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ORIGINAL ARTICLE

Consensus on level descriptors for a functional children's eating and drinking activity scale

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Abstract

Aim: To agree wording of level descriptors for a measure of functional outcome of children's eating and drinking.

Method: An online, modified Delphi method was used to gather feedback on current level descriptor wording and generate rewording suggestions. Thirty speech and language therapists, working in a variety of settings and geographical locations, were invited to be part of the Delphi expert panel. Content analysis was used to evaluate participants' comments and develop consensus level descriptors. Consensus for acceptable wording was set at 80% agreement. Face validity was assessed using 5-point Likert scales.

Results: Nineteen expert speech and language therapists (median experience 18 years) completed round one; 15 out of 19 completed round two. Level descriptor rating reached 80% agreement in two rounds. Additionally, 93% of participants agreed the scale would accurately capture change in their setting, with 87% likely to use the scale in practice.

Interpretation: This study has produced agreed wording for a functional measure of eating and drinking activity suitable for use with paediatrics feeding disorders, regardless of disease aetiology, presentation, age, or setting. Potential for widespread use is supported. Further evaluation of the tool's reliability and validity is required.

Paediatric feeding disorders are described as 'impaired oral intake that is not age-appropriate, and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction'.[1] Upwards of 80% of children with developmental delay and neurological impairment present with such a feeding disorder.[2] These include physiological impairments (e.g. oropharyngeal dysphagia); rigid or limited food preferences; food refusal and/or challenging mealtime behaviours; and difficulty mastering self-feeding.[3] The need for nutritional support via alternative feeding methods or supplementation, dietary modifications, and/or the use of specialist equipment may be indicated. Crucially, paediatric feeding disorders are associated with parental stress and reduced quality of life,[4] poor respiratory health,[5] and faltering growth.[6] Thus, they carry significant burden for the child, family, and health care systems.

Outcome measurement is central to ensure effectiveness in both clinical and research practice and economic accountability. It provides a replicable, quantifiable measure to demonstrate patient progress and evaluate treatment effectiveness. These data inform service design and delivery, and treatment options and can be used for benchmarking activity.[7]

Although widely acknowledged as being important, routine outcome measurement remains limited in clinical practice.[8,9] To facilitate use, outcome tools must be 'fit for purpose', easy and quick to use, and demonstrate good

Abbreviations: CEDAS, Children's Eating and Drinking Activity Scale; FOIS, Functional Oral Intake Scale; IDDSI, International Dysphagia Diet Standardization Initiative.

psychometric properties.[10–12] They must also be sensitive to the needs of the targeted population.

The Functional Oral Intake Scale (FOIS)[13] is an outcome measure (Table 1) initially designed for use in poststroke dysphagia. It has undergone extensive evaluation and is widely used in adult settings.[14,15] The FOIS has been adapted for use in paediatrics by a number of researchers. Christiaanse et al.[16] first modified the FOIS by adding paediatric examples to the level descriptors. However, these adaptations did not take account of developmental stages of feeding. Coppens et al.[17] modified it for use with infants with oesophageal atresia, addressing the developmental issues by collapsing levels 4 to 6 into a single level, defining it as 'Expansion of oral diet not reached', that is, not having met expected developmental progression with solid foods. Yi and Shin[18] then psychometrically evaluated this version with infants under 1 year of age. They subsequently created a separate version for use in children over 1 year of age.[19] However, having different tools for different ages makes it difficult to track change over time, while limiting the tool to a 5-point scale reduces the sensitivity to meaningful change. Dodrill and Gosa also reported creation of a paediatric FOIS[20] which has been used in several research projects.[21,22] This tool was adapted to have six levels with level 4 split into 4 and 4.5 to reflect solids and liquids. It is not clear whether a score of 4 represents poorer functional outcome than the 4.5 score or if the tool can be considered ordinal as it consists of an unequal scale. Report of how any of the adaptations were made are limited and psychometric evaluation exists only for the Yi and Shin adapted versions.[18,19] Regardless of the iteration, each author agrees upon the necessity (and challenge) of taking typical developmental feeding into account when measuring change.

What this paper adds

- There was level descriptor consensus for a functional outcome measure of eating and drinking.
- Eighty per cent or more consensus on level descriptors was achieved in two rounds.
- The tool demonstrates good face validity for use in children 0 to 18 years old.

In order to address this void, our team completed an investigation aimed at developing a reliable and valid measure of functional eating and drinking for use with children aged 0 to 18 years old.[23] The aims of this investigation were to (1) refine wording of the level descriptors to maximize clarity and (2) establish face validity.

METHOD

An online Delphi study was conducted to achieve consensus on the wording of the level descriptors for a functional

TABLE 1 FOIS iterations

	FOIS (Crary et al.[13])	pFOIS (Weststrate et al.[23])	Revised scale
Level 1	Nothing by mouth	Nothing by mouth (non-nutritive sucking/dummy dips/mouthcare only)	Tube use for all nutrition and hydration. Nothing by mouth. Non-nutritive sucking and/or mouthcare only
Level 2	Tube-dependent with minimal attempts of food or liquids	Tube dependent for all nutrition/hydration needs with minimal attempts at oral intake for experience and/or pleasure	Tube use for all nutrition and hydration. Oral intake offered for experience and/or pleasure only
Level 3	Tube-dependent with consistent intake of food or liquid	Tube-dependent with consistent intake of food and/or fluid that meets some of the nutrition/hydration needs	Tube use with consistent intake of food and/or drink. Oral intake partially meets nutrition and/or hydration needs
Level 4	Total oral diet of a single consistency	Total oral intake but special preparation required e.g. thickened fluids, pureed diet (where not age-appropriate)	Total oral intake but requires special preparation of drinks (IDDSI level 1–4) and/or food (IDDSI level 3–5, where not age-appropriate) and/or supplements needed for nutrition support
Level 5	Total oral diet with multiple consistencies, but requiring special preparation or compensations	Total oral intake but requiring special conditions/modification (e.g. slow flow teat/side lying/pacing) or specific food limitations (e.g. soft or fork mashable diet)	Total oral intake but requiring special conditions (equipment/positioning/pacing/supervision) or food modification at IDDSI level 6–7 (where not age-appropriate) or food types/groups restricted by avoidance (where not age-appropriate) but without the need for supplements
Level 6	Total oral diet with multiple consistencies without special preparation, but with specific food limitations	Total, age-appropriate, oral intake with no restrictions	Total oral intake. Age-appropriate food and drink with no restrictions
Level 7	Total oral diet with no restrictions	N/A	N/A

Abbreviations: FOIS, Functional Oral Intake Scale; IDDSI, International Dysphagia Diet Standardization Initiative; N/A, not applicable; pFOIS, paediatric Functional Oral Intake Scale.

outcome measure and assess face validity, using a previously adapted version of the FOIS as an initial template (Table 1). The author of the FOIS, Professor Crary, had been contacted and consented to refinement for use in paediatrics. The study was approved by the University College London Research Ethics Committee (number: LCD-2019-11).

Participants

Purposive sampling was used to invite 30 expert speech and language therapists to participate via e-mail. An 'expert' was defined as a speech and language therapist with at least 7 years of paediatric feeding disorder experience and/or publication on the topic. Recruitment was targeted to individual therapists (vs broad advertising) to ensure all had the experience required to obtain a balance of hospital-based and community-based speech and language therapists and to ensure geographical representation from across the UK. Experts were invited if they were known to the authors through their research in the field, being a clinical educator/lecturer, being an experienced clinical lead, or their participation in a Royal College of Speech and Language Therapists paediatric dysphagia clinical excellence network.

Questionnaire design

REDCap (Research Electronic Data Capture) hosted at University College London,[24] a web-based application, was used to create and manage the online questionnaires. Piloting was undertaken by three speech and language therapists, and format adjustments were made accordingly.

Participants provided electronic consent and demographic information (years of experience, place of work, type of work, and previous use of the FOIS). Participation was anonymous.

