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Editor's Choice

ORIGINAL ARTICLE

Eating and drinking ability and nutritional status in adults with cerebral palsy

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Abstract

Aim: To describe eating and drinking ability in adults with cerebral palsy (CP) relative to sex, age, subtype, and severity of gross motor and hand function and nutritional status.

Method: This was a cross-sectional study based on data of 2035 adults with CP, median age 26 years (range 18–78 years). The Eating and Drinking Ability Classification System (EDACS), Gross Motor Function Classification System (GMFCS), and Manual Ability Classification System (MACS) were used in addition to subtype, body weight, height, body mass index (BMI), skin fold thickness, and gastrostomy. Linear regression models were used to estimate associations between body weight and the other variables.

Results: More than half of the adults (52.5%) eat and drink safely and 32.4% have dysphagia with limitations to eating and drinking safety. Weight, height, and BMI decreased with increasing EDACS levels. In EDACS level V, 86% had a gastrostomy, 23.4% in EDACS levels III to V were underweight, whereas 42.3% in EDACS levels I to II had a BMI over 25, indicating overweight or obesity. Increasing EDACS levels and need of support during meals were associated with lower body weight.

Interpretation: Adults with CP should be routinely screened and treated for dysphagia to avoid nutritional complications. Being dependent on others during mealtimes is a risk factor for low body weight.

Dysphagia, or disorders of eating and swallowing, is common in children with cerebral palsy (CP)[1,2] but less is known about dysphagia in adulthood. Several aspects of eating and swallowing may be affected including requiring more time and effort to swallow liquids and/or food. Dysphagia is associated with the severity of Gross Motor Function Classification System (GMFCS) levels[1] and includes penetration of food, drink, or saliva into the larynx, aspiration into the trachea, and oropharyngeal residue.

In individuals with CP, aspiration and pulmonary complications are among the most common causes of death.[3,4] It accounts for more than half the deaths in adults with CP, and almost two in three deaths in individuals with the most severe motor impairments.[4] Aspiration associated with dysphagia has been linked to pneumonia and respiratory compromise[5,6] and a greater risk of pulmonary complications.[7] In older population norm adults there is a loss of pharyngeal muscle mass and pressure during swallowing.[8] In individuals with CP this decline occurs earlier with changes in swallowing function reported around 30 years of age.[9] Also, the decline in gross motor function, recognized before the age of 40 years in adults with CP,[10,11] affects breathing and breath-control.[12]

This original article is commented on by Yi on pages 939–940 of this issue.

Abbreviations: EDACS, Eating and Drinking Ability Classification System; MACS, Manual Ability Classification System.

This change in ventilation can compromise swallowing and the coordination between swallowing and ventilation.[13,14]

Adults with CP may experience gradual changes in swallowing and mealtime capabilities including increased coughing and choking, digestive or gastroesophageal symptoms, diet modification, loss of independence, and psychosocial consequences. These changes need to be monitored to ensure compliance with recommendations, safety, and optimal well-being for the individual.[9] Inclusion of assessment and intervention of eating and drinking ability in multidisciplinary rehabilitation programmes is also supported by a recent qualitative study.[15] Participants experienced several restrictions in eating and drinking leading to negative feelings such as shame, frustration, fear of choking, lower levels of participation, and/or concerns about the future.[15]

Yi et al.[16] investigated characteristics of dysphagia and their impact on quality of life in adults with CP on a full oral diet compared with population norm adults. The adults with CP reported worse outcomes across all swallowing quality of life items, with the lowest scores for meal duration, followed by communication, burden, fatigue, sleep, and eating desire.[16] Frequent symptoms were choking on food, coughing and choking on liquids, and chewing problems. Over 30% reported mealtime durations of 30 minutes or longer.[16] Longer mealtime duration, exceeding 20 to 30 minutes, may be a sign of dysphagia, as well as of inefficient eating and insufficient nutritional intake.[17] Children and young adults with CP are generally smaller and have less overall body weight than their typically developing peers, but it is unclear whether this relates to dysphagia.[18]

