Development and validation of a screening tool for feeding/swallowing difficulties and undernutrition in children with cerebral palsy

KRISTIE L BELL[1,2] | KATHERINE A BENFER[3] | ROBERT S WARE[4] | TANIA A PATRAO[4] | JOSEPHINE J GARVEY[1] | JOAN C ARVEDSON[5] | ROSLYN N BOYD[3] | PETER SW DAVIES[1] | KELLY A WEIR[4,6]

1 Child Health Research Centre, The University of Queensland, Brisbane, Queensland; **2** Dietetics and Food Services, Children's Health Queensland, Brisbane, Queensland; **3** Queensland Cerebral Palsy and Rehabilitation Research Centre, Child Health Research Centre, The University of Queensland, Brisbane, Queensland; **4** Menzies Health Institute Queensland, Griffith University, Gold Coast, Queensland, Australia. **5** Children's Hospital of Wisconsin-Milwaukee, Medical College of Wisconsin-Milwaukee, Milwaukee, Wisconsin, USA. **6** Gold Coast University Hospital, Gold Coast Health, Southport, Queensland, Australia.

Correspondence to Kristie L Bell, Dietetics and Food Services, Level 7A Queensland Children's Hospital, 501 Stanley Street, South Brisbane, Queensland 4101, Australia.
E-mail: k.bell@uq.edu.au

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ABBREVIATIONS

DDS	Dysphagia Disorders Survey
EDACS	Eating and Drinking Ability Classification System
SGNA	Subjective Global Nutrition Assessment
VFSS	Videofluoroscopic swallow study

AIM To develop and validate a screening tool for feeding/swallowing difficulties and/or undernutrition in children with cerebral palsy (CP).
METHOD This cross-sectional, observational study included 89 children with CP (63 males, 26 females; median age 6y 0mo; interquartile range 4y 0mo–8y 11mo), across all Gross Motor Function Classification System levels. Children with feeding tubes were excluded. Children were classified as well-nourished or moderately to severely undernourished, using the paediatric Subjective Global Nutrition Assessment. Eating and drinking abilities were classified using the Eating and Drinking Ability Classification System (EDACS) from mealtime observation and videofluoroscopic swallow studies when indicated. Parents/caregivers answered 33 screening questions regarding their child's feeding/swallowing abilities and nutritional status. The diagnostic ability of each question for identifying children with feeding/swallowing difficulties and undernutrition was calculated and the combination of questions with the highest sensitivity and specificity identified.
RESULTS Feeding difficulties impacted on swallow safety in 26 children (29%) and 26 children (29%) were moderately or severely undernourished. The 4-item final tool had high sensitivity and specificity for identifying children with feeding/swallowing difficulties (81% and 79% respectively) and undernutrition (72% and 75% respectively). The tool successfully identified 100 per cent of children with severe undernutrition and 100 per cent of those classified as EDACS level IV or V.
INTERPRETATION Screening for feeding/swallowing difficulties and undernutrition will enable early identification, assessment, and management for those children in need.

Feeding difficulties and poor nutritional status occur frequently in children with cerebral palsy (CP), particularly in children with increasing gross motor impairment and increasing age, and may impact detrimentally on health, physical, and cognitive development.[1–3] Children with CP who have feeding/swallowing difficulties or undernutrition have lower global health scores, increased health care utilization, and decreased participation in usual activities for the child and their family.[1,2,4] There is increasing awareness of the importance of prevention, early detection, and treatment of feeding difficulties and undernutrition in children with CP to avoid acute and long-term negative consequences.

Detailed feeding/swallowing and nutrition assessment methods are too lengthy and resource intensive to be routinely completed for all children with CP. A valid screening tool could be utilized to identify children with feeding/swallowing difficulties or undernutrition early who may benefit from full assessment and treatment. Nutrition screening tools have been developed and validated for this purpose in a variety of different paediatric populations;[5] however, there is no simple, validated tool for use in individuals with CP across a broad age range that address feeding/swallowing difficulties in addition to undernutrition. Questions addressing four key areas (feeding duration, mealtime stress, weight gain, and respiratory status) were proposed by Arvedson[6] to obtain information from parents regarding feeding difficulties for children with CP. Whilst these questions have not been validated, the use of parent reported indicators were found to be accurate for detecting feeding difficulties and undernutrition in preschool aged children with CP in a secondary data analysis of a

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prospective cohort study data.[7] The current study aimed to build on this previous work by developing and validating a simple parent-reported screening tool, a priori, to identify feeding/swallowing difficulties and/or undernutrition in children and young people with CP across a broad age range and the full spectrum of gross motor severity.

What this paper adds

- A screening tool with high sensitivities and specificities for identifying children with feeding/swallowing difficulties and undernutrition.
- The tool identified 100 per cent of children with severe undernutrition.
- The tool identified 100 per cent of children in Eating and Drinking Ability Classification System levels IV or V.

METHOD

This prospective, cross-sectional, observational study took place in Brisbane, Australia and recruited children with CP between 2 and 19 years of age. Children with feeding tubes or acutely unwell/hospitalized children were excluded. Families were approached through coordinated mail-outs to the Queensland Paediatric Rehabilitation Service database and the Queensland CP Register between February 2017 and March 2018, reaching a total of 966 families of individuals with CP. In addition, children were referred through hospital clinics. Written informed consent was obtained from parents/legal guardians. Children assented to the procedures. Full ethical approvals were obtained from the Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (HREC/16/QRCH/339), The University of Queensland Human Research Ethics Committee (2016001695), and the Human Research Ethics Committees of the Cerebral Palsy League (CPL-2017-003). This study was registered with the Australian New Zealand Clinical Trials Registry (ANZCTRN12616001419459).

Gross motor functional abilities were classified using the Gross Motor Function Classification System[8,9] and motor type and distribution according to the Surveillance of CP in Europe Guidelines by trained clinicians.[10] Additional diagnoses (e.g. epilepsy, autism spectrum disorder) and birth history (gestational age at birth, plurality, and birthweight) were reported by parents using a study checklist.

Feeding and nutrition screening tool questions

Parents independently completed a 33-item questionnaire about their child's feeding/swallowing abilities and nutritional status before the study assessments. Research personnel provided minor clarification of questions, as required. The questionnaire was developed based on Arvedson's 'Red Flags' for feeding difficulties,[6] input from two international expert advisory panels and previous findings.[7] The final questions addressed five areas: respiratory health, feeding duration, stress associated with feeding, nutritional status, and gastrointestinal factors. In addition, one question regarding mealtime behaviours and two 10cm visual analogue scales for overall eating difficulty and overall drinking difficulty were included.

Feeding outcomes

Presence and severity of feeding/swallowing difficulties were determined by direct feeding evaluation by paediatric dysphagia trained speech-language pathologists. Whilst positioned in their usual mealtime seating, children were fed three standardized presentations of a minimum of three textures (puree, chewable, and fluid) with their usual utensils. Children could then continue eating if desired. The feeding evaluation was scored using the Dysphagia Disorders Survey (DDS) part 2 with modified cut-off points for children 3 years of age and under (cut-off ≥3), and standard ratings for children over 3 years (cut-off ≥2).[11,12] The DDS has established validity in individuals with developmental disability and CP.[12] Clinical signs suggestive of possible aspiration/pharyngeal phase dysfunction were assessed with assistance of cervical auscultation:[13] coughing, gagging, choking, throat clearing, multiple swallows (greater than two per bolus), wet/gurgly voice, wet breathing, wet/rattly chest/fremitus, nasal regurgitation/congestion/snuffly nose, wheezing, stridor, vomiting, eye tearing, increased respiratory rate, laboured breathing, and circumoral cyanosis.[14] Children who demonstrated one sign on multiple occasions, or two or more different signs on one or more occasions, were referred for a videofluoroscopic swallow study (VFSS). The VFSS was conducted by a VFSS-trained speech-language pathologist, radiologist, and radiographer. Children were fed a minimum of two presentations of each barium impregnated food texture and fluid consistency, which were part of their usual mealtime (thin fluid, puree, lumpy/ground, chewable/solid), and additional therapeutic textures as determined by the clinician if indicated.[15] Screening time was capped at 3.5 minutes per child. A pulse rate of 30 pulses per second was used for thin fluids for a maximum of 30 seconds, and 15 pulses per second for all other food textures/fluid consistencies.[15,16] The VFSS was rated using a standard checklist for each food texture/fluid consistency. Presence of laryngeal penetration/aspiration for each texture was rated using the Penetration-Aspiration Scale and post-swallow residue rated using the Residue Rating Scale.[17]

Eating and drinking ability was classified using the Eating and Drinking Ability Classification System (EDACS) based on observation, DDS, clinical signs of pharyngeal phase dysfunction, and VFSS results.[18] The EDACS is a 5-level classification system ranging from level I (eats and drinks safely and efficiently) to level V (unable to eat or drink safely – tube feeding may be considered to provide nutrition).[18] An EDACS classification of level III or above (eats and drinks with some limitations to safety – may be limitations to efficiency) was considered a feeding/swallowing difficulty impacting on safety of oral feeding and was used as the primary feeding outcome for this study.

