



Development of a standardized dietetic assessment for medical nutrition therapy in neurological disorders using the ICF-Dietetics

A systematic literature search and Delphi survey

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Abstract

The aim of this study is to lay the foundation for a standardized dietetic assessment for patients with neurological disorders using the ICF-Dietetics. A Delphi survey and a systematic literature search were conducted for this purpose. The quality of the assessment and outcome instruments that were included was assessed using COSMIN, and the nutrition-related questions were linked to and compared with the ICF-Dietetics categories using established ICF linking rules.

From the 15 assessment and outcome instruments, a total of 116 nutrition-related questions were identified and these were used to define 121 key terms and 35 secondary terms. These terms were then linked to 65 precise ICF-Dietetics categories. These nutrition-related aspects were supplemented with those from the Delphi survey.

This lays the foundation for the first dietetic assessment using the ICF-Dietetics and will contribute to quality assurance and outcome research in dietetics.

Keywords: Nutrition assessment, dietetic assessment, dietetics, neurological disorders, International Classification of Functioning, Disability and Health (ICF), ICF-Dietetics

Citation

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Introduction

Globally, neurological disorders are the main cause of physical functional impairments and disabilities. They also have a substantial effect on the course of disease and on patients' quality of life [1, 2]. The fact that neurological disorders can cause various nutrition-related disorders such as dysphagia, aspiration, malnutrition and disorders of gastrointestinal motility means that medical nutrition therapy has a key role to play in the management of neurological diseases [3, 4].

There is an increasing demand for a standardized approach to medical nutrition therapy in this context—an approach based on transparency, quality assurance and the evaluation of outcomes. For this reason, more emphasis is now being placed on the use of standardized language [8] in addition to a standardized process [5], e.g., the dietetic process [6] and the German-Nutrition Care Process [7]. Currently, there are two standardized languages used for documentation in the field of medical nutrition therapy in Europe (they are also referred to as “terminology” or “classifications”). One of these is the Nutrition Care Process Terminology (NCPT) developed in the USA by the Academy of Nutrition and Dietetics, and the other is the Classifications and Coding lists for Dietetics (CCD) developed in the Netherlands [8]. The ICF¹-Dietetics is the most prominent classification of the CCD.

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¹ International Classification of Functioning, Disability and Health

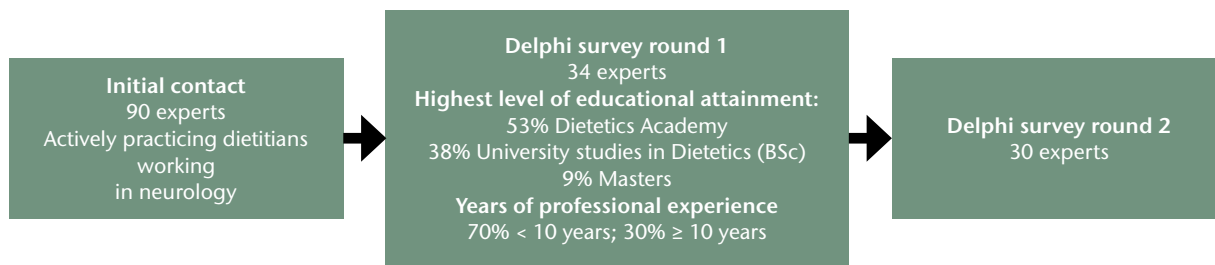


Fig. 1: Numbers and characteristics of the experts

It is based on the ICF (which can be used across disciplines) and on the biopsychosocial health model of the World Health Organization (WHO) [9]. A version translated into Austrian German from the 2017 English version of the ICF-Dietetics² became available in 2018 when the Austrian German version was developed and published as part of a dissertation [10]. A multicenter study conducted in Austria [11] demonstrated that the ICF-Dietetics can be integrated into the dietetic process and a recently published focus group study [12] demonstrated that implementation is viewed positively. However, what is still needed is a multi-layered implementation strategy, and within that, studies mention that there is a need for ICF core sets for standardized dietetic assessment³ [12]. A core set is a validated, diagnosis-specific selection of the most important ICF categories for a particular condition (i.e., disease-specific) or a specific setting [13, 14]. Currently, there are 37 ICF core sets [15], including core sets for acute [16] and post-acute [17] neurological conditions, for multiple sclerosis [18–20] and for stroke [21–23]. There is a need to develop additional core sets, and the recommended approach for this is a multi-method scientific process [13]. Furthermore, as yet, there are no disease-specific core sets for standardized dietetic assessments.