Recently, Hyun et al.[19] investigated interrater reliability and validity of an instrument to classify eating and swallowing, the Eating and Drinking Ability Classification System (EDACS), in adults with CP. EDACS was originally designed to evaluate dysphagia in children with CP[20] but has since been found to be valid and reliable for both children and adults with CP.[19,20] In 2016, EDACS was added to the comprehensive classifications used in the combined Swedish national follow-up programme and quality registry for adults with CP, where adults are examined regularly by multiprofessional teams.[21]

Thus, the purpose of this study was to describe eating and drinking ability in adults with CP relative to their sex, age, CP subtype, severity of gross motor and hand function, and their nutritional status.

What this paper adds

- One-third of adults with cerebral palsy (CP) have dysphagia with limitations to eating and drinking safety.
- Weight, height, and body mass index (BMI) decrease with increasing Eating and Drinking Ability Classification System (EDACS) levels.
- Being dependent on others during mealtimes is a risk factor for low body weight.
- EDACS can be used to screen for dysphagia in adults with CP.

METHOD

This was a cross-sectional study based on data from adults with CP reported into the CP follow-up programme and registry from 2016 until the end of June 2021. All adults from 18 years old with data on their eating and drinking ability were included. A total of 217 out of 2252 (9.6%) were excluded because of missing data for the primary outcome variable EDACS. A drop-out analysis showed a similar distribution in gross motor function between participants and nonparticipants ($p = 0.701$).

All adults enrolled in this health care programme are examined regularly by their multiprofessional adult specialist team, which usually consists of a speech and language pathologist, occupational therapist, and physical therapist. The examinations are scheduled once a year or every second or third year depending on gross motor function.[21]

Classifications and measurements

The inclusion and exclusion criteria of CP were based on guidelines of the Surveillance of Cerebral Palsy in Europe with a non-progressive brain lesion before the age of 2 years independent of pathology or etiology.[22] The neurological subtype was classified into spastic unilateral, spastic bilateral, ataxic, and dyskinetic CP or unclassified/mixed type.[22] The expanded and revised version of the GMFCS levels I to V[23] and the Manual Ability Classification System (MACS) levels I to V[24] were used to describe their functional levels.

The five levels of the EDACS[20] were used to describe the key features of safety and efficiency when eating and drinking: level I, eats and drinks safely and efficiently; level II, eats and drinks safely but with some limitations to efficiency; level III, eats and drinks with some limitations to safety; maybe limitations to efficiency; level IV, eats and drinks with significant limitations to safety; and level V, unable to eat or drink safely, tube feeding may be considered to provide nutrition.

EDACS includes information on biting, chewing, swallowing, how food and fluids are managed, changes in breathing associated with swallowing, and the prevalence of aspiration or choking during mealtimes. In the present study, EDACS levels III, IV, and V were considered indicative of dysphagia. Notably, EDACS does not address silent aspiration. In addition, the level of assistance required during a meal was rated according to the EDACS grading of support assistance and was rated as (1) independent, (2) requires assistance, and (3) totally dependent.[20] EDACS was either classified during mealtime by a speech and language pathologist or through interviews during the examination.

We also included information about gastrostomy, weight (kg), height (cm), and skinfold thickness (<0.5cm indicating a lack of subcutaneous fat). Weight was measured either on a standing or sitting scale (chair weigher) or a digital scale mounted on a hoist. Height was measured standing or

supine lying using a measuring board with the legs straightened and the head erect or with a measuring tape for those unable to passively extend the legs. The skinfold of the abdomen was measured above the iliac crest, at the level of the umbilicus in line with the mamilla, and reported as less than 0.5cm or 0.5cm and above. We calculated body mass index (BMI) according to the World Health Organization,[25] as body weight (kg)/height (m).[2] BMI was categorized into (1) underweight (<18.5); (2) normal weight (18.5–24.9); (3) overweight (25–29.9); (4) obese (≥30).[25] Age was grouped into 18 to 24 years, 25 to 29 years, 30 to 39 years, 40 to 49 years, and 50 to 78 years for group comparisons.