Nutrition outcomes

Weight was measured to the nearest 0.05kg, and 0.01kg for those under 10kg using standard equipment. Height (n=64) or supine length (n=13) was measured to the last

completed millimetre. When a direct measurement of height or length was not possible, height was estimated from knee height (n=12).[19,20] All measurements were conducted by trained observers in duplicate with the mean of the two measurements used. Anthropometric data were converted to *Z*-scores using reference data for the general population.[21,22] *Z*-scores of between –2.00 and –2.99 were considered moderate and less than –3.00 as severe undernutrition.[23]

For the primary nutrition outcome, children were classified as well-nourished, moderately-undernourished, or severely-undernourished using the paediatric Subjective Global Nutrition Assessment (SGNA).[24] The SGNA is a comprehensive structured approach to nutrition assessment that combines a nutrition-focused medical history and physical examination to determine a global nutritional status rating using clinical judgement.[24] The nutrition-focused medical history includes current and historical anthropometric data, dietary intake assessment, presence and severity of gastrointestinal symptoms impacting on dietary intake, changes in functional capacity caused by undernutrition, and the metabolic demands of any underlying condition. The physical examination included assessment of subcutaneous fat and muscle stores at specified sites of the body using a head to toe approach as described elsewhere.[24] The child's face, arms, and chest were examined for clearly defined, bony, or muscular outlines. Hollow facial cheeks, little space between the fingers when pinching fat stores over the biceps and triceps, and depressions between the ribs were considered signs of low subcutaneous fat stores. Prominent or protruding bone structure at the clavicle, shoulder, scapula, and knee, and flat or hollow areas in the upper or lower legs, were considered suggestive of muscle wasting. Parents were asked whether there had been any recent change in muscle stores. Consideration was given if low muscle mass was due to neuropathy or myopathy rather than nutritional depletion.[24] The SGNA has established validity for assessing nutritional status in children with a wide range of conditions including children with CP and Down syndrome aged 31 days to 17 years 11 months.[24] In the absence of a criterion standard objective measurement of nutritional status, validation studies of nutrition screening tools have utilized various techniques for comparison.[5] More recently, studies have utilized the SGNA as a structured version of a full nutritional assessment with an overall scoring system.[5] In addition, the SGNA has recently been tested in a population of children with CP.[25]

Both the speech pathologist and the dietitian were present at the time of the assessments; however, the results for each component were individually scored and neither clinician was aware of the other's results at the time of scoring.

Statistical analysis

The recruitment target was 100 children with CP, a sample size considered 'excellent' by the Consensus-based Standards for the Selection of Health Measurement Instruments group and comparable to those in previous studies where nutrition screening tools have been developed.[5] Data analysis was conducted using Stata version 14.2 (StataCorp, College Station, TX, USA).

Development of the screening tool

Summary statistics were described using mean (standard deviation) for continuous outcomes and frequency (percentage) for categorical outcomes. To develop the screening tool, the diagnostic statistics of each of the 33 questionnaire-items were calculated and the association between each item and both the feeding and nutrition outcomes were summarized using the χ^2 statistic. The individual questions with the best diagnostic properties were identified, and successive versions of the screening tool were constructed and tested by combining different test items. Items that did not contribute significantly to the overall discrimination of the tool were eliminated. The threshold screening score needed to identify feeding difficulties and undernutrition was identified by comparing the optimal diagnostic properties of different versions of the tool. This process was undertaken considering both feeding/swallowing difficulties, by EDACS, and undernutrition, by SGNA.

Validation of the screening tool

The screening tool was validated using a 10-fold cross-validation approach, also called rotation estimation, in which the data set was randomly divided into 10 mutually exclusive subsets of approximately equal size. Each of the 10 subsets was omitted in turn and diagnostic statistics were calculated for the remaining data. This method was repeated for each of the primary outcomes (i.e. DDS, EDACS, SGNA, weight, and body mass index [BMI]).

