

## **Dysphagia Symptoms in Adults with Cerebral Palsy: Prevalence and Impact on Quality of Life**

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### **Objectives**

To investigate the prevalence and characteristics of dysphagia symptoms, evaluate the dysphagia-related quality of life (QOL), and determine the factors affecting dysphagia-related QOL in adults with cerebral palsy (CP).

### **Methods**

This cross-sectional, interview-based survey study enrolled adults with CP (N = 117) and healthy individuals (N = 117). The Swallowing-QOL (SWAL-QOL) questionnaire, Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS), and Functional Oral Intake Scale (FOIS) were evaluated by a rehabilitation physician. The Swallowing-QOL (SWAL-QOL) scores were the main outcome measure, with lower scores indicating symptoms with stronger effect on QOL. The SWAL-QOL questionnaire included 14 items regarding dysphagia symptoms and 30 regarding swallowing-related QOL.

### **Results**

Among pharyngeal symptoms, choking on food occurred most frequently (sometimes or more 76.9%), followed by coughing and choking on liquid. Among oral symptoms, chewing problems occurred most frequently (sometimes or more 59.8%), followed by food dribbling from the mouth (sometimes or more 53.8%). Compared to healthy adults, those with CP showed worse QOL across all SWAL-QOL items, with the lowest scores obtained for meal duration, followed by communication, burden, fatigue, sleep, and eating desire. On multiple linear regression analysis, higher MACS level, lower FOIS level, and older age were predictors of worse SWAL-QOL score.

### **Conclusions**

In adults with CP, dysphagia symptoms are very frequent and have a profound effect on SWAL-QOL. Thus, when managing CP patients, it is necessary to evaluate swallowing function and establish an active intervention plan even if total oral diet is established. Interventions for environmental factors, as well as medical interventions, might be also necessary in this population because factors associated with SWAL-QOL are less modifiable (hand function) or not modifiable (age).

**Table 1.** Demographics and functional status of adults with cerebral palsy

Characteristic	GMFCS level I– III ( <i>n</i> = 50)	GMFCS level IV ( <i>n</i> = 31)	GMFCS level V ( <i>n</i> = 36)	Total ( <i>N</i> = 117)
Sex, male	29 (58)	19 (61.3)	22 (61.1)	70 (59.8)
Age, years*	41.2±12.5	39.0±13.6	33.0±9.4	38.1±12.4
BMI	21.1±3.1	21.3±3.4	19.6±5.6	20.7±4.1
History of epilepsy	25 (50)	13 (41.9)	19 (52.8)	57 (48.7)
Preterm birth	11 (22)	12 (38.7)	16 (44.4)	39 (33.3)
Dominant type of motor impairment				
Spastic	17 (34)	14 (45.2)	19 (52.8)	50 (42.7)
Dyskinetic	30 (60)	15 (48.4)	16 (44.4)	61 (52.1)
Ataxic	2 (4)	1 (3.2)	0 (0)	3 (2.6)
Mixed spastic and dyskinetic	1 (2)	1 (3.2)	1 (2.8)	3 (2.6)
Distribution of motor impairment				
Hemiplegia	13 (26)	4 (12.9)	0 (0)	17 (14.5)
Diplegia	9 (18)	4 (12.9)	1 (2.8)	14 (12.0)
Quadriplegia	28 (56)	23 (74.2)	35 (97.2)	86 (73.5)
MACS level				
Level II	21 (42)	6 (19.4)	0 (0)	27 (23.1)
Level III	25 (50)	17 (54.8)	1 (2.8)	43 (36.8)
Level IV	4 (8)	7 (22.6)	10 (27.8)	21 (18.0)
Level V	0 (0)	1 (3.2)	25 (69.4)	26 (22.2)
FOIS level				
Level 5	13 (26)	6 (19.4)	19 (52.8)	38 (32.5)
Level 6	25 (50)	16 (51.6)	11 (30.6)	52 (44.4)
Level 7	12 (24)	9 (29.0)	6 (16.7)	27 (23.1)

Values represent frequency (percentage) or mean ± standard deviation.

\**P* < .01 for the analysis of variance test.

**Table 2.** Prevalence of dysphagia symptoms in adults with cerebral palsy (*N* = 117)

Symptom	Almost always	Often	Sometimes	Hardly ever	Never	Converted score*
<b>Pharyngeal symptoms</b>						
Choking on food	7 (6.0)	33 (28.2)	50 (42.7)	20 (17.1)	7 (6.0)	47.2
Coughing	8 (6.8)	24 (20.5)	42 (35.9)	34 (29.1)	9 (7.7)	52.6
Choking on liquid	2 (1.7)	26 (22.0)	54 (46.2)	24 (20.5)	11 (9.4)	53.4
Coughing out food or liquid stuck in the mouth	5 (4.3)	22 (18.8)	52 (44.4)	26 (22.2)	12 (10.3)	53.8
Having to clear the throat	2 (1.7)	21 (17.9)	50 (42.7)	30 (25.6)	14 (12.0)	57.1
Food sticking in the throat	4 (3.4)	19 (16.2)	46 (39.3)	36 (30.8)	12 (10.3)	57.1
Gagging	3 (2.6)	6 (5.1)	31 (26.5)	47 (40.2)	30 (25.6)	70.3
<b>Oral symptoms</b>						
Problems chewing	18 (15.4)	23 (19.7)	29 (24.8)	35 (29.9)	12 (10.3)	50.0
Food or liquid dribbling from the mouth	9 (7.7)	26 (22.2)	28 (23.9)	37 (31.6)	17 (14.5)	55.8
Food sticking in the mouth	2 (1.7)	22 (18.8)	43 (36.8)	37 (31.6)	13 (11.1)	57.9
Drooling	11 (9.4)	17 (14.5)	25 (21.4)	45 (38.5)	19 (16.2)	59.4
Food or liquid coming out through the nose	0 (0)	6 (5.1)	33 (28.2)	45 (38.5)	33 (28.2)	72.4
<b>Salivary symptoms</b>						
Thick saliva or phlegm	5 (4.3)	25 (21.4)	39 (33.3)	35 (29.9)	13 (11.1)	55.6
Excess saliva or phlegm	5 (4.3)	22 (18.8)	43 (36.8)	34 (29.1)	13 (11.1)	56.0

Prevalence is expressed as frequency (percentage).

\*Dysphagia symptom scores are shown after conversion to a 0–100 scale, with lower scores indicating symptoms with stronger effect on quality of life.

**Table 3.** Swallowing-Quality of Life (SWAL-QOL) score in adults with cerebral palsy and in healthy participants

SWAL-QOL item	Healthy participants ( <i>n</i> = 117)		Adults with cerebral palsy ( <i>n</i> = 117)		<i>P</i> -value
	Mean	SD	Mean	SD	
Food selection	99.36	3.97	71.90	18.56	<.001
Burden	98.83	4.92	57.16	23.92	<.001
Mental health	99.62	2.09	66.75	20.88	<.001
Social functioning	99.87	1.03	65.00	22.58	<.001
Fear	99.04	3.82	65.17	18.02	<.001
Eating duration	95.62	10.03	49.89	25.08	<.001
Eating desire	97.08	6.59	63.25	15.29	<.001
Communication	99.89	1.16	51.50	27.03	<.001
Sleep	91.45	11.21	61.00	24.30	<.001
Fatigue	93.16	10.01	57.98	22.96	<.001
Overall SWAL-QOL composite score	97.39	3.04	60.96	13.30	<.001

Scores are shown after conversion to a 0–100 scale. The overall SWAL-QOL composite score represents the average of converted scores of all items, as recommended by the SWAL-QOL developers.