This study was carried out in accordance with the Declaration of Helsinki for experiments involving humans. Ethical approval was granted by the Medical Research Ethics Committee in Lund (dnr: 2009/341), and permission was obtained to extract data from the registry. The participants in the registry provided consent for the collected data to be used for research.

Statistical analyses

Normally distributed data are presented as mean values with standard deviations (SD), whereas skewed data are presented as median and interquartile range (IQR). χ^2 was used to detect any statistical differences between subgroups. Simple and multivariable linear regression models were used to estimate the magnitude of associations between independent variables and weight in kg, presented as unadjusted and adjusted unstandardized coefficients with 95% confidence intervals. In the multivariable regression analyses, non-significant variables were removed stepwise until only statistically significant variables remained. Age and height were treated as continuous variables. GMFCS, MACS, EDACS, and EDACS support were treated as ordinal categories, and subtype as nominal categories using spastic unilateral CP as the reference. Complete cases analysis was used in all regression models. R^2 was used as a goodness-of-fit measure to indicate the percentage of the variance in the dependent variable explained by the independent variables collectively. The significance level was set to a p-value lower than 0.05. IBM SPSS Statistics version 26 (IBM Corp., Armonk, NY, USA) was used for all analyses.

RESULTS

In total 2035 adults had data reporting eating and drinking ability (1122 males [55.1%] and 913 females [44.9%], 18 to 78 years old, with a median age of 26 years [IQR 14]). A majority were classified with spastic bilateral CP (52.5%) and in MACS levels I or II (51.9%), whereas there was an approximately equal distribution of adults in GMFCS levels I (23.9%) and V (22.3%) (Table 1).

More than half (52.5%) could eat and drink safely and efficiently and were classified in EDACS level I, whereas 15% ate and drank safely but less efficiently and were classified in EDACS level II. In total, 660 of the 2035 adults (32.4%) were classified in EDACS levels III to V and had limited safety when eating and drinking (Table 2). EDACS levels were similar for males and females but differed significantly between younger and older adults, and between adults with different CP subtypes and motor skills (p<0.001). A slightly higher proportion of older adults were classified in EDACS levels II (19%) and III (19–20%) compared with adults up to 30 years old (13–14% each for males and females) (Table 2). Most adults with spastic unilateral (83.1%), spastic bilateral (49.4%), and ataxic CP (45.6%) were classified in EDACS level I, whereas EDACS levels were more evenly distributed from level I (20.2%) to V (21.3%) in adults with dyskinetic CP (Table 2). GMFCS and MACS levels were associated with EDACS with an increasing trend of adults with less gross motor and hand function also having more challenges with safety and efficiency when eating (Table 2).

A total of 60% could eat and drink independently, and 19% and 21% respectively were partly or totally dependent on assistance during meals across EDACS levels. At EDACS level I, most adults could eat independently (90.3%). This was also true for adults in EDACS level II, where a majority (57.2%) ate and drank independently. A higher proportion of the adults in EDACS level III, who ate and drank with some limitations to safety, required assistance (45.7%) or were totally dependent on others for eating and drinking (31%). Most adults with more pronounced safety concerns, in EDACS levels IV (63.6%) or V (95.4%), were totally dependent on others for feeding (Table 2).

TABLE 1 Characteristics of the 2035 adults with cerebral palsy (CP)

	n	%
Male	1122	55.1
Female	913	44.9
Spastic unilateral CP	472	23.2
Spastic bilateral CP	1068	52.5
Ataxic CP	79	3.9
Dyskinetic CP	258	12.7
Unclassified/mixed type	158	7.8
GMFCS level I	487	23.9
GMFCS level II	429	21.1
GMFCS level III	290	14.3
GMFCS level IV	376	18.5
GMFCS level V	453	22.3
MACS level I	508	25.0
MACS level II	548	26.9
MACS level III	317	15.6
MACS level IV	295	14.5
MACS level V	359	17.6
Missing	8	0.4

Abbreviations: GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System.

TABLE 2 Eating and drinking ability in relation to sex, age, CP subtype, GMFCS, and MACS levels

	EDACS level										
	I		II		III		IV		V		
	n	%	*n*	%	*n*	%	*n*	%	*n*	%	*p*
Males (*n*=1122)	595	53	155	13.8	156	13.9	96	8.6	120	10.7	0.105
Females (*n*=913)	474	51.9	151	16.5	144	15.8	69	7.6	75	8.2	
18–24 years (*n*=913)	505	55.3	124	13.6	115	12.6	74	8.1	95	10.4	<0.001
25–29 years (*n*=372)	193	51.9	51	13.7	52	14	24	6.5	52	14	
30–39 years (*n*=381)	190	50.1	62	16.3	62	16.3	31	8.1	36	9.4	
40–49 years (*n*=196)	92	46.9	37	18.9	39	19.9	23	11.7	5	2.6	
50–78 years (*n*=173)	89	51.4	32	18.5	32	18.5	13	7.5	7	4	
Spastic unilateral (*n*=472)	392	83.1	54	11.4	21	4.4	3	0.6	2	0.4	<0.001
Spastic bilateral (*n*=1068)	528	49.4	161	15.1	166	15.5	100	9.4	113	10.6	
Ataxic (*n*=79)	36	45.6	14	17.7	18	22.8	9	11.4	2	2.5	
Dyskinetic (*n*=258)	51	19.8	50	19.4	64	24.8	38	14.7	55	21.3	
Unclassified/mixed (*n*=158)	62	39.2	27	17.1	31	19.6	15	9.5	23	14.6	
GMFCS level I (*n*=487)	452	92.6	29	6.0	3	0.6	3	0.6	0	0	<0.001
GMFCS level II (*n*=429)	294	68.5	73	17.0	52	12.1	7	1.6	3	0.7	
GMFCS level III (*n*=290)	177	61	68	23.4	32	11	11	3.8	2	0.7	
GMFCS level IV (*n*=376)	120	31.9	94	25	100	26.6	42	11.2	20	5.3	
GMFCS level V (*n*=453)	26	5.7	42	9.3	113	24.9	102	22.5	170	37.5	
MACS level I (*n*=508)	478	94.1	21	4.1	6	1.2	3	0.6	0	0	<0.001
MACS level II (*n*=548)	392	71.5	101	18.4	42	7.7	11	2	2	0.4	
MACS level III (*n*=317)	136	42.9	91	28.7	73	23	13	4.1	4	1.3	
MACS level IV (*n*=295)	43	14.6	61	20.7	103	34.9	56	19	32	10.8	
MACS level V (*n*=359)	16	4.5	31	8.6	74	20.6	82	22.8	156	43.5	
Missing (*n*=8)	4		1		2		0		1		
Independent (*n*=1223)	965	90.3	175	57.2	70	23.4	13	7.9	0	0	<0.001
Requires assistance (*n*=380)	94	8.8	93	30.4	137	45.7	47	28.5	9	4.6	
Totally dependent (*n*=432)	10	0.9	38	12.4	93	31.0	105	63.6	186	95.4	

Abbreviations: CP, cerebral palsy; EDACS, Eating and Drinking Classifications System; GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System.

TABLE 3 Gastrostomy, skinfold less than 0.5cm, mean weight, height, BMI, and age for adults at different EDACS levels

	EDACS level					
	I (*n*=1069)	II (*n*=306)	III (*n*=300)	IV (*n*=165)	V (*n*=195)	*p*
Gastrostomy, *n* (%)	14 (1.3)	11 (3.6)	31 (10.3)	42 (25.5)	168 (86.2)	<0.001
Skinfold <0.5cm, *n* (%)	53 (5)	19 (6.2)	29 (9.7)	20 (12.1)	24 (12.3)	<0.001
Weight, kg, mean (SD)	68.9 (17.2)	64.5 (17.9)	57.2 (14.9)	53.1 (12.5)	49.6 (11.1)	<0.001
Height, cm, mean (SD)	166.1 (10.5)	161.5 (11.3)	158.4 (11.2)	157.2 (12.4)	153.3 (13.2)	<0.001
BMI, kg/m^2, mean (SD)	24.9 (5.8)	24.7 (6.0)	22.9 (5.5)	21.3 (4.1)	21.4 (4.3)	0.047
Age, years:months, mean (SD)	29:2 (11:4)	31:2 (12:6)	31:11 (12:8)	30:6 (12:8)	26:4 (8:5)	<0.001