The aim of this study is to lay the foundation for the development of a standardized dietetic assessment for patients with neurological disorders using the ICF-Dietetics. The key research question was: What aspects are of relevance for dietetic assessment in the presence of neurological disorders? The following subordinate questions were also investigated:

- What assessment and outcome instruments that include nutritional aspects are available for use in neurological disorders in Europe?
- How should the quality of the selected measurement instruments be assessed?
- To what extent can nutrition-related questions in selected measurement instruments be linked to the categories of the ICF-Dietetics?
- To what extent does the content of nutrition-related questions differ between selected measurement instruments insofar as the existing ICF-Dietetics categories are concerned?

Methodology

The methods used were a two-round Delphi survey of experts in order to reach a consensus [24], a systematic literature search for measurement instruments based on the PRISMA statement (Pre-

ferred Reporting Items for Systematic Reviews and Meta-Analyses) [25] and a subsequent evaluation of the reliability and validity studies included using COSMIN (CONsensus-based Standards for the selection of health Measurement INstruments) [26–28]. The established linking method was used to compare the nutrition-related aspects of the measurement instruments that were included [29].

Delphi survey

In a survey conducted across Austria from October to December 2019, experts were asked about the requirements for a standardized dietetic assessment in the context of neurology and about the requirements for assessment and outcome instruments. The survey was conducted via an online platform (www.umfrageonline.com/students). ♦ Figure 1 shows the numbers and characteristics of the survey sample.

The survey was literature-based [3, 4, 30] and was developed and pretested using the ICF [14, 31] and the ICF-Dietetics [10]. The first round of the Delphi survey included 30 questions, which were divided into the following categories: 1. General information about the experts, 2. Basic information about neurological disorders in dietetic practice, 3. Nutrients of concern, 4. Nutrition-related additional diagnoses and findings, 5. Nutrition-specific aspects of the ICF components and 6. Closing questions. Each question had multiple choice answers (with check boxes) based on the literature or

² In Germany, there is a German translation of the original Dutch “*ICF-Diëtetiek*” available. Efforts are underway to harmonize the two German translations and to use a single, unified version of the ICF-Dietetics in German-speaking countries in the future.

³ In Austria, dietetic assessment is the first step in the dietetic process and it involves collecting, structuring and assessing relevant information. It is equivalent to nutrition assessment in the German-Nutrition Care Process and is comparable to assessments used in other process models in medical nutrition therapy.



on the ICF-Dietetics categories and a free text field for comments. These qualitative results from the first round of the Delphi survey were analyzed using MAXQDA 2018 (Qualitative Data Analysis Software, 1989–2019, VERBI Software. Consult. Sozialforschung. GmbH, Berlin). The second round was based on the results of the first round and it included 16 questions that underwent a standardized, quantifying evaluation process (consensus process). Where at least 60% of participants agreed that a question was relevant to practice, this was considered a consensus.

Data protection and ethical considerations

The Delphi survey was conducted in accordance with the ethical principles of the Declaration of Helsinki [32]. To protect the anonymity of the participants, neither gender, name nor employment details were recorded. The experts were informed about the objectives, methodology and benefits of the study. Informed consent was obtained via email.

Systematic literature search and evaluation using COSMIN

The systematic literature searches were conducted in two stages from June to November 2019, searching in PubMed and the CINAHL Database. Measurement instruments were searched for in the first stage and the corresponding reliability and validity studies were searched for in the second stage. To be included, the studies had to be European studies of measurement instruments written in either German or English with a study population aged 18 years or older. Once these studies were found, they were checked for nutrition-related questions and they were included in the remainder of the process if they contained at least three such questions. This resulted in the identification of measurement instruments for patients with neurological disorders, for nutrition-related additional diagnoses and findings and for nutrients of concern (key terms: ♦ Table 1). The measurement instruments that were identified were checked for nutrition-related questions and corresponding reliability and validity studies were researched (excluding malnutrition screenings).

The measurement properties (internal consistency, reliability, content validity, construct validity, criterion validity) of the reliability and validity studies that were included were evaluated using the COSMIN Risk of Bias Checklist (RoBC), the quality criteria (Rating of the Measurement Properties), and the evidence using the Grading of Recommendations Assessment, Development and Evaluation Approach (GRADE) [26, 27]. A minimum of two reliability or validity studies were required for overall assessment using COSMIN and for the purpose of making an evidence-based recommendation for use in clinical practice.

Measurement instruments		
Neurological diseases	Additional nutrition-related diagnoses	Nutrients of concern
Stroke	Dementia	Dietary fiber
Parkinson's disease	Dysphagia	Fatty acids
Multiple sclerosis	Fatigue	Vitamin D
Amyotrophic lateral sclerosis	Gastrointestinal symptoms	Vitamin B ₁₂
	Malnutrition	
	Oral symptoms	

Table 1: Key terms from the systematic literature search

Linking method

The health information in the nutrition-related questions was linked to the standardized taxonomy of the ICF-Dietetics [10] using established ICF linking rules [29]. ♦ Figure 2 outlines the linking process.

Results

The nutrition-related aspects in the measurement instruments that were identified in the systematic literature search and subsequently evaluated that are relevant for standardized dietetic assessment in the presence of neurological disorders (summary of the linked ICF-Dietetics categories for the key terms and secondary terms) are shown in ♦ Table 2 along with the relevant aspects derived from the Delphi survey (for which there was at least a 60% consensus) that were not present in the evaluated measurement instruments.

Delphi survey

The majority of the experts surveyed (85%) consider standardized dietetic assessment to be useful in clinical practice. Factors found to be relevant included personal and environmental facilitating factors and barriers, as well as patient participation.

A total of 86% of the survey population indicated that instruments for collecting measurable data were being used in everyday dietetic practice for assessment, monitoring, and the evaluation of outcomes. However, it emerged that only a few measurement instruments were currently being used, and none that capture aspects relevant to dietetics were being used. According to the experts surveyed, the measurement instruments that should always be used in a standardized assessment are a food record (90%), a plate waste record (80%), an appetite scale (77%), a fluid intake record (77%), and the Mini Nutritional Assessment (60%).

Systematic literature search and evaluation using COSMIN

74 search strategies were implemented in a systematic literature search. All searches were depicted using PRISMA flowcharts [25] (example in ♦ Figure 3).

A total of 102 measurement instruments were identified. 15 of these were included in the study and reliability and validity studies were found for them. These 15 measurement instruments were assessed using COSMIN and are listed in ♦ Table 3.

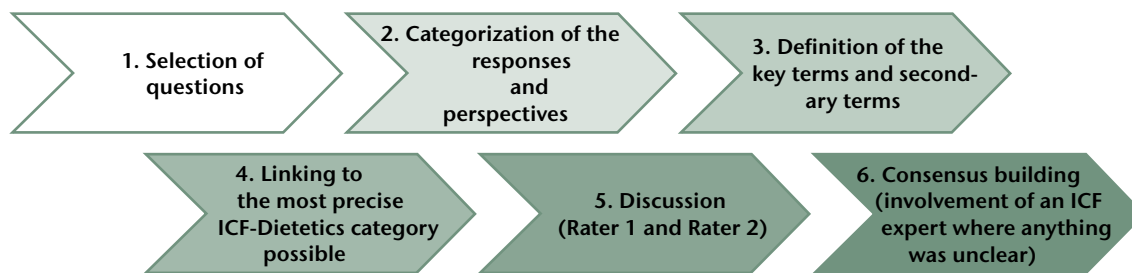


Fig. 2: The linking process

For seven of the measurement instruments (ALSAQ-40, ALSFRS-R, DYMUS questionnaire, EAT-10, MDS-UPDRS, PDQ-39, SWAL-QOL questionnaire) that had at least two reliability and validity studies, it was possible to perform the full COSMIN assessment and formulate an evidence-based recommendation for use in clinical practice. For the other eight measurement instruments (ALSFRS-EX, CAS, DFI-FFQ, EdFED scale, FIM+FAM, NMSS-PD, PAC-QOL questionnaire, READL index), the first step of the COSMIN assessment (RoBC) was performed. For all seven measurement instruments that had existing comparative studies available, the quality assessment resulted in evidence level B (potential for application in clinical practice). ♦ Table 4 shows the COSMIN assessment of the PDQ-39 as an example.

