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ORIGINAL ARTICLE

Dysphagia-Related Quality of Life in Adults with Cerebral Palsy on Full Oral Diet Without Enteral Nutrition

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Abstract

There have been no quantitative studies on dysphagia and its impact on quality of life (QOL) of adults with cerebral palsy (CP). In this cross-sectional study, we aimed to investigate the characteristics of dysphagia symptoms and their impact on QOL in adults with CP on a full oral diet compared with healthy adults. Additionally, we aimed to determine the factors affecting dysphagia-related QOL in this population. We enrolled adults with CP on full oral diet ($N = 117$) and healthy individuals ($N = 117$) and interviewed them using the swallowing-quality of life (SWAL-QOL) questionnaire which includes 14 items regarding dysphagia symptoms and 30 items regarding swallowing-related QOL. The functional status of each participant with CP was evaluated using the gross motor function classification system, the manual ability classification system (MACS), and the Functional Oral Intake Scale (FOIS). Among pharyngeal symptoms, choking on food was reported most frequently (sometimes or more 76.9%), followed by coughing and choking on liquid. Among oral symptoms, chewing problems were reported 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 reported 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. Among adults with CP, it is necessary to evaluate swallowing function and establish an active intervention plan even if a full oral diet is established.

Keywords Cerebral palsy · Deglutition · Deglutition disorders · Dysphagia · Swallowing-quality of life · Quality of life

Introduction

Persons with cerebral palsy (CP) have several health problems associated with their neurological disorder [1]. Among these, dysphagia is particularly important. Dysphagia represents dysfunction in the oral [2, 3], oropharyngeal [4, 5], and/or esophageal phase of swallowing [6]. In persons with CP, dysphagia may occur due to motor impairment [7], abnormal neurological maturation, sensory deficits [2, 8], or impaired esophageal motility and may be exacerbated by gastroesophageal reflux disease [5, 9]. If nutritional intake is inadequate due to dysphagia, weight loss may occur, which affects development [6, 10]. Pneumonia or chronic respiratory problems due to aspiration may also occur [11]. Many adults with CP may remain on a full oral diet without enteral nutrition, but will still experience coughing, choking, and breathing difficulties during meals [12]. Aspiration can occur before or after swallowing, and there is an increased risk of silent aspiration in those with more severe neurological impairment [12, 13]. According to Benfer et al., the prevalence of oropharyngeal dysphagia (OPD) in children with CP was 85%, and there was a relationship between OPD and gross motor function classification system (GMFCS) levels [14].

Many studies have evaluated the changes in swallowing function depending on age, disease etiology, and functional status in children with CP [3, 4, 7, 15]. In contrast, few reports have evaluated such aspects in adults with CP. Balandin et al. [16] interviewed 32 adults with CP and reported

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qualitative findings regarding mealtime experience, including restricted food choices, reduced social interaction during mealtime, and feelings of anxiety associated with prolonged meal duration; these experiences worsened gradually as the individuals became older. However, to our knowledge, there have been no quantitative studies of dysphagia and its impact on quality of life (QOL) in adults with CP. Knowledge about the frequency and severity of dysphagia symptoms and their impact on QOL would not only broaden our understanding of CP manifestations but would also be useful for developing interventions to improve QOL in community-dwelling adults with CP.

The swallowing-quality of life (SWAL-QOL) questionnaire, which evaluates self-reported QOL outcomes in patients with oropharyngeal dysphagia [17], has been developed for use in clinical research and effectiveness research on social, psychological, and cultural experiences [18]. The SWAL-QOL questionnaire was first validated in patients with oropharyngeal dysphagia and has been successfully used to assess the impact of dysphagia on QOL in persons with advanced age [19], Parkinson's disease [20, 21], oculopharyngeal muscular dystrophy [22], and head and neck cancer [23].

In this study, we aimed to investigate the characteristics of dysphagia symptoms and their impact on QOL in adults with CP on a full oral diet compared with healthy adults. Additionally, we aimed to determine the factors affecting dysphagia-related QOL in this population and to investigate the relationship between meal duration and nutritional status.

Methods

Study Design and Participants

Between January 2018 and June 2018, this cross-sectional, interview-based survey study enrolled adults with CP and healthy individuals. We recruited adults (age ≥ 20 years) with a confirmed diagnosis of CP, who attended a community center specialized for persons with CP and were able to provide informed consent for participation. Each candidate was evaluated using the 10 orientation items of the Korean version of the Mini-Mental State Examination questionnaire. Adults with CP were enrolled in the present study if they were able to express their opinion, regardless of the correctness of the answer. Individuals who were unable to respond to more than two items were excluded.

Healthy adults (> 20 years) were also recruited. The exclusion criteria were neurological disease and anatomical problems of the head or neck. Healthy adults who provided informed consent were administered the SWAL-QOL questionnaire. Demographic data such as sex and age were also collected.

Procedures

A rehabilitation physician evaluated the functional status of the participants. Among adults with CP, the type of motor impairment (spastic, dyskinetic, mixed spastic and dyskinetic, or ataxic motor type) and distribution of motor impairment (hemiplegia, diplegia, or quadriplegia) were classified based on the European guidelines [24]. Motor ability was assessed using the GMFCS [25], whereas manual ability was assessed using the manual ability classification system (MACS) [26]. Although the MACS and GMFCS were initially developed and validated in the pediatric population, studies have supported their reliability and validity in young adults with CP [27, 28]. The Functional Oral Intake Scale (FOIS) [29] was employed to evaluate diet status. The informants were caregivers and/or adults with CP, and an occupational therapist, who had more than 2 years of experience in swallowing therapy, conducted the interview for the FOIS evaluation. The FOIS is a 7-point numerical scale that employs the following ratings: level 1, no intake by mouth; level 2, tube feeding with minimal food or liquid intake; level 3, tube feeding with consistent oral intake of food or liquid; level 4, total oral diet (TOD), single consistency; level 5, TOD, multiple consistencies, but requiring special preparation; level 6, TOD, multiple consistencies, no requirement for special preparation but limitation to specific foods; and level 7, TOD, no restrictions [29]. Demographic and medical history information including age, sex, height, weight, comorbid diagnoses, history of epilepsy, and preterm birth was also obtained from the participants. Although body mass index (BMI) is not a sufficient measurement to predict nutritional adequacy, it was calculated as weight/height^2 (kg/m^2). The average time taken to eat one's meal was also investigated. The participants were stratified according to reported average meal duration: Group 1, < 15 min; Group 2, 15–30 min; Group 3, 30–45 min; Group 4, > 45 min.

Dysphagia Symptoms

The frequency of three types of dysphagia symptoms was evaluated using 14 items, which covered (i) seven pharyngeal symptoms (choking on food, choking on liquid, coughing when food became stuck, coughing, clearing the throat, food sticking in the throat, and gagging), (ii) two salivary symptoms (thick saliva and excess saliva), and (iii) five oral symptoms (chewing problems, food sticking in the mouth, food/liquid dribbling from the mouth, drooling, and food/liquid coming out through the nose). While such items are included in the SWAL-QOL questionnaire, we calculated a separate dysphagia symptom score [17, 18].

SWAL-QOL Questionnaire

Adults with CP were interviewed by an occupational therapist who had at least 2 years of experience with SWAL-QOL evaluation in patients undergoing swallowing therapy. The evaluator read the questions and recorded the answers. If the meaning of the individual's statements was unclear, the evaluator encouraged the individual to express their thoughts with caregiver assistance or using a communication device, as needed.

The SWAL-QOL questionnaire has been validated in Korea [30] and has been reported as a clinically valid and reliable tool for assessing the QOL of Koreans with dysphagia. The SWAL-QOL questionnaire consists of 44 items covering 11 domains for which the frequency or severity of symptoms is captured on 5-point Likert scales. Items include food selection (two items), burden (two items), mental health (five items), social functioning (five items), fear (four items), meal duration (two items), eating desire (three items), communication (two items), sleep (two items), fatigue (three items), and symptom frequency (14 items) [17]. It also includes three questions about the participant's diet.

The primary outcome for this study was the mean score across 11 SWAL-QOL domains (burden, eating duration, eating desire, food selection, fear, mental health, social functioning, communication, sleep, fatigue, and symptom frequency). All scores were converted to a weighted 0–100 scale, with 100 indicating the least effect on QOL and 0 indicating the worst effect. Scaling was performed using Likert's summated ratings method. Finally, an overall scale was generated by including all items with equal weight, and the SWAL-QOL composite score was calculated [22].

Statistical Analysis

Independent-sample *t*-tests were used to compare healthy participants and adults with CP regarding age and SWAL-QOL scores. Chi-square tests were used to analyze categorical data. To identify the impact of each covariate affecting the SWAL-QOL composite score, univariate regression analysis was performed. To reveal independent factors affecting the SWQL-QOL composite score, multiple linear regression analysis was performed through a stepwise selection (entry condition, $P<0.05$; removal condition, $P>0.15$). A P value <0.05 was considered to indicate statistical significance. Participants from each group (healthy participants and adults with CP) were divided into four subgroups (Groups 1–4) according to the average meal duration, and analysis of variance with post hoc Bonferroni testing was used to compare BMI among the subgroups. Statistical analyses were performed using SPSS version 20 (IBM Corporation, Armonk, NY, USA).

Results

Demographics of Adults with CP

Interviews were completed with 117 adults with CP (age 20–79 years; mean BMI 20.67 kg/m^2), whose characteristics are summarized in Table 1. Thirty-five participants (29.9%) were underweight (BMI <18.5 kg/m^2), while 29 (24.8%) were overweight (BMI ≥ 23 kg/m^2). Regarding the dominant type of motor impairment, spastic type was diagnosed in 50 participants (42.7%), dyskinetic type in 61 (52.1%), ataxic type in three (2.6%), and mixed type in three (2.6%). Motor function ranged from GMFCS levels I to V, with level IV or V in 67 participants (57.3%), indicating that more than half of participants relied on wheelchair for mobility. Manual ability ranged from MACS levels II to V, with levels III to V in 90 participants (76.9%), indicating that most participants needed some help in daily activities. All participants received a full oral diet. FOIS levels ranged from 5 to 7, with levels <7 noted in 90 participants (76.9%), indicating that most participants needed some modifications or restrictions in the oral diet. There was no statistically significant difference in age between healthy adults (mean age 37.2 years; SD 12.1 years) and adults with CP (mean age 38.1; SD 12.4 years).

Prevalence of Dysphagia Symptoms in Adults with CP

The average score regarding the frequency of 14 symptoms was 65.6 (SD 12.6). Among pharyngeal symptoms, choking on food was reported most frequently (sometimes or more 76.9%, weighted QOL impact score 47.2), followed by coughing and choking on liquid (Table 2). Gagging was the least frequent pharyngeal symptom, with a weighted impact score of 70.3. Among oral symptoms, chewing problems occurred most frequently (sometimes or more 59.8%, weighted impact score 50), followed by food dribbling from the mouth (sometimes or more 53.8%) or sticking to the mouth. Salivary symptoms were also frequently reported.

Self-Reported SWAL-QOL in Healthy Adults and in Adults with CP

Table 3 summarizes the overall SWAL-QOL scores and the SWAL-QOL across the 11 individual items. The overall SWAL-QOL score was significantly higher in healthy adults than in adults with CP (97.39 vs. 60.60, $P<0.001$). Compared to healthy adults, adults with CP exhibited worse dysphagia-related QOL across all SWAL-QOL items. Meal duration had the lowest mean score, followed by communication, burden, fatigue, sleep, and eating desire.

Table 1 Demographics and functional status of adults with cerebral palsy

Characteristics	GMFCS levels I–III (*n* = 50)	GMFCS level IV (*n* = 31)	GMFCS level V (*n* = 36)	Total (*N* = 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

*$P < 0.01$ for the analysis of variance test

GMFCS gross motor function classification system, *MACS* manual ability classification system

Factors Influencing SWAL-QOL in CP

On univariate analysis, history of epilepsy, quadriplegia, MACS level, and FOIS level had significant associations with the SWAL-QOL composite score (Table 4). On multiple linear regression analysis, FOIS level, MACS level, and age were predictors of the SWAL-QOL composite score ($R = 0.608$; Table 5).

Meal Duration and Nutritional Status

Reported average meal duration was < 15 min (Group 1) for 34 participants (29.1%), 15–30 min (Group 2) for 49 participants (41.9%), 30–45 min (Group 3) for 25 participants (21.4%), and > 45 min (Group 4) for 9 participants (7.7%). Average meal duration was significantly longer among adults with CP than among healthy adults ($P = 0.010$). Most healthy adults reported durations of their meal within 15 min (62 participants, 53.0%), and none ate more than 45 min. Among adults with CP, there was a statistically significant difference in BMI according to meal duration as shown in Fig. 1 ($P = 0.006$). Low BMI was noted for individuals who required more than 45 min (mean BMI 16.87 kg/m^2; SD 4.00 kg/m^2; range 10.7–23.9 kg/m^2) compared to < 15 min to eat one meal.

Discussion

To our knowledge, this is the first study regarding dysphagia symptoms and their impact on QOL in adults with CP. Among adults with CP, we found a SWAL-QOL score of 65.6 (SD 12.6) for the dysphagia symptom frequency domain, which is lower (i.e., more severe dysphagia symptoms) than previously reported among patients with Parkinson's disease (70.4 and 78) [19, 21] or amyotrophic lateral sclerosis (72.1) [30]. Importantly, even though all participants were receiving full oral diets, the majority had pharyngeal symptoms (choking on food, choking on liquid, coughing when food became stuck, coughing, clearing the throat, and food sticking in the throat) except for gagging. These findings suggest that even though an individual with CP may be on a full oral diet, they may still demonstrate signs and symptoms of dysphagia. Benfer et al. reported

Table 2 Prevalence of dysphagia symptoms in study participants with cerebral palsy ($N = 117$)

Symptom	Almost always	Often	Sometimes	Hardly ever	Never	Weighted impact score[a]
Pharyngeal symptoms						
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
Oral symptoms						
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
Salivary symptoms						
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)

[a] Dysphagia symptom scores are shown after conversion to a weighted 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 ($n = 117$)		Adults with cerebral palsy ($n = 117$)		*P* value
	Mean	SD	Mean	SD	
Food selection	99.36	3.97	71.90	18.56	< 0.001
Burden	98.83	4.92	57.16	23.92	< 0.001
Mental health	99.62	2.09	66.75	20.88	< 0.001
Social functioning	99.87	1.03	65.00	22.58	< 0.001
Fear	99.04	3.82	65.17	18.02	< 0.001
Eating duration	95.62	10.03	49.89	25.08	< 0.001
Eating desire	97.08	6.59	63.25	15.29	< 0.001
Communication	99.89	1.16	51.50	27.03	< 0.001
Sleep	91.45	11.21	61.00	24.30	< 0.001
Fatigue	93.16	10.01	57.98	22.96	< 0.001
Symptom frequency	97.34	4.31	57.04	15.72	< 0.001
Overall SWAL-QOL composite score	97.39	2.95	60.60	12.99	< 0.001

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

that children with mild motor dysfunction can demonstrate swallowing difficulties [31]. Consideration should be given to offering a swallowing assessment to adults with CP for

Table 4 Factors affecting the swallowing-quality of life (SWAL-QOL) composite score in adults with cerebral palsy (CP)

Variable	B	95% CI for B		*P* value
		Lower	Upper	
Age	− 0.056	− 0.250	0.137	0.564
Sex, male versus female	3.402	− 1.431	8.235	0.166
Epilepsy, yes versus no	− 7.015	− 11.728	− 2.301	0.004
Preterm birth, yes versus no	4.493	− 0.879	9.864	0.100
Spastic type of CP, yes versus no	2.108	− 2.706	6.922	0.388
Dyskinetic type of CP, yes versus no	− 1.735	− 6.507	3.037	0.473
Ataxic type of CP, yes versus no	3.185	− 11.920	18.290	0.677
Mixed type of CP, yes versus no	− 6.502	− 21.571	8.566	0.394
Quadriplegia, yes versus no	− 7.523	− 12.756	− 2.290	0.005
GMFCS level	− 1.200	− 3.046	0.646	0.200
MACS level	− 4.050	− 6.154	− 1.945	< 0.001
FOIS level	7.418	4.491	10.345	< 0.001

Data were obtained using univariate linear regression

CI confidence interval, *FOIS* Functional Oral Intake Scale, *GMFCS* gross motor function classification system, *MACS* manual ability classification system

Table 5 Factors significantly associated with the swallowing-quality of life (SWAL-QOL) composite score in adults with cerebral palsy

Variable	Estimate	95% confidence limits		*P* value
		Lower	Upper	
FOIS level	7.865	4.761	10.970	<0.001
MACS level	−4.450	−6.634	−2.266	<0.001
Age	−0.313	−0.507	−0.120	0.002

Data were obtained using multiple linear regression analysis ($R = 0.608$, $R^2 = 0.369$). Only factors with significant association are listed here

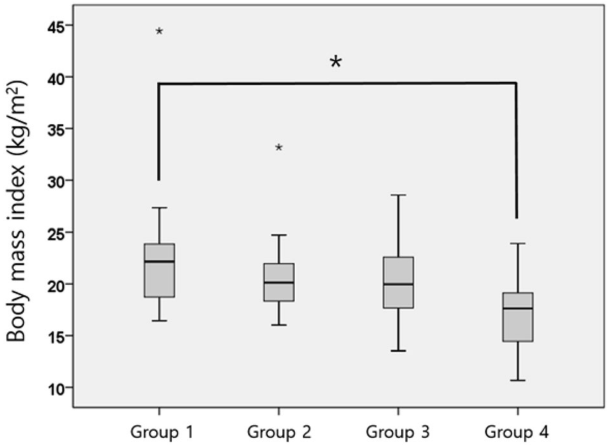

Fig. 1 Body mass index in adults with cerebral palsy. The participants were stratified according to meal duration. Group 1, <15 min ($n = 34$); Group 2, 15–30 min ($n = 49$); Group 3, 30–45 min ($n = 25$); Group 4, >45 min ($n = 9$). *$P < 0.0083$, Group 1 versus Group 4

all levels of motor ability. Assessment may be conducted via interviews at the clinic, and if necessary, an objective evaluation such as video fluoroscopic swallowing examination could be considered. More than 50% of the adults with CP in the present study reported oral symptoms including thick saliva, excess saliva, chewing problems, food sticking in the mouth, and food/liquid dribbling from the mouth. Only 27 participants (23.1%) had oral diets of FOIS level 7 (no restriction), and most participants needed modification or restriction of certain foods, probably attributable to the above-described oral symptoms.

In this study, adults with CP with reported average mealtime durations of more than 45 min had a significantly lower BMI than those with reported meal durations of less than 15 min. Moreover, malnutrition has been reported in adults with severe functional disability [6]. Although we did not measure skinfold thickness and lean body mass, nutritional status may be compromised when an individual takes an extended period of time to complete a meal. It is therefore important to evaluate the average time taken per meal for an individual with CP as well as any factors contributing to an extended meal duration.

The SWAL-QOL score was significantly lower in adults with CP than in healthy participants across all domains, which is similar to previous observations regarding other disease groups. In adults with CP, the overall SWAL-QOL composite score was 60.96, which is lower than the scores reported in Parkinson's disease, a degenerative condition (74.9 [19] and 77.6 [21]); in fact, the score for most SWAL-QOL domains seems to be lower in adults with CP (present study) than in those with later-stage Parkinson's disease (72.7) [19] and 76.9 [19, 21] in patients with stage > 3 on the Hoehn and Yahr scale).

In this study of adults with CP, we found that, among the SWAL-QOL domains, eating duration had the lowest score, followed by communication, which corresponds to previous observations in persons with Parkinson's disease [19]. On multiple regression analysis, overall SWAL-QOL score was lower in adults with CP with higher MACS level, lower FOIS level, and older age.

FOIS and SWAL-QOL

In this study, adults with CP who were on a diet without modifications or restrictions (FOIS level 7) were also found to have dysphagia symptoms. Seo et al. reported that individuals with dyskinetic CP who had been eating unrestricted diets and had not been previously evaluated for swallowing function also demonstrated frequent aspiration on video fluoroscopic swallowing examination [32]. It is important to consider that the swallowing function of adults with CP evaluated as FOIS level 7 may not be the same as healthy individuals, even though they consumed food similar to that of healthy individuals.

Fifteen adults with CP, who were on a diet without modifications or restrictions (FOIS level 7), were classified with significant motor impairment GMFCS IV and V. Among these individuals, some participants might have actual diet modifications or restrictions that they failed to recognize because of long-term dietary pattern. In this study, the FOIS evaluation was based on interviews rather than analysis of a 3-day dietary journal [29].

In multiple regression analysis, the overall SWAL-QOL score increased by 7.865 for each one-level increase in FOIS scores. Although diet modification may help reduce dysphagia symptoms, it can be perceived by adults with CP as impacting negatively on QOL. Further studies are needed to identify whether diet modification can help improve SWAL-QOL, including dysphagia symptoms. Although the FOIS, which focuses on the food the individual consumes, was investigated in the present study, it would be better if the relationship between safety, efficiency, and SWAL-QOL could be analyzed using the Eating and Drinking Ability Classