Nutrition therapy in neurological diseases

Development of an ICF-Dietetics core-assessment set including qualitative patient interviews

Sonja Visontai, Gabriele Gäbler

Abstract

Background: The objective of this study is to develop the first standardized ICF-Dietetics core-assessment set for patients with selected neurological diseases.
Method: The standardized development process that was used includes previously published preliminary studies (a multicenter retrospective study, a systematic literature search, and a Delphi expert survey) as well as the qualitative study described in this article for the patient perspective and the consensus-building process in which the dietitians participated.
Method: The ICF-Dietetics core-assessment set contains a total of 128 ICF-Dietetics categories, arranged in levels: 74 in the second level, 27 in the third level, 25 in the fourth level and one in the fifth level, plus one chapter. Distribution of components: Body functions and structures 58, Activities 35, Participation 5, Environmental factors 12, Personal factors 18.
Result: This ICF-Dietetics core-assessment set for neurology enables dietitians to collect patient-specific information in a structured and systematic manner.

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Background

According to the Global Burden of Disease Study 2017, age-related neurological diseases, especially stroke and dementia, and the resulting disability-adjusted life years (DALYs) and deaths are increasing worldwide, with Europe being particularly affected. Neurological diseases are the third most frequent cause in the DALYs ranking in Europe [1]. Neurological diseases are often chronic and life-threatening, resulting in immense costs to the healthcare system [2] and an increased need for multidisciplinary, patient-centered care [3]. Neurological diseases require a long-term approach to nutrition therapy because patients often have comorbidities such as weight loss with associated malnutrition, dysphagia, aspiration or gastrointestinal motility disorders. These nutritional problems place a variety of limitations on how patients live in their everyday lives [4, 5].
The ESPEN dementia guidelines advocate for a standardized approach to nutrition therapy in order to increase transparency and patient outcomes [6]. This requires international terminology and process models. There are currently two sets of dietetic terminology in use worldwide [7–9]:

- In 2003, the Academy of Nutrition and Dietetics in the USA developed the Nutrition Care Process Terminology (NCPT), a specific set of terminology for dietetics [10], together with the Nutrition Care Process and Model (NCP) [11].
- In the Netherlands, the Dietetic Care Process Terminology (DCPT)[1] was established together with the classification of the International Classification of Functioning, Disability and Health-Dietetics 2023 (ICF-Dietetics)

[1] formerly Classifications and Coding Lists for Dietetics (CCD)

	Designation	Level	Original ICF component/category; precise ICF-Dietetics category	Forest-tree-branch-twig-leaf-bud diagram
Domain	Activities and participation classification code a	none	original ICF component d	"forest"
Chapter 5	Self-care	1	original ICF category	"tree"
a570	Looking after own health	2	original ICF category d570	"branch"
a5701	Managing nutrition, diet and fitness	3	original ICF category d5701	"twig"
a57010	Managing nutrition	4	precise ICF-Dietetics category	"leaf"
a570100	Selecting and eating meals	5	precise ICF-Dietetics category	"bud"

Tab. 1: **Hierarchical representation of ICF-Dietetics categories** (modified in accordance with Schuntermann 2019 [15])

[12, 13]. This is based on the International Classification of Functioning, Disability and Health (ICF) from the World Health Organization (WHO) [14]. The ICF-Dietetics contains most of the original ICF categories, plus more than 900 specific categories relevant to nutrition and dietetics [12].

As a uniform multidisciplinary language, the ICF provides an organizational framework. The ICF is based on the **biopsychosocial model of functioning and disability**. It describes a state of human functioning and impairment and consists of **five components, each of which is assigned a prefix**: body functions and structures (b, s), activity and participation (d), environmental factors (e) and personal factors (pf) (not categorized) [14].

In contrast to the ICF, in the ICF-Dietetics, the components of activity (a) and participation (p) are treated separately and the person-related factors (pf) are categorized [12].

The ICF/ICF-Dietetics classification has a hierarchical structure, similar to an extended "branch-twig-leaf diagram" [15], which is illustrated in ◆ Table 1 using the example of the domain activity in ICF-Dietetics, Chapter 5 self-care.

In accordance with this hierarchical structure (◆ Table 1), a term at the fifth level includes the general characteristics of the corresponding fourth-level category. At the same time, a term must not contradict the attributes of the superordinate category [14].

Doctors use the ICD[2] to map out and diagnose health problems. The WHO recommends using the ICD and ICF classifications together so that people's health status can be described in a holistic manner [14].

Since 2005, there have been international efforts to harmonize the NCPT and DCPT [7, 13, 16]. The results of the study by Gäbler et al., in which more than 900 NCPT concepts were linked to the corresponding original ICF categories or ICF-Dietetics categories with a degree of agreement of 86.5%, demonstrate the comparability of different technical languages used by a professional group [7].

Since 2018, Austria has had a first published version of the Austrian-German ICF-Dietetics – a translation of the 2017 version of the English ICF-Dietetics [17]. A uniform German ICF-Dietetics 4.0 has now been developed through a harmonization and update process [13].

The ICF core set is an internationally established list of selected ICF categories that are used to facilitate standardized assessment for a group of specific health conditions or a specific health condition in a defined area of care. An ICF core set is developed in a process that is divided into phases [23].

In Austria, the profession of "dietitian" is a legally protected health profession designation [18]. Dietitians' professional and methodological activities are based on the dietetic process and precise quality standards for them have been in place since 2020 [19]. The dietetic assessment forms the basis for all subsequent steps in the dietetic process. Nutrition-related information on nutritional status is collected, structured, and assessed according to guidelines and reference values [20]. A nutritional problem is defined as such when it causes problems for the patient in their everyday life. It can be improved, influenced, or resolved with the support of dietitians and an adapted diet [21, 22].

The application of the ICF's biopsychosocial model supports a holistic view of patients [14].

The creation of an ICF-Dietetics core-assessment set supports a standardized assessment procedure, which contributes to quality assurance [20].

[2] International Statistical Classification of Diseases and Related Health Problems

The ICF core set for stroke [24] has been used in clinical practice since 2004. Because taking a uniform approach to assessment is so useful, experts decided to create additional ICF core sets for neurology. Now, there are twelve different ICF core sets (comprehensive, short, and generic sets) for use in acute, post-acute, and long-term care [24, 25].

At present, there is no ICF-Dietetics core-assessment set for nutrition therapy in the context of neurological diseases, which is why work has been underway in Austria since 2020 to develop one.

Three studies have been published as preliminary studies: a multicenter retrospective study to acquire clinical data on documentation [26], a systematic literature search for assessment instruments, and a subsequent Delphi expert survey [27].

Study objective and research questions

The objective of this study is to record the patient perspective and to create the first ICF-Dietetics core-assessment set for patients with selected neurological diseases. This leads to the following two research questions:

- Which ICF-Dietetics categories do patients with neurological diseases consider important for dietetic assessment in the case of neurological diseases?
- Which categories do experts consider relevant for an ICF-Dietetics core-assessment set for neurology?

Method

Patients were interviewed to identify their perspectives on the most common nutritional problems associated with selected neurological diseases (stroke, Parkinson's disease, multiple sclerosis and amyotrophic lateral sclerosis).

In order to reach a consensus, a Delphi survey of experts was conducted in two rounds based on the ICF-Dietetics categories identified from all of the preliminary studies.

◆ Table 2 shows the entire development process for an ICF-Dietetics core-assessment set for patients with selected neurological diseases using the preliminary studies that have already been published.

Qualitative patient interviews

Eleven semi-structured, guideline-based interviews were conducted with affected individuals from three Austrian rehabilitation facilities specializing in neurology. ◆ Table 3 shows a detailed breakdown of the patient interview data.

Inclusion and exclusion criteria (◆ Table e1 in the e-supplement) were defined and guidelines were developed based on the WHO ICF checklist in accordance with the components of the biopsychosocial model [14].

The categories were defined based on ICF-Dietetics 2.0 [17] and the results of the 2021 publication [27]. A total of **21 categories** were assigned to the **five components of the biopsychosocial model**. In the *Body functions and structures* component, the following example questions were given for the categories of *Motivation to eat* and *Appetite*: How would you rate your appetite on a scale of 1–10? Has this changed since your illness started? If so, how? [28].

Preparatory phase	Phase 1 – consensus building	Phase 2 – validation process
Empirical multicenter study Gäbler G, et al. (2019) [26] *Towards a standardized nutrition and dietetics terminology for clinical practice: an Austrian multicenter clinical documentation analysis based on the International Classification of Functioning, Disability and Health (ICF)-Dietetics*	**Content of this publication**	Validation phase for the initial version of the ICF-Dietetics core-assessment set for neurology
Systematic literature search and Delphi expert survey Böhm I, et al. (2021) [27] *Development of a standardized dietetic assessment for medical nutrition therapy in neurological disorders using the ICF-Dietetics. A systematic literature search and Delphi survey*	Consensus building through Delphi expert survey & Initial version of the ICF-Dietetics core-assessment set for neurology Miklautsch L, Pewal I (2024) [29]	
Qualitative study **Content of this publication** Haberl J, Tabery A (2022) [28] *Identification of the most common nutritional problems of patients with selected neurological diseases (stroke, Parkinson's disease, multiple sclerosis, amyotrophic lateral sclerosis) to develop a standardized dietetic assessment method using the ICF-Dietetics*		

Tab. 2: **Development of an ICF-Dietetics core-assessment set for patients with neurological diseases**

Detailed breakdown of patient interview data								
					Conditions			
Person-related data		**Interviews, total**	**Interviews per facility**	**Rehabilitation facility**	**Amyotrophic lateral sclerosis**	**Stroke**	**Parkinson's disease**	**Multiple sclerosis**
gender	m/f/non-binary/ intersex	11	5	Facility 1	1	0	3	1
gender distribution	5 m 6 f 0 nb/ intersex		3	Facility 2	0	2	0	1
			3	Facility 3	0	0	1	2
age in years	mean 57.1	time period						
youngest person	32	11 Feb–1 Apr 2022						
oldest person	73							

Tab. 3: **Detailed breakdown of patient interview data** (authors' own presentation)

The preliminary version of the guideline was evaluated in a pretest to assess its suitability as a research instrument [30]. These data were not included in the presentation of the results. The data were pseudonymized via the assignment of codes [31] and then analyzed using qualitative thematic analysis [32]. The focus was on recording patients' subjective perspectives in order to identify attitudes and behaviors relating to the nutritional problems that were asked about. Whether a "linked" category constituted a nutritional problem was left to the discretion of the study investigators [28].

The results of the qualitative thematic analysis were linked to the ICF-Dietetics [17] in accordance with the ICF linking rules [33]. To this end, the health information was first divided into main concepts and secondary concepts in a "linking sheet." This information was then linked to the most precise level of the ICF-Dietetics. ◆ Figure 1 shows an excerpt from the linking process using the example of feelings and food intake in the case of stroke.

The ICF-Dietetics core-assessment set was developed by combining all aspects of the preliminary studies that are relevant to nutrition. A two-round expert consensus process then took place. ◆ Figure 2 shows the methodological approach used.

Two-round Delphi survey for consensus building

The method selected to build the consensus was the Delphi method, consensus type 4, conducted in two rounds [34]. Details on how the experts were recruited are shown in ◆ Table 4.

What feelings do you associate with eating/food intake?								1st Rater							
								Linking main concept				Linking secondary concept			
Clinical picture ICD-Code	Interview number	Reference	Quote	Perspective of health information	Main concept	Secondary concept	Nutritional problem yes/no	ICF-Code (2nd level)	ICF-Category	ICF-Code (most precise level)	ICF-Category	ICF-Code (2nd level)	ICF-Category	ICF-Code (most precise level)	ICF-Category
				descriptive: performance/efficiency, assessment/evaluation, need or dependency	basic concept and content What is the information about?	other concepts contained in the information									
Stroke	1	p.1, l.10	Good, pleasant feeling.	assessment/ evaluation	emotional functions		no	b152	Emotional functions	b1522258	Positive feelings, otherwise known as: pleasant				
Stroke	3	p.1, l.15, 16	It's somehow more comfortable up here, but um, um, I'll choose what I want.	assessment/ evaluation	emotional functions	convenience	no	b152.2	Emotional functions	b152298.2	Range of emotions, not specified	a570.3	Take care of your health		Ensuring his physical comfort

Fig. 1: **Example linking sheet** [28]

Methodological presentation	
patient interviews n = 11	
evaluation based on qualitative topic formation	linking process according to main/secondary concepts most precise level nutritional problem yes/no
Delphi expert survey (preliminary work) n = 30	
results of the preliminary survey	linking process according to main/secondary concepts most precise level
comparative tabular presentation of the linking results of both surveys according to ICF-Dietetics coding	
integration of nutrition-related aspects for a dietary assessment in the components of the biopsychosocial model with ICF-Dietetics coding as the basis for the ICF-Dietetics core set	
consensus process for ICF-Dietetics core set in 2 rounds	
Delphi expert survey 1 n = 21	Delphi expert survey 2 n = 21
presentation of results ICF-Dietetics core set for neurology	

Fig. 2: **Outline of the methodological approach used** (authors' own presentation)