Linking process

From the 15 assessment and outcome instruments included in the linking process, 116 nutrition-related questions were identified and these were used to define 156 terms (121 key terms⁴ and 35 secondary terms⁵), and these terms were linked to a total of 65 precise ICF-Dietetics categories. In the

⁴ The key term reflects the central concept of the question and is identified first in accordance with the linking rules

⁵ Additional concepts included in the questions are referred to as secondary terms.

	Aspects in the evaluated measurement instruments	Additional relevant aspects from the Delphi survey
Body functions and structures	Body weight, body weight trend, sensation of hunger, problems with chewing, salivation/saliva composition, swallowing/difficulty swallowing, appetite, sense of smell and taste, fear of symptoms/complications (e.g., aspiration), defecation, constipation and gastrointestinal problems, emotional state with regard to symptoms due to the disease (e.g., disinclined to socialize, frustration, depressed mood), tiredness/fatigue, motivation to eat	General physical condition, body mass index (BMI), body composition, relevant laboratory parameters, additional diagnoses and findings, nutritional supplements, neuropsychological status, energy, nutrient and fluid requirements, aversions, attentional capacity, mental status, state of consciousness, ability to communicate, dyspnea while eating, other gastrointestinal problems
Activities	Food preparation/preparation of meals, eating/drinking (including in public and using eating utensils), food intake, managing food selection and food consistency, appropriate portion sizes, time taken to eat, intake of nutrients of concern (dietary fiber)	Everyday procedures related to nutrition (e.g., shopping), paying attention to health, mobility/movement behaviors, intake of other nutrients of concern (protein, vitamin D/B ₁₂ , polyunsaturated fatty acids), intake of relevant food groups
Participation	Social contacts, relationships with family/friends	Making decisions, problem-solving, participation in social aspects of life, hobbies
Personal factors	Resilience/feeling of coherence in dealing with swallowing difficulties, ability to enjoy eating, impairment in everyday life due to swallowing difficulties (personal efficacy)	Understanding of the relationship between diet and disease, willingness to adjust dietary behavior, coping with chronic disease and impairment, basic attitude, language barrier, adherence, inadequate diet (diet history).
Environmental factors	No aspects included in the measurement instruments	Adequate care from health care professionals, provision of medication, ability and need for special dietetic foods (e.g., thickeners, liquid nutrition preparations), enteral/parenteral nutrition, access to liquid nutrition preparations, support from family/friends/acquaintances/caregivers, financial support, assistance with shopping/cutting/meal preparation/nutritional intake

Table 2: Relevant nutrition-related aspects for standardized assessment in the presence of neurological disorders, based on a systematic literature search and a Delphi survey