Abbreviations: BMI, body mass index; EDACS, Eating and Drinking Classifications System.

In total, 266 of the 2035 adults (13.1%) had a gastrostomy and most of them were classified in EDACS level V. Adults with gastrostomy classified in EDACS level I or II were in higher GMFCS or MACS levels. There were also 145 adults (7.1%) with a skinfold less than 0.5cm, indicating an almost total lack of subcutaneous fat (Table 3). A skinfold less than 0.5cm was twice as frequent in adults with gastrostomy (13.5%) compared to adults without gastrostomy

TABLE 4 Simple and multivariable linear regression models, presented as unadjusted and adjusted[a] coefficients (*B*), with 95% confidence intervals (CIs), estimated for body weight (kg)

	Simple, unadjusted				Multivariable, adjusted[a]			
	B	95% CI		*p*	*B*	95% CI		*p*
Age	0.25	0.18	0.31	<0.001	0.27	0.21	0.32	<0.001
Height	0.77	0.71	0.83	<0.001	0.68	0.6	0.75	<0.001
Female	−5.72	−7.29	−4.15	<0.001	1.82	0.21	3.43	0.027
Gastrostomy	−15.9	−18.09	−13.61	<0.001	−3.11	−5.57	−0.65	0.013
Spastic unilateral	*(ref)*				*(ref)*			
Spastic bilateral	−9.72	−11.63	−7.82	<0.001	−1.58	−3.09	−0.06	0.041
Dyskinetic	−14.59	−17.25	−11.93	<0.001	−3.97	−6.27	−1.66	0.001
Ataxic	−6.06	−10.23	−1.88	0.004				
Unclassified	−7.08	−10.24	−3.91	<0.001				
EDACS level I	*(ref)*				*(ref)*			
EDACS level II	−4.93	−6.53	−2.25	<0.001				
EDACS level III	−11.77	−13.91	−9.64	<0.001	−3.6	−5.68	−1.52	0.001
EDACS level IV	−15.83	−18.59	−13.07	<0.001	−4.37	−7.06	−1.67	0.001
EDACS level V	−19.34	−21.93	−16.76	<0.001				
EDACS support (independent)	*(ref)*				*(ref)*			
EDACS support (requires assistance)	−7.9	−9.83	−5.97	<0.001	−2.03	−4.02	−0.03	0.046
EDACS support (totally dependent)	−18.05	−19.87	−16.22	<0.001	−6.32	−8.76	−3.88	<0.001
GMFCS level I	*(ref)*							
GMFCS level II	−0.94	−3.12	1.23	0.395				
GMFCS level III	−4.99	−7.43	−2.57	<0.001				
GMFCS level IV	−8.8	−11.06	−6.5	<0.001				
GMFCS level V	−18.04	−20.2	−15.88	<0.001				
MACS level I	*(ref)*							
MACS level II	0.02	−1.99	2.03	0.983				
MACS level III	−3.43	−5.78	−1.08	<0.001				
MACS level IV	−12.02	−14.42	−9.63	<0.001				
MACS level V	−18.04	−20.31	−15.78	<0.001				

Abbreviations: EDACS, Eating and Drinking Classifications System; GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System.
[a]In the multivariable model, all variables are adjusted for all other variables in the model. R^2=0.38 for the final model.