RESULTS

Families of 104 children were referred to the study or responded to mail-outs. Of these, six were ineligible because of the presence of a feeding tube and nine declined to participate. The sample characteristics of the final 89 participants are included in Table I. The median (interquartile range) age of children was 6 years 0 months (4y 0mo–8y 11mo) and the majority of participants were male (n=63; 71%). Most children were in Gross Motor Function Classification System level I (28%) or level II (36%). Spasticity was the most common primary motor type (69%) and dyskinesia was the most common secondary motor type (41%). Almost three-quarters of children had bilateral motor distribution (n=64; 72%) and one-third of participants had epilepsy (n=28; 32%).

Feeding difficulties were identified in 60 (67%) children using the DDS and feeding difficulties were severe enough to impact on feeding safety in 26 (29%) (EDACS level III, IV, or V) (Table II). Clinical signs suggestive of possible aspiration were observed on two or more occasions in 11 children (12.4%). Parents of six children consented to the VFSS. Aspiration was confirmed by VFSS in four children

Table I: Characteristics of children and young people with cerebral palsy (*n*=89)

Demographics	*n* (%)
Age, median (IQR)	6y 0mo (4y 0mo–8y 11mo)
Sex, males	63 (71)
GMFCS level	
I	25 (28)
II	32 (36)
III	9 (10)
IV	12 (14)
V	11 (12)
Primary motor type	
Spasticity	61 (68)
Dyskinesia	19 (21)
Ataxia	1 (1)
Hypotonia	8 (9)
Secondary motor type	
Spasticity	12 (38)
Dyskinesia	13 (41)
Ataxia	0 (0)
Hypotonia	7 (22)
Motor distribution	
Unilateral	25 (28)
Bilateral	64 (72)
Number of limbs involved	
1	0 (0)
2	42 (47)
3	3 (3)
4	44 (49)
Epilepsy	28 (32)
Autism spectrum disorder	11 (12)
Plurality (multiple birth)	17 (19)
Gestational age (wks), median (IQR)[a]	37 (30–39)
Preterm birth (<37 wks)[a]	40 (47)

[a]*n*=4 missing. IQR, interquartile range; GMFCS, Gross Motor Function Classification System.

Table II: Feeding/swallowing and undernutrition outcomes for children and young people with cerebral palsy (*n*=89)

Feeding outcomes	*n* (%)
Feeding difficulties on DDS	60 (67)
Referral for VFSS	11 (12)
Clinical signs of aspiration confirmed on VFSS[a]	4 (67)
EDACS level	
I	30 (34)
II	33 (37)
III	17 (19)
IV	6 (7)
V	3 (3)
EDACS independence	
Independent	50 (56)
Requires assistance	23 (26)
Totally dependent	16 (18)
Undernutrition outcomes	
SGNA	
Well-nourished	63 (71)
Moderately undernourished	20 (22)
Severely undernourished	6 (7)
Weight-for-age z-score	
>–1.99	64 (72)
–2 to –2.99	16 (18)
≤–3.00	9 (10)
Height-for-age z-score	
>–1.99	70 (79)
–2 to –2.99	13 (15)
≤–3.00	6 (7)
BMI-for-age z-score	
>–1.99	69 (78)
–2 to –2.99	13 (15)
≤–3.00	7 (8)

[a]*n*=5 missing because of non-consent for videofluoroscopic swallow study (VFSS). DDS, Dysphagia Disorders Survey; EDACS, Eating and Drinking Ability Classification System; SGNA, Subjective Global Nutrition Assessment; BMI, body mass index.

(67%), predominantly on thin fluid (*n*=3), mildly thick fluids (*n*=2), purees (*n*=2), and all textures (*n*=1). After the VFSS, one child was recommended for gastrostomy tube feeding, and recommendations for texture and/or fluid modifications (e.g. thickened fluids) were made for five. Moderate or severe undernutrition was identified in almost 30 per cent of the study sample (*n*=26) using the SGNA (Table II). Fewer children had weight-for-age, height-for-age, or BMI-for-age *Z*-scores of –2 or less than were considered undernourished by SGNA (25%, 21%, and 22% respectively) (Table II).