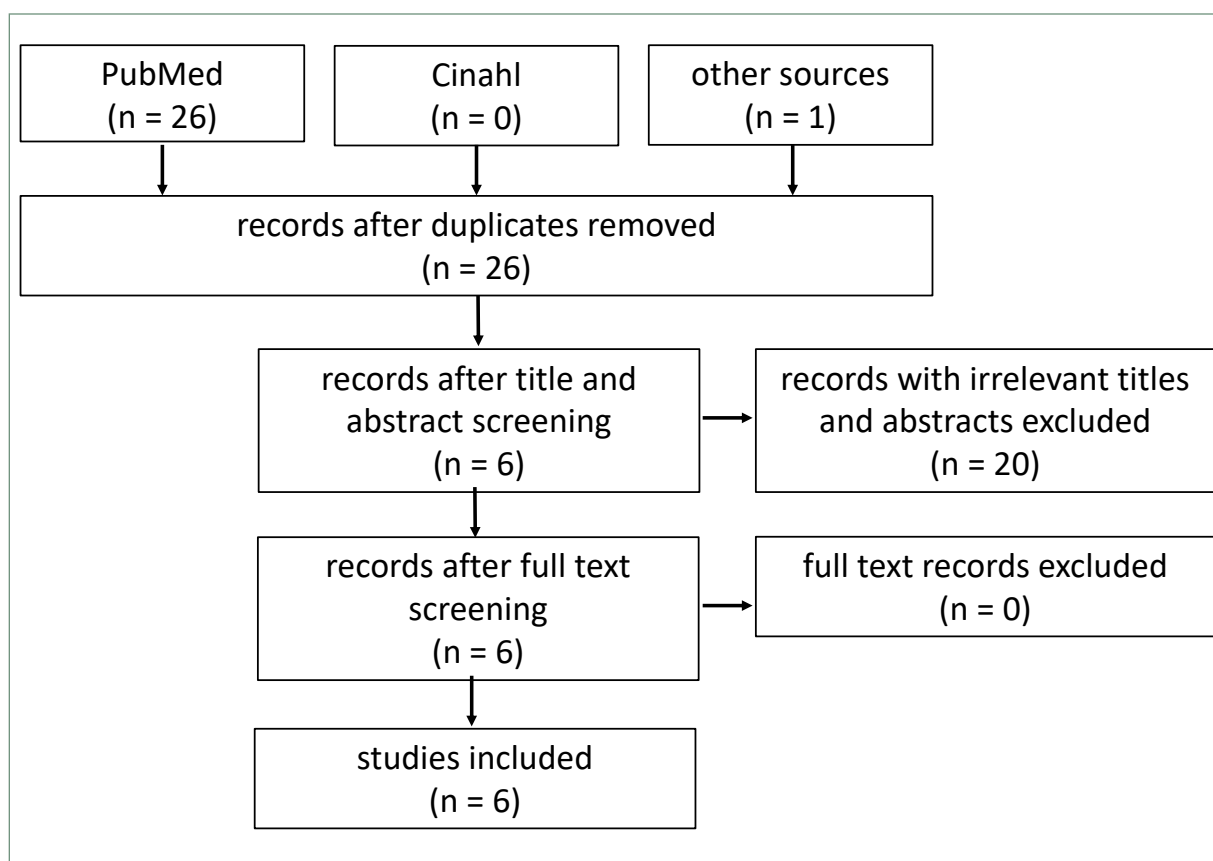


Fig. 3: PRISMA flow chart for the search strategy for PDQ-39

case of the CAS (8 questions), the DFI-FFQ (5 questions), the DYMUS questionnaire (10 questions), the EdFED scale (10 questions), and the EAT-10 (10 questions), all included questions were linked to the ICF-Dietetics. In the case of the SWAL-QOL questionnaire, out of a total of 44 questions, 32 nutrition-related questions were linked, and in the case of the PAC QOL questionnaire, 12 out of 28 were linked. The other measurement instruments only contained a few nutrition-related aspects.

♦ Figure 4 shows an excerpt of the linked ICF-Dietetics categories for the defined key and secondary terms from the nutrition-related questions in the DYMUS questionnaire. An overview of the measurement instruments and the nutrition-related aspects derived from them, as well as the number of questions, key and secondary terms, and linked ICF components can be requested from the corresponding author.

The ICF-Dietetics category “swallowing” was linked a total of 40 times (from eight measurement instruments). The category “defecation functions” was linked 14 times and the category “motivation to eat” was linked seven times. “Weight change” and “weight loss” in the category of “body function” were only allocated in three measurement instruments. Categories such as “aspiration”, “appetite” and “managing diet” were only linked once, but they play an important role in standardized assessment. This was also evident from the results of the Delphi survey.

