.
5. Janse van Mantgem MR, van Rheenen W, Hackeng AV, van Es MA, Veldink JH, van den Berg LH, et al. Association between serum lipids and survival in patients with amyotrophic lateral sclerosis. Neurology 2023;100: e1062–e71.
6. Kasarskis EJ, Mendiondo MS, Matthews DE, Mitsumoto H, Tandan R, Simmons Z, et al. Estimating daily energy expenditure in individuals with amyotrophic lateral sclerosis123. Am J Clin Nutr. 2014;99:792–803.
7. Jésus P, Marin B, Fayemendy P, Nicol M, Lautrette G, Sourisseau H, et al. Resting energy expenditure equations in amyotrophic lateral sclerosis, creation of an ALS-specific equation. Clin Nutr. 2019;38:1657–65.
8. Rio A, Ellis C, Shaw C, Willey E, Ampong MA, Wijesekera L, et al. Nutritional factors associated with survival following enteral tube feeding in patients with motor neurone disease. J Hum Nutr Diet. 2010;23:408–15.
9. Desport JC, Preux PM, Truong TC, Vallat JM, Sautereau D, Couratier P. Nutritional status is a prognostic factor for survival in ALS patients. Neurology 1999;53:1059–63.
10. López-Gómez JJ, Ballesteros-Pomar MD, Torres-Torres B, De la Maza BP, Penacho-Lázaro M, Palacio-Mures JM, et al. Malnutrition at diagnosis in amyotrophic lateral sclerosis (als) and its influence on survival: Using glim criteria. Clin Nutr. 2021;40:237–44.
11. 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.
12. Van Damme P, Al-Chalabi A, Andersen PM, Chiò A, Couratier P, De Carvalho M, et al. European Academy of Neurology (EAN) guideline on the management of amyotrophic lateral sclerosis in collaboration with European Reference Network for Neuromuscular Diseases (ERN EURO-NMD). Eur J Neurol. 2024;31:e16264.

13. 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.
14. Oliver D, Radunovic A, Allen A, McDermott C. The development of the UK National Institute of Health and Care Excellence evidence-based clinical guidelines on motor neurone disease. Amyotroph Lateral Scler Frontotemporal Degener. 2017;18:313–23.
15. Van Eenennaam RM, Kruithof WJ, Kruitwagen-Van Reenen ET, van den Berg LH, Visser-Meily JMA, Beelen A. Current practices and barriers in gastrostomy indication in amyotrophic lateral sclerosis: a survey of ALS care teams in The Netherlands. Amyotroph Lateral Scler Frontotemporal Degener. 2022;23:242–51.
16. Zhang M, Hubbard J, Rudnicki SA, Johansen CS, Dalton K, Heiman-Patterson T, et al. Survey of current enteral nutrition practices in treatment of amyotrophic lateral sclerosis. Espen J. 2013;8:e25–e8.
17. Rio A, Cawadias E. Nutritional advice and treatment by dietitians to patients with amyotrophic lateral sclerosis/ motor neurone disease: a survey of current practice in England, Wales, Northern Ireland and Canada. J Human Nutrition Diet. 2007;20:3–13.
18. Halliday V, Zarotti N, Coates E, McGeachan A, Williams I, White S, et al. Delivery of nutritional management services to people with amyotrophic lateral sclerosis (ALS). Amyotroph Lateral Scler Frontotemporal Degener. 2021;22:350–9.
19. Sharma A, Trần M, Tai L, Hai Nam N, Ng SJ, Nguyen H, et al. Checklist for reporting of survey studies (CROSS). J General Internal Med. 2021;36:3179–87.
20. O'Brien MR. Healthcare professionals' knowledge of motor neurone disease. Br J Nurs. 2004;13:1080–4.
21. Genton L, Viatte V, Janssens J-P, Héritier A-C, Pichard C. Nutritional state, energy intakes and energy expenditure of amyotrophic lateral sclerosis (ALS) patients. Clin Nutr. 2011;30:553–9.
22. Marin B, Desport JC, Kajeu P, Jesus P, Nicolaud B, Nicol M, et al. Alteration of nutritional status at diagnosis is a prognostic factor for survival of amyotrophic lateral sclerosis patients. J Neurol Neurosurg Psychiatry. 2011;82: 628–34.
23. Kondrup J, Allison SP, Elia M, Vellas B, Plauth M. ESPEN guidelines for nutrition screening 2002. Clin Nutr. 2003;22:415–21.
24. Roubeau V, Blasco H, Maillot F, Corcia P, Praline J. Nutritional assessment of amyotrophic lateral sclerosis in routine practice: value of weighing and bioelectrical impedance analysis. Muscle Nerve. 2015;51:479–84.
25. Kasarskis EJ, Tandan R. Why is nutrition vital for advancing ALS care and clinical research? Amyotroph Lateral Scler Frontotemporal Degener. 2023;24:359–61.
26. Sherman MS, Pillai A, Jackson A, Heiman-Patterson T. Standard equations are not accurate in assessing resting energy expenditure in patients with amyotrophic lateral sclerosis. JPEN J Parenter Enteral Nutr. 2004;28:442–6.
27. Roscoe S, Skinner E, Kabucho Kibirige E, Childs C, Weekes CE, Wootton S, et al. A critical view of the use of predictive energy equations for the identification of hypermetabolism in motor neuron disease: A pilot study. Clin Nutr ESPEN. 2023;57:739–48.
28. Jenkinson C, Coulter A, Bruster S, Richards N, Chandola T. Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care. Qual Saf Health Care. 2002;11:335–9.
29. Crow R, Gage H, Hampson S, Hart J, Kimber A, Storey L, et al. The measurement of satisfaction with healthcare: implications for practice from a systematic review of the literature. Health Technol Assess. 2002;6:1–244.