Recruitment of experts for consensus building		
Study population details	**Round 1 participants**	**Round 2 participants**
• dietitians • completed professional training as a dietitian • specialism in Neurology • neurological facility in Austria • time period: Feb./March 2024	contacted: 116 agreed to take part: 26 actually took part: 21	agreed to take part: 26 actually took part: 21

Tab. 4: **Recruitment of experts for consensus building** (authors' own presentation)

The questionnaire for the first Delphi survey was developed based on 300 ICF-Dietetics categories collected from all of the preliminary studies [7, 27, 28], and was structured according to the components of the biopsychosocial model. Nutrition-specific categories of the ICF-Dietetics that are relevant to dietetics are often only found below the second level, i.e., in levels three to five, so these have been included in the rating process where relevant [17]. Where possible, items were grouped together into higher-level categories to reduce the number of items. ◆ Figure 3 shows an example of this process of reduction to a higher level (the three items at level five are contained in the characteristics of the category at level four, which allows them to be reduced to this category [without loss of content]).

After reduction to higher levels, the questionnaire for the first Delphi survey round contained a total of 136 categories (61 from the *Physical functions and structures* component, 37 from the *Activity* component, six from the *Participation* component, 14 from the *Environmental factors* component, and 18 from the *Personal factors* component), as well as an open text field for comments. A pre-test was conducted to evaluate the practicality and comprehensibility of the questionnaire. Data collection and data analysis were carried out using the online survey tool "LimeSurvey" [35].

In the **1st Delphi round**, 21 experts decided on the degree of relevance of the 136 ICF-Dietetics categories for the ICF-Dietetics core-assessment set. The data was categorized according to cut-off values based on the percentage of responses of "relevant" or "not relevant." Values with an agreement rate of < 40% were excluded, values with ≥ 40% to ≤ 75% were surveyed again in the **2nd Delphi round**, and values with > 75% were immediately transferred to the ICF-Dietetics core-assessment set [23].

There was no third round of consensus building because the participants were all well-known experts and no change in the assessment was expected.

Ethics committee vote and informed consent

A positive ethics committee vote was issued by the Ethics Committee of FH Campus Wien for the Haberl & Tabery 2022 study [22], EC no.: 34/2022. The study participants gave their informed consent via an informed consent form. The informed consent form listed the purpose, processes, benefits, and methodology of the study as well as details about data processing, including pseudonymization of personal identifiers via codes [31, 36].

Results

The first ICF-Dietetics core-assessment set for neurology (◆ Table e2 in the e-supplement) contains a total of 128 ICF-Dietetics categories (74 in the second level, 27 in the third level, 25 in the fourth level and one in the fifth level, plus one chapter).

Results of the patient survey

The results of the patient survey were summarized according to the components of the biopsychosocial model and presented in ICF-Dietetics categories. Secondary concepts were presented in tabular form and described

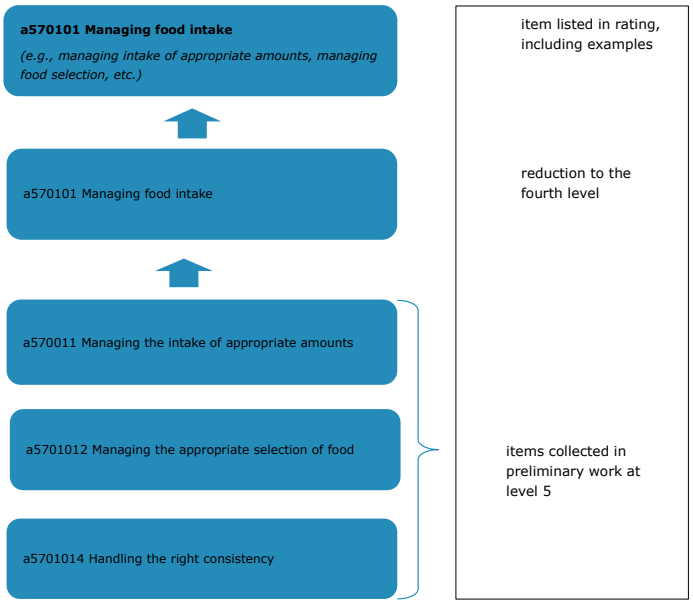

Fig. 3: **Reducing categories to a higher level** (authors' own presentation)

(multiple responses were allowed, each counted once). Examples of ICF-Dietetics categories: *appetite, chewing and swallowing, weight change, digestion, support from dietitians* [28]. ◆ Table 5 shows how the results were presented using the ICF-Dietetics category of *Appetite* as an example [28].