Measurement instruments included	
<ul style="list-style-type: none"> • Amyotrophic Lateral Sclerosis Assessment Questionnaire-40 (ALSAQ-40) [33–35] • Revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFERS-R) [36, 37] • Extended Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFERS-EX) [38] • Constipation Assessment Scale (CAS) [39] • Dietary Fibre Intake Short Food Frequency Questionnaire (DFI-FFQ) [40] • Dysphagia in Multiple Sclerosis (DYMUS) Questionnaire [41, 42] • Eating Assessment Tool-10 (EAT-10) [43–47] • Edinburgh Feeding Evaluation in Dementia (EdFED) Scale [48] 	<ul style="list-style-type: none"> • Functional Independence Measure + Functional Assessment Measure (FIM + FAM) [49] • Movement Disorder Society-Unified Parkinson’s Disease Rating Scale (MDS-UPDRS) [50, 51] • Non-Motor Symptom Assessment Scale for Parkinson’s Disease (NMSS-PD) [52] • Patient Assessment of Constipation Quality of Life (PAC-QOL) Questionnaire [53] • Parkinson’s Disease Questionnaire-39 (PDQ-39) [54–59] • Rivermead Extended Activities of Daily Living (READL) Index [60] • Swallowing Quality of Life (SWAL-QOL) Questionnaire [61–65]

Table 3: Measurement instruments included in the COSMIN assessment



Measurement Properties	Risk of Bias Checklist Score	Rating the Measurement Properties	Quality of Evidence
Structural validity	Hagell and Nygren [57]: Doubtful	Hagell and Nygren [57]: Sufficient	High
Internal consistency	Galeoto et al. [56], Krikmann et al. [58], Hagell and Nygren [57], Martinez-Martin et al. [59], Marinus et al. [55], Berger et al. [54]: Very good	Galeoto et al. [56], Krikmann et al. [58], Martinez-Martin et al. [59], Marinus et al. [55], Berger et al. [54]: Indeterminate Hagell and Nygren [57]: Sufficient	Moderate
Reliability	Galeoto et al. [56]: Very good Krikmann et al. [58], Hagell and Nygren [57], Berger et al. [54]: Doubtful	Galeoto et al. [56], Krikmann et al. [58], Hagell and Nygren [57]: Sufficient Berger et al. [54]: Indeterminate	High
Construct validity	Convergent validity: Galeoto et al. [56], Krikmann et al. [58], Martinez-Martin et al. [59], Marinus et al. [55]: Adequate	Galeoto et al. [56], Krikmann et al. [58], Martinez-Martin et al. [59], Marinus et al. [55]: Indeterminate	Low
	Discriminant validity: Marinus et al. [55]: Adequate		
Recommendation level: B			

Table 4: COSMIN assessment, quality levels and recommendation level of the PDQ-39

The components “body structures” and “environmental factors” are not represented in the nutrition-related health information in the selected measurement instruments. ♦ Table 5 shows the number of linked ICF-Dietetics categories for all ICF components. A detailed compilation of the linked ICF-Dietetics categories can be requested from the corresponding author.

Discussion

This study represents the first steps towards the development of a standardized dietetic assessment for use in neurological disorders based on the ICF-Dietetics, which can be used to create a disease-specific ICF-Dietetics core

set. The approach for this study was to evaluate the perspective of experts on the one hand (Delphi survey) and the scientific perspective on the other hand (literature search and linking of measurement instruments), as recommended by Selb et al [13]. Based on this evaluation, a list of nutrition-related aspects was compiled.

The experts who were surveyed expressed clear support for a standardized approach to dietetic assessment. However, the literature search showed that there are only a few measurement instruments available in the European area for the field of neurology that are suitable for use in medical nutrition therapy and that met the inclusion criteria. The majority of them contained only a very small number of nutrition-related questions (< 3) and they lacked corresponding reliability and validity studies. As indicated in the results section, 8 out of the 15 measurement instruments included in the COSMIN assessment could only be assessed with the RoBC and therefore no recommendation for application in clinical practice could be given for these. Nevertheless, these measurement instruments were included in the linking process because the nutrition-related questions were considered essential to the

DYMUS questionnaire				Consensus on key term linked category (level)		Consensus on secondary term linked category (level)	
Health information/item	Possible responses	Key term	Secondary term	ICF code	ICF category	ICF code	ICF category
Do you need to swallow several times before solid food "goes down" completely?	0 = No 1 = Yes	Swallowing	-	b51051.xx3	Pharyngeal swallowing, swallowing of solid food	-	-
Do you need to cut food into small pieces to be able to swallow it?		Swallowing	Cutting food into smaller pieces	b5105.xx3	Swallowing solid food	a5502	Cutting/dividing food in smaller pieces
Do you need to make many sips in order to drink?		Swallowing	Drinking in sips	b5105.xx0	Swallowing thin liquid food	a56062	Drinking sip by sip
Have you lost weight?		Weight loss	-	b5310	Weight loss	-	-