Development of level descriptors

For tool familiarization, participants rated 10 vignettes using the scale (an example vignette is provided in Table 2 and all vignettes are provided in Appendix S1). The vignettes represented a range of paediatric feeding disorder presentations, ages, and scale levels. Percentage agreement with a reference value set by the research team was calculated. Scale levels with an agreement rating of less than 80% were determined as requiring alteration to the wording of the level descriptor.

Participants were asked to (1) describe any difficulties they had assigning a score (open text response), (2) whether the wording needed changing (yes/no), and (3) whether the number of levels within the scale was sufficient (fewer levels; no change; more levels). Where participants indicated the wording needed changing, they were asked to rewrite the level descriptor in their own words (open text response). Consensus was set a priori at 80% (i.e. if 80% of participants felt that the wording did *not* require alteration, it was deemed accepted).

Open text responses were analysed using content analysis.[25] The whole data set was reviewed in a data familiarization exercise (EH and AS). All data were then line-by-line coded by EH. AS independently analysed part of the data set to assess coding reliability. No substantial differences existed; therefore, full recoding of the data set was not carried out. Themes were generated from the codes. After review of the identified themes, level descriptors were reworded using amalgamated participant suggestions jointly by EH, AS, and EJ.

TABLE 2 Example vignette

Michael is a 13-year-old boy with cerebral palsy (GMFCS level V). He is a non-intentional/preverbal communicator and is fully dependent on caregivers for eating and drinking. He is fully orally-fed, drinking mildly thick fluids (IDDSI level 2) via a specialist cup. He eats a minced and moist diet (IDDSI level 5) using a non-breakable, shallow bowled spoon. He is undergoing annual review from the specialist SLT at school.

Abbreviations: GMFCS, Gross Motor Function Classification System; IDDSI, International Dysphagia Diet Standardization Initiative; SLT, speech and language therapist.

Face validity

Participants were asked to rate whether (1) the current scale would accurately capture change (i.e. be useful as an outcome measure) within their current client/patient population using a 5-point Likert scale ('strongly agree' to 'strongly disagree') and (2) how likely were they to use this outcome measure in their specific setting ('very likely' to 'very unlikely'). Data were analysed descriptively using percentages.

RESULTS

Participants

Nineteen out of 30 invited expert speech and language therapists completed the first questionnaire, and 15 out of 19 completed a second round. All participants had at least 7 years of experience, median 18 years (range 7–32 years). Nine participants worked in hospital settings (inpatient and outpatient) and nine in community settings (patient home, clinic, school and preschool education); 16 out of 19 worked across multiple settings. Six had published peer-reviewed research in the field of paediatric feeding disorders. Three had previously used a version of the FOIS within clinical practice.

Development of level descriptors

Seven out of 10 vignettes in round one had high level (94–100%) agreement with the reference ratings. The remaining three, all reference levels 4 or 5, had moderate (57–69%) agreement.

Responses to the question 'Do you feel the wording of level __ (*reminder of level descriptor wording*) needs to be changed?' (yes/no response options) are provided in Table 3. Only level 6 reached the 80% consensus for *not* requiring rewording in round one. Themes derived from open text responses relating to difficulties assigning a level are presented in Table 4, alongside examples of participant rewording suggestions.

After rewording of the scale, all six levels were deemed acceptable, with 80% or more of participants agreeing that no further changes were required (Table 3). The reworded level descriptors are presented in Table 1. The three vignettes with less than 80% agreement with the reference rating in the first questionnaire were rerated. One vignette remained at less than 80% agreement. Analysis of comments demonstrated differences in determining age appropriacy. One participant rated it as level 6, stating, 'For an 18-month preterm infant, [their] diet is age-appropriate'. Another rated it as level 4 because the child has 'food modification required where not age-appropriate'.

TABLE 3 Level descriptor consensus ratings

Level	Round 1	Round 2
1	53%	93%
2	78%	93%
3	68%	80%
4	26%	93%
5	21%	87%
6	95%	93%

Number of levels

Ninety-four per cent of participants agreed that no change to the number of levels was needed. The tool therefore remained a 6-point ordinal scale.

Face validity

Results of usefulness and utilization questions from both rounds are presented in Table 5. After round two, 14 out of 15 participants agreed the scale would accurately capture change and 13 out of 15 would be likely to use the tool.

DISCUSSION

Numerous efforts to adapt the FOIS[13] for use with children have been made, but none were suited to assessing outcomes in a population with paediatric feeding disorders irrespective

TABLE 4 Themes and example participant rewording

Level	Themes	Example(s)
1	• Dummy dips related to oral intake for experience/pleasure; change/remove dummy dips • Change 'nothing by mouth' to 'nothing taken orally/no oral intake' • Add tube dependency for consistency	'"Dummy dips" can cause confusion between level 1 and 2. I feel that level 1 should be for children who have nothing orally, not even tastes and are exclusively [nil by mouth]'
2	• Clarify examples • Reword 'attempts' • Reword 'dependent' • Define minimal	'Tube use for all nutritional/hydration needs with minimal recommended offers of oral intake for experience and/or pleasure'
3	• Clarify nutritional needs • Reword 'dependent' • Align with IDDSI • Change 'meets some' to 'partially meets'	'"Drink" rather than "fluid" should be used as per IDDSI descriptors. Tube dependent with consistent intake of food and/or drink that meets some of the nutrition/hydration needs'
4	• Clarify examples • Align with IDDSI • Add supplements • Clarify special preparation vs specific food limitations • Equipment	'Total oral intake but special preparation required (e.g. thickened fluids, pureed diet [where not age-appropriate]) or supplements required to support very limited range of intake' 'Total oral intake where special preparations are required e.g. thickened fluids (IDDSI levels 2–4) or pureed diet (where not age-appropriate; IDDSI levels 3 and 4)'
5	• Clarify examples • Align with IDDSI • Clarify textures vs special conditions • Equipment • Add positioning • Thickened fluids not included • Add supplements	'Total oral intake requiring use of specific strategies e.g. slow flow teat/side lying/pacing or specific food limitations (e.g. avoidance of particular food types/groups)' 'Total oral intake but requires minimal consistency modification to IDDSI level 5/6 and/or specialist equipment to support oral feeding'
6	• Reword for consistency	'Total oral intake—age-appropriate with no external restrictions'

Abbreviations: IDDSI, International Dysphagia Diet Standardization Initiative.

TABLE 5 'Usefulness' and 'utilization' results

		Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Do you feel this current scale would accurately capture change (i.e. useful as an outcome measure) within your current client/patient population?	Round 1 (n = 19)	1	13	3	2	0
	Round 2 (n = 15)	1	13	1	0	0
		Very likely	**Likely**	**Neutral/unknown**	**Unlikely**	**Very unlikely**
How likely are you to use this outcome measure in your specific setting?	Round 1 (n = 19)	4	9	3	1	2
	Round 2 (n = 15)	4	9	2	0	0

of the child's age, underlying aetiology, or care setting.[16–20] This study used systematic compilation of expert opinions to develop collective agreement on level descriptor wording for a 6-point ordinal scale measuring functional oral intake in children. To reduce confusion, given the number of previously reported paediatric FOIS versions, the study team proposes calling this scale the Children's Eating and Drinking Activity Scale (CEDAS). The tool's face validity, the measure to which a tool 'on the face of it' assesses the phenomenon in question,[26] was good. Agreement was high within the panel that the tool would adequately capture change in functional eating/drinking and would likely be used in clinical practice. Using a tool that is fit for purpose is key to routine outcome measurement collection.[10] This study suggests that the CEDAS is such a tool.

An important consideration in outcome measurement is determining what the tool is measuring. In developing the CEDAS, we used the World Health Organization International Classification of Functioning, Disability and Health (ICF) framework to define the purpose of the tool and structure what to include at each of the six levels. The CEDAS aims to assess the 'functional' impact of paediatric feeding disorders. Within the ICF framework, the term 'functioning' signifies all body functions, activity, participation, and well-being.[27] According to Enderby and Moyse,[7] all outcome measures should target and measure restrictions in at least one of these domains. The CEDAS level descriptors were mainly considered within the 'activities' and overlapping 'participant' components of the ICF. Limitations in activities arise when an individual has difficulties in carrying out a particular action, and limitations in participation occur when involvement in life experiences/situations is restricted.[27] Each CEDAS level was structured so that the further a child is from full, unrestricted eating/drinking activity and/or participation, the lower the assigned level. For example, a child who requires tube use but is receiving some nutrition via oral means (CEDAS level 3) is closer to full eating/drinking function than a child who requires a tube but only receives oral intake for experience and/or pleasure (CEDAS level 2).

Participant suggestions of including International Dysphagia Diet Standardization Initiative (IDDSI) levels and dietary supplementation were included using this framework. For example, if not age-appropriate, a child who eats pureed or minced and moist foods (IDDSI levels 4 or 5) imposes greater meal preparation difficulties than soft and bite-sized or easy to chew foods (IDDSI levels 6 or 7). This activity restriction further imposes limitation within participation as children and their families will find it more challenging to participate in certain life situations (e.g. eating meals outside the house).[27] Additionally, regardless of oral abilities, if malnutrition concerns warrant nutritional supplementation, then a child is arguably further from full activity (meeting nutritional requirements for appropriate growth) and participation (meals with family/at school etc.) than one who does not require oral supplements, hence is placed in CEDAS level 4.

When writing the level descriptors, the functional impact of eating and drinking were considered in the context of a paediatric feeding disorder.[1] The framework and diagnostic definitions provided by Goday et al.[1] includes children with difficulties associated with feeding skill (e.g. oro-motor dysfunction or pharyngeal dysphagia) as well as those with food avoidance behaviours (e.g. those associated with autistm spectrum disorder). As such, inclusion of restrictive/avoidant limitations to eating and drinking was an important addition to the level descriptors, ensuring the functional impact of eating/drinking difficulties can be measured in children where food or drink limitations are not associated with a specific IDDSI level.

The addition of IDDSI texture descriptors was a significant change. The IDDSI framework has been implemented in clinical settings internationally and is widely recognized by health professionals.[28] Participant comments supported its addition to clarify the CEDAS level descriptors, particularly between levels 4 and 5, and increase clinician confidence. Other adjustments such as changing 'fluids' to 'drinks' and 'diet' to 'food', as per IDDSI descriptors, were made.

The CEDAS documents and measures change in a child's functional oral intake regardless of impairment aetiology or severity but is not designed to be a measure of body functions or structure. It is not a measure of impairment severity or other health outcomes relevant to eating/drinking, such as weight gain or respiratory health. Being applicable to the broad, paediatric feeding disorder population is beneficial for comparing intervention outcomes across populations, settings, and conditions.[29] It also allows for greater consistency in comparisons and decision-making when considering the impact of treatment and/or its cost-effectiveness. However, it is suggested that impairment-specific measures are more sensitive to individual disease changes.[29] It would therefore be beneficial

to consider using the CEDAS in conjunction with outcome measures that fill these gaps.

Limitations

This study was conducted in April to June 2020, which was at the height of the first wave of the COVID-19 pandemic in the UK. While study participants worked in a wide variety of settings, the pandemic may have impacted on clinicians' willingness and ability to participate. A higher initial response rate may have been achieved if the study had been delayed. This was not possible because of the project being conducted as part of a taught programme of study.

Attrition in multi-stage questionnaire studies is an acknowledged limitation.[25] Those who complete the study may not be representative of all those who began it.[25] While interstage participant drop-out was small, the lack of negative responses to usefulness and utilization questions may have resulted from withdrawal of individuals who saw less value in the tool. As participants' responses were anonymized (per Delphi method recommendations),[25] individual replies could not be matched between surveys to determine if any participants changed their opinion of the CEDAS.

Future research

Further psychometric evaluation of the CEDAS is required. We are planning studies to ensure it is a reliable and valid tool and to assess its value as a tool for use within the multidisciplinary team.

Conclusion

The CEDAS has been designed as an outcome measure that can be used with a paediatric feeding disorder population, regardless of age, underlying aetiology, or care setting. Development of level descriptor wording based on expert consensus and good face validity supports its potential for use as a simple, effective clinical or research tool.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

The following additional material may be found online:
Appendix S1. Vignettes.

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