Responses to each of the 33-items of the questionnaire are presented in Table SI. Diagnostic statistics were calculated for each item for both the feeding/swallowing difficulties outcome (Table SII, online supporting information) and the undernutrition outcome (Table SIII, online supporting information). Individual items with the best sensitivity and specificity for both feeding/swallowing difficulties and undernutrition were identified. All combinations of identified items were considered, and the diagnostic values of each combination were compared. The final tool consisted of four-items and used the scoring system identified in Table III. An overall score of 3 or higher for the four questions combined identified 43 (48%) children as being at risk of feeding/swallowing difficulties and undernutrition requiring further assessment. A similar number, 41 (46%), were classified as having either feeding/swallowing difficulties impacting on feeding safety (identified via EDACS) or as being undernourished (identified via SGNA).

Table IV shows the sensitivity, specificity, and their corresponding 95 per cent confidence intervals, for the final 4-item tool when considered against the outcomes for feeding/swallowing dysfunction (EDACS, DDS) and undernutrition (SGNA and z-score age-appropriate cut-offs for weight, height, and BMI). The sensitivity and specificity of the screening tool for the primary feeding outcome, EDACS, was 81 per cent and 79 per cent respectively, and for the primary nutrition outcome, SGNA, was 72 per cent and 75 per cent. The tool successfully identified 100 per cent of children with severe undernutrition and 100 per cent of children in EDACS level IV or V. The tool fared well when compared to weight-for-age, height-for-age, and BMI-for-age z-score cut-offs with similarly high sensitivities and specificities. Results of the 10-fold cross-validation were not significantly different for each iteration of the procedure, indicating good cross-validity of the tool (Table SIV, online supporting information).

Table III: Final screening questions for identifying children and young people with cerebral palsy who may have feeding difficulties and/or undernutrition

Question	Possible response	Scoring
Do you think your child is underweight?	Yes	1
	No	0
	Unsure	1
Does your child have problems gaining weight?	Yes	1
	No	0
	Unsure	1
Rate, on a scale from 0–10, whether you think your child has any problems eating compared to other children of his/her age	10cm long VAS with numbers at each centimetre	≥7 on the VAS=score 1
Rate, on a scale from 0–10, whether you think your child has any problems drinking compared to other children of his/her age	10cm long VAS with numbers at each centimetre	≥7 on the VAS=score 1
Total score of ≥3=refer for further assessment of feeding/swallowing and nutritional status		

VAS, visual analogue scale.

DISCUSSION

This study identified a screening tool consisting of four simple questions that can be completed independently by parents/caregivers of children and young people with CP, to identify risk of feeding/swallowing difficulties or undernutrition to determine if further assessment and management strategies are warranted. The questions that performed best in this study were the ones that asked directly about the outcomes studied. The two visual analogue scales relating to problems with eating and drinking were best able to identify children with feeding/swallowing difficulties. The questions 'Do you think your child is underweight?' and 'Does your child have problems gaining weight?' performed the best for identifying children with undernutrition. When combined, these four questions had good to excellent sensitivity and specificity for identifying risk of both feeding/swallowing difficulties and undernutrition.

Table IV: Sensitivity and specificity for the final screening tool for feeding/swallowing difficulties and undernutrition in children and young people with cerebral palsy

Measure	No. disease positive	Sensitivity % (95% CI)	Specificity % (95% CI)
Feeding dysfunction			
DDS	60	46.7 (33.7, 60.0)	79.3 (60.3, 92.0)
EDACS	26	80.8 (60.6, 93.4)	79.4 (67.3, 88.5)
Undernutrition			
SGNA			
Moderate and severe	26	72.0 (50.6, 87.9)	75.0 (62.6, 85.0)
Severe only	6	100 (54.1, 100.0)	66.3 (55.1, 76.3)
Weight-for-age z-score			
≤–2	19	76.0 (54.9, 90.6)	76.6 (64.3, 86.2)
≤–3	9	77.8 (40.0, 97.2)	66.3 (54.8, 76.4)
Height-for-age z-score			
≤–2	19	68.4 (43.4, 87.4)	70.0 (57.9, 80.4)
≤–3	6	83.3 (35.9, 99.6)	65.1 (53.8, 75.2)
BMI-for-age z-score			
≤–2	20	70.0 (45.7, 88.1)	71.0 (58.8, 81.3)
≤–3	7	71.4 (29.0, 96.3)	64.6 (53.3, 74.9)

CI, confidence interval; DDS, Dysphagia Disorders Survey; EDACS, Eating and Drinking Abilities Classification System; SGNA, Subjective Global Nutrition Assessment; BMI, Body Mass Index.

These results are similar to our previous investigation into the use of parent reported indicators for detecting feeding difficulties and undernutrition in preschool aged children with CP.[7] In the previous study, the two visual analogue scales were the most accurate screening tools for detecting both feeding/swallowing difficulties and undernutrition. This previous study was a post hoc analysis of data collected for a larger study where not all the indicators were asked as direct screening questions. The nutritional status outcome was limited to a cross-sectional assessment of anthropometric variables, and the mealtime evaluation did not include cervical auscultation or VFSS. The current study expanded on this previous study by directly asking parents multiple screening questions and by using more robust, clinically relevant outcome measures in a broader age range of participants.

Many of the questions asked in the current study were related to feeding/swallowing difficulties or undernutrition; however they were not necessarily adequate screening questions. One out of seven questions in the area of respiratory health ('Does your child cough during feeding or drinking?') and one out of four questions regarding duration of feeding ('How long does it take to feed your child to eat the main meal of the day?') were significantly related to feeding/swallowing difficulties; however, the sensitivities and specificities were not sufficiently high for these to be considered adequate screening questions. Eight questions were asked that related to mealtime stress, mealtime enjoyment, fatigue, and food refusal. Of these, only one was related significantly to feeding/swallowing difficulties: 'Does your child refuse food or drinks?' These results differ to our previous study where parent reported mealtime stress was associated with feeding difficulties in children with CP.[7] Nevertheless, in the current study, these questions had low sensitivity and were not included in the final tool. Of the questions about gastrointestinal factors, two were related to feeding difficulties and/or undernutrition:

'Does your child have a diagnosis of gastroesophageal reflux?' and 'Does your child vomit regularly?' However, sensitivities and specificities were not sufficiently high for these questions to be included in the final model. All six questions regarding nutritional status were related to SGNA scores; however, not all were considered adequate screening questions. 'Does your child have problems gaining weight?' identified 100 per cent of undernourished children; though the specificity of this question was only 50 per cent. As such, if used in isolation this question would over identify 50 per cent of children who were well-nourished and is likely reflective of the concern that many parents have regarding their child's weight gain, rather than true undernutrition. When combined with 'Do you think your child is underweight?' and the visual analogue scales for eating and drinking problems, the balance between sensitivity and specificity was improved.

The final 4-item tool provides a short and simple means to identify children at risk of feeding/swallowing difficulties and undernutrition. Our sample size of 89 did not reach our recruitment target of 100 children with CP. Despite this, the final screening tool fared well when compared to the criterion standards (DDS, EDACS, and SGNA) with high sensitivity and specificity in identifying children at risk of feeding/swallowing difficulties and undernutrition. Importantly, the final screening tool was able to identify 100 per cent of children rated as severely undernourished by the dietitian and 100 per cent of children rated as EDACS level IV or V (supplemented by cervical auscultation and VFSS) by the speech pathologist.

This screening tool is designed for use in an outpatient setting in a population of individuals with CP with a high prevalence of chronic undernutrition and feeding/swallowing difficulties. Children who were acutely unwell, where acute malnutrition may be present, were not included. As such, the results are not generalizable to an inpatient setting. Nor are the results generalizable to infants and children under 2 years of age. A separate study validating feeding/swallowing and nutrition screening questions in this younger population is warranted, with developmentally appropriate outcome measures, to aid in early identification and treatment of undernutrition and feeding.

CONCLUSION

This study was the first to validate a screening tool for feeding/swallowing difficulties and undernutrition in children with CP that can be used independently by parents/caregivers. It is anticipated this screening tool will have significant clinical implications through increasing awareness of feeding difficulties and undernutrition and identifying children with concerns early, to enable early intervention and management plans and ultimately better long-term outcomes.

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SUPPORTING INFORMATION

The following additional material may be found online:

Table SI: Screening questions and participant responses

Table SII: Sensitivity and specificity of proposed screening questions for detecting feeding difficulties in children with cerebral palsy

Table SIII: Sensitivity and specificity of proposed screening questions for detecting undernutrition in children with cerebral palsy

Table SIV: Tabular results for 10-fold cross validation for all folds and outcomes

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