Fig. 4: Excerpt of linked key terms and secondary terms for nutrition-related questions (health information/item) in the DYMUS questionnaire



ICF component	Total ICF-Dietetics categories	Assessment and outcome instruments													
		READL	PDQ-39	NMSS-PD	MDS-UP-DRS	ALSFRS-R/EX*	ALSAQ-40	CAS	EdFED	DYMUS	EAT-10	SWAL-QOL	PAC-QOL	FIM +FAM	DFI-FFQ
Body functions (b)	107			7	4	2	3	8	6	10	13	34	18	2	
Body structures (s)	/														
Activities (a)	44	3	4		1	3	1		4	2	1	10	2	3	10
Participation (p)	2											2			
Environmental factors (e)	/														
Personal factors (pf)	3											3			
Linked ICF-Dietetics categories for each measurement instrument		3	4	7	5	5	4	8	10	12	14	49	20	5	10

Table 5: Number of linked ICF-Dietetics categories

* As the nutrition-related questions in the ALSFRS-R and the ALSFRS-EX are identical, the key terms and secondary terms that were defined were also identical, so both measurement instruments have been presented in a single column.

development of a standardized dietetic assessment. The results of the Delphi survey confirm this.

The measurement instruments that were included were highly heterogeneous in terms of their content. They focus on topics such as quality of life in neurological disorders, physical functions with regard to everyday activities such as meal preparation, nutrition-related additional diagnoses such as constipation, or the intake of nutrients of concern such as dietary fiber.

Unlike the survey of the experts, these measurement instruments only include the categories for the components “body functions” and “activities”, with the exception of the SWAL-QOL [61–65]. This study therefore confirms that there is a need for a paradigm shift in terms of how the ICF-Dietetics are used. Consideration should be given not only to the disease, but also to the patient’s participation and to personal and environmental factors [11]. Such a shift could be supported the further development of existing measurement instruments in line with the ICF, or through the development of new ICF-based assessment instruments for medical nutrition therapy. Existing ICF core sets could be used for this, or alternatively a combination of existing ICF core sets and the knowledge gained from developing those core sets [13].

Limitations

The literature search was limited to European studies and only measurement instruments with at least three nutrition-related questions were included. Validated measurement instruments that play a role in interdisciplinary rehabilitation, such as the extended Barthel Index and the Functional Independence Measure [66], were excluded. Furthermore, due to the complexity of the ICF-Dietetics and its large number of categories, there is some room for interpretation, however parallel linking by two raters, subsequent discussion, and the inclusion of a third expert were used as quality control measures.

In this study, the scientific perspective that was selected was a systematic literature search and the linking of measurement instruments used in the field of neurology. The S3 guidelines of the Ger-

man Society for Nutritional Medicine [*Deutsche Gesellschaft für Ernährungsmedizin* (DGEM)] and the European Society for Clinical Nutrition and Metabolism (ESPEN) [3, 4, 30] were included in the questionnaire design for the Delphi survey but not in the design of the linking process. In addition, the existing, relevant ICF core sets [15–23] were not taken into account. By compiling a list of nutrition-related aspects, this study provides a starting point for the first disease-specific dietetic core set that can be combined with existing ICF core sets for neurological diseases. For it to be complete, the clinical perspective is still required (e.g., in the form of documentation analyses), as is the perspective of those affected (e.g., in the form of patient interviews). It would be desirable to reach an international consensus on this.

Conclusion

This study has laid the initial foundation for standardized dietetic assessment of patients with neurological disorders using the ICF-Dietetics. This will contribute to transparency regarding quality in dietetic practice and will facilitate outcomes research. Assessment in line with the ICF classification of the WHO and consequently with the ICF-Dietetics means that consideration is given not only to a disease, but also to the patient’s activities and participation, and to personal and environmental facilitating factors and barriers.



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Conflict of Interest

The authors declare no conflict of interest.

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