Data analysis using qualitative thematic analysis shows that patients reported at least one nutritional problem during the course of their illness. Both reduced appetite and medication intake associated with

ICF-Dietetics category APPETITE								
	2nd category (level)		Main concept (most precise level)		Secondary concept (most precise level)		n (= number of mentions)	Nutritional problem yes/no
ICF component	ICF code	ICF category	ICF code	ICF category	ICF code	ICF category		
Body functions (b)	b130	Energy and drive functions	b130200.x0	Normal desire to eat, in general			5	no
	b130	Energy and drive functions	b130200.x1	Reduced desire to eat, in general			4	yes
	b130	Energy and drive functions	b130200.x1	Reduced desire to eat, in general	e1101	Medications (B)	1	yes
	b130	Energy and drive functions	b130200.x2	Increased desire to eat, in general			5	yes
	b130	Energy and drive functions	b130200.x2	Increased desire to eat, in general	e1101	Medications (B)	1	yes
	b130	Energy and drive functions	b130201	Desire for a particular food or nutrient			1	yes
Activities and participation (a)	a570	Looking after own health	a5701011	Managing intake of adequate amounts			1	yes

Tab. 5: **Presentation of results in the ICF-Dietetics category APPETITE [28]**
multiple responses allowed
B: Barrier

unintended weight loss were identified as nutritional problems. Seven out of eleven respondents reported unintentional weight loss due to rehabilitation stays, gastrointestinal disorders, or the neurological disorder itself, as illustrated by the following quote:

"[only that I lost so much weight – most likely as a result of the illness. In 5 years, 3,3,3 years. I used to weigh about 115 [kilos], and then by Christmas I was down to 95, and I've stayed at that weight for the whole of the last year.[…]"

(04, Parkinson's disease, p. 2, line 1, 2)

Results of the Delphi surveys

128 ICF-Dietetics categories were adopted into the ICF-Dietetics core-assessment set for neurology. 21 experts rated these as "relevant" to dietetic assessment. ◆ Table e3 in the e-supplement shows the results of the consensus-building process.

99 of the ICF-Dietetics categories asked about (cut-off ≥ 75%), were adopted directly after the first Delphi round. 8 ICF-Dietetics categories (cut-off < 40%), were excluded from the rest of the process. 29 ICF-Dietetics categories, for which no consensus was reached in the first Delphi round, formed the basis for the second round. After this second Delphi round, six additional items were directly incorporated into the ICF-Dietetics core-assessment set. For 23 ICF-Dietetics categories, the cut-off was between ≥ 40% and ≤ 75%. ◆ Table e4 in the e-supplement shows the ICF-Dietetics categories after the second Delphi survey round.

There was 100% consensus among the experts for 29 out of 128 ICF-Dietetics categories (◆ Table 6).

Discussion

This study led to the creation of the first ICF-Dietetics core-assessment set for neurology. It was developed based on international standards from the WHO and the *ICF research* sector [25, 37]. This new set differs from existing ICF core sets in the field of neurology [24, 25] in that it uses specific dietetics terminology, making it possible to inquire about items specific to nutrition in the context of neurological disorders [17]. It is advisable for dietitians to adhere to a standardized approach. The results of the 2021 Delphi expert survey showed that 85% of dietitians were in favor of creating a standardized method of dietetic assessment [27]. This ICF-Dietetics core-assessment set provides an organizational framework of standardized terminology, enabling a much more targeted classification and synthesis of patient data within the context of dietetic assessment [14]. The relevant categories identified for the assessment can be used as a basis for developing a core outcome set. This would achieve the benefit of having standardized terminology throughout the dietetic process, through to outcomes management [38, 39]. Healthcare services would be recorded more transparently at the national and international level, thereby ensuring scientific comparability [38].

The logical next step is to implement this ICF-Dietetics core-assessment set for neurology in dietetic practice. This first comprehensive version will be tested extensively in neurological institutions throughout Austria to evaluate its suitability for everyday use and its benefits for patients. It will then be necessary to generate a short version to increase its practicality [37]. In the international context, it has become apparent that neither the ICF-Dietetics nor the NCPT will become the