(6.5%). The mean body weight was 63.4kg (SD 15.6), height 162.4cm (SD 12.0), and BMI 24.0 (SD 5.7) in the whole cohort. Weight (19.3kg), height (12.8cm), and BMI (3.5) decreased significantly with increasing EDACS levels from a mean weight of 68.9kg in adults in EDACS level I down to 49.6kg in those in EDACS level V (Table 3). Mean BMI decreased from 24.9 in adults in EDACS level I to 21.3 and 21.4 in EDACS levels IV and V respectively (Table 3). More adults in EDACS levels III (21.1%), IV (27.7%), and V (23.5%) had a BMI less than 18.5 corresponding to underweight compared to those in EDACS levels I (9.6%) and II (13.5%). The reverse was seen for overweight and obesity, where more adults in EDACS levels I (26.3%) and II (24.4%) were overweight and obese (16.2% vs 17.3%) compared with 13.9% versus 3% in EDACS level V.

Analysis using simple linear regression models showed that weight increased with age and height and was significantly reduced by higher GMFCS, MACS, and EDACS levels and EDACS need of support. Weight was lower in females, and in adults with all other subtypes compared to spastic unilateral CP. Weight was also substantially lower in adults with a gastrostomy (Table 4). When adjusted for all other variables in the multivariable regression models, GMFCS, MACS, ataxic CP, unclassified/mixed CP, EDACS level II, and EDACS level V were no longer significant and were omitted from the final model (Table 4). Age and height increased body weight also when adjusted for all other variables. Body weight was higher in females than in males when adjusted for all other variables. Having a gastrostomy or spastic bilateral and dyskinetic CP significantly reduced body weight. There

was also a clear association between weight and EDACS levels III and IV, where body weight was reduced by 3.6kg at level III and by 4.4kg at level IV. The need for support to eat and drink had the most significant impact on weight. Body weight was reduced by 2kg (95% CI −4.02 to −0.03kg) in adults requiring assistance during meals, and by 6.3kg (95% CI −8.76 to −3.88kg) in those totally dependent compared to those eating independently (Table 4).

DISCUSSION

This study describes eating and drinking ability in 2035 adults with CP relative to their sex, age, CP subtype, GMFCS and MACS levels, and nutritional status. Around half of the adults eat and drink safely and efficiently, while a third (32.4%) have dysphagia and varying degrees of limitation to their eating and drinking safety. A total of 60% eat and drink independently, and 19% and 21% respectively are partly or totally dependent on assistance during meals. A vast majority of the adults in EDACS level I are independent during meals (90.3%) and the reverse is found for individuals in EDACS level V, where most are totally dependent on others (95.4%). Most concerning was the difference in weight, height, and BMI between the adults who could eat safely and efficiently compared to those with problems related to safety during meals. In addition, the degree of independence during meals influences weight.

Despite the risks associated with reduced eating and drinking ability in adults with CP, there are few studies describing their effects on health to date. In two studies, Balandin et al. and Yi et al.[9,16] reported frequent choking, coughing, and chewing problems in adults with CP. Balandin et al. also found that digestive or gastroesophageal symptoms, diet modification, and loss of independence with psychosocial consequences were common. Participants also reported unsatisfactory collaboration with service providers over mealtime management, decisions, and interventions.[9]

We found a substantial and significant difference in weight (19.3kg), height (12.8cm), and BMI (3.5) between individuals in EDACS levels I and V. This is a concern because low weight is associated with a higher proportion of concurrent chronic major medical conditions,[18] and the difference in height may indicate a long-term history of compromised eating and nutritional intake. This observation is similar to previous findings where children in GMFCS levels II to V were shorter, and those in GMFCS levels III to V also had slower growth than children in GMFCS level I.[26] In contrast to previous findings in children, we found a clear association between eating and drinking ability and weight in adults with CP, even when adjusted for GMFCS and several other potential risk factors. A higher proportion with a gastrostomy had low weight and BMI, and 12% had a skinfold less than 0.5cm indicating an almost total lack of subcutaneous fat. In addition, in the EDACS level IV group, 12% had a skinfold less than 0.5cm and 25.5% had a gastrostomy. These findings are surprising since the expected outcome in individuals with a gastrostomy is improved nutritional status and a higher skinfold measurement. This indicates that the number of calories needs to be more closely monitored also in patients with a gastrostomy. In agreement with previous findings in children,[27] spastic bilateral and dyskinetic CP were also identified as predictors of low body weight.

Being dependent on others during meals was a strong risk factor for low body weight. Individuals partially or totally dependent on assistance during meals had significantly lower body weight compared with those eating independently. The communication and the feeder's sensitivity to subtle signs regarding different aspects of feeding such as portion size, food preferences, and hunger in the person being fed may be important factors to investigate further. Over 30% of adults in the study by Yi et al.[16] reported mealtime durations of 30 minutes or more. Longer mealtimes is a factor contributing to insufficient nutritional intake,[17] and those with longer mealtimes (>45 minutes) had significantly lower BMI compared to those with shorter mealtimes (<15 minutes).[9]

Overweight and obesity could be risk factors for cardiovascular disease in adults with CP.[28] We found that overweight and obesity were more common in adults in EDACS levels I and II compared to adults in EDACS levels III to V. The mean BMI of 24 for the whole cohort was substantially lower than the BMI of 29.1 reported for adults with CP in the US.[29] Even so, the risk of cardiovascular disease is substantially higher in adults with CP compared to the general population and needs to be considered.[30] Results suggests that nutritional status including weight, height, and skinfold thickness should be measured routinely.

EDACS was developed to classify eating and drinking ability in children with CP[20] but has recently been evaluated and used for adults.[19] In a recent study EDACS was compared with the Swallowing Quality of Life questionnaire and was found to be a reliable and valid tool also in adults with CP.[16] The current study further validates the use of simple classification instruments as a method to identify individuals at risk needing further assessment to ensure safe eating and drinking and sufficient nutritional intake. We used EDACS levels III to V to describe the presence of dysphagia. According to this definition, 660 adults (32.4%) with CP had dysphagia. However, EDACS does not address silent aspirations. This may explain the somewhat lower prevalence in our study compared to that reported by Speyer et al.[31] However, only six of the reviewed studies included adults (>18 years) while two studies were on adults only.[31]

There are several limitations to this study. The cross-sectional design reflects one assessment of each individual and not changes over time. We relied on data reported to a national CP registry. Classifications of eating and drinking ability have been included in the registry since 2016. This allowed the inclusion of nationwide data for a large number of individuals, 2035 in total. However, despite the relatively high number compared to other studies, it is not possible to conclude that our results are representative of the total adult population with CP. Nevertheless, adults with all motor and cognitive functions are included. All

are enrolled in the health care programme for adults with CP and have access to adult specialist teams for regular examinations. The population is slightly skewed regarding age with a low median age, possibly affecting results. There were significantly more males (55%) than females (45%) in the study, corresponding to the male/female ratio also reported for children with CP. Some classifications of EDACS have been performed during a 'mealtime observation' with a speech and language pathologist and some through interviews with a multiprofessional team. The use of BMI and skinfold thickness can be questioned, but are currently the most common methods to examine total body fat in individuals with CP.[32] A study comparing body fat percentage obtained from skinfold measurements with dual-energy X-ray absorptiometry scans showed strong agreement between the methods (concordance correlation coefficients 0.86).[33] Future studies, such as a longitudinal follow-up of changes in body weight, cardiovascular diseases, or respiratory failures, would be valuable. A video fluoroscopic swallowing study could be useful to validate severity and safety of eating, drinking, and swallowing problems in adults with CP.

Our findings suggest that adults with CP should be routinely screened and treated for problems related to dysphagia to avoid nutritional complications and potential underweight. Being partly or totally dependent on others during mealtimes is a risk factor for low body weight.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the CPUP registry. Restrictions apply to the availability of these data, which were used with permission by KVB Region Skåne. Requests to access the datasets should be directed to KVB Region Skåne https://vardgivare.skane.se/kompetens-utveckling/forskninginom-region-skane/utlamnande-av-patientdata-samradkvb/.

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