ICF-Dietetics categories for dietetic assessment with 100% expert consensus		
b1302 Appetite	b515 Digestive functions	s7052 Body weight
b5106 Functions that expel contents from the stomach, esophagus, and throat	b5153 Tolerance to food	a550 Eating
b152200 Fear	b525 Defecation functions	a560 Drinking
b250 Taste functions	b530 Weight maintenance functions	a570100 Selecting and eating meals
b280 Sensation of pain	b531 Weight change	a630 Preparing meals
b431 Clinical chemical blood composition	b532 Nutritional status	e1151 Assistive products and technology for personal use in daily living
b510 Ingestion functions	b535 Sensations associated with the digestive system	pf130 Cultural/religious background
b5102 Chewing	b53500 Nausea and vomiting	pf615 Use of alcohol
b5105 Swallowing	b5408 Other specified general metabolic functions: Fluid requirements	pf630 Nutritional habits
b51081 Aspiration	s3200 Teeth	

Tab. 6: **ICF-Dietetics categories for dietetic assessment with 100% expert consensus**

sole terminology used by dietitians. Efforts are underway to link both terminologies with the Systematized Nomenclature of Medicine-Clinical Terms (SNOMED-CT), a medical terminology [38, 40].

Discussion of individual results

The rating process in this study is based on the results of preliminary scientific studies [7, 27, 28] (◆ Table 2).

128 of the 136 ICF-Dietetics categories surveyed were included in the first ICF-Dietetics core-assessment set. For 29 of these, there was 100% consensus among the experts that they should be assessed in the dietetic assessment of patients with neurological diseases (◆ Table 6). Most of these items come from the *Body functions/structures* component and the *Activities* component. The results of the latter component are specific to ICF-Dietetics. The category *a5701 Managing nutrition, diet, and fitness* at level 3 is a generic term that includes a variety of nutrition-related categories. These were classified as "relevant" both in the preliminary studies [7, 27, 28] and in this study.

This shows that although the hierarchical classification of ICF-Dietetics is complex, with up to five levels of classification, it is possible to expand nutrition-specific ICF-Dietetics categories in depth [7, 12]. The relevance for dietetic assessment is based on the need to identify an identified nutritional problem as precisely as possible to determine a dietetic diagnosis [20].

The secondary concepts identified from the patients' perspective indicate that nutritional problems are often influenced by predisposing factors. For example, taking medication can have a positive or negative effect on nutrition, which in turn influences appetite (◆ Table 5). Information from ICF-Dietetics categories such as chewing and swallowing difficulties, digestive problems, or weight change since the onset of the disease is relevant to patients, but was not collected in this form in the 2021 expert survey [27, 28]. Information about functional impairments is an important component of health information that shows how well a person is able to cope with general areas of life [41]. Patient individuality is preserved by mapping a person's participation in society and individual promoting factors and barriers within the context of environmental and personal factors [14]. The relevance of this was also emphasized in the 2021 expert survey [27].

Methodological limitations

The consensus-building process aimed to achieve consensus on the relevance of all categories for the ICF-Dietetics core-assessment set. Ultimately, after the second Delphi round, agreement for 23 of the categories was ≥ 40% to ≤ 75%. These 23 categories were included in this initial version of the ICF-Dietetics core-assessment set (◆ Table e4 in the e-supplement) in order to integrate them into the validation process. One argument in favor of this is that not including them in the dietetic assessment could risk insufficient data collection [20].

Despite the professional expertise of the dietitians surveyed, the possibility that the decision as to whether an item was "relevant" or "not relevant" was based on subjective opinion cannot be ruled out. This could cause bias in the results. Therefore, the validation process of this initial version of the ICF-Dietetics core-assessment set is an important part of the development of core sets [42].

A total of 116 dietitians were contacted for these studies, and of these, 21 experts (18%) participated in the consensus-building process. A few dietitians withdrew from the study because they did not identify themselves as "experts." A third round of surveys was not conducted, as all the same experts from the first two rounds would have participated again and therefore no clear decision on relevance (consensus above 75%) was to be expected.

An ICF core set should describe the entire range of functions of a person in a specific health context. Although this study was conducted using a systematic approach, there is a risk that essential aspects of functioning were not described. This is another reason why the validation process is important in practice. This will allow additional items to be added to the list [23].

Conclusions

The creation of this first ICF-Dietetics core-assessment set for neurology represents a significant step forward for quality assurance in dietetics. When used in dietetic assessments, it will support dietitians to collect data in a standardized, holistic manner and ensure greater patient safety, which will strengthen the professionalization of the profession.

Disclosures on Conflicts of Interest and the use of AI
The authors declare that there is no conflict of interest. AI was used to create/check translations.

You can find the e-supplement to this article, including the references, online at → www.ernaehrungs-umschau.de/fachzeitschrift/heftarchiv/ edition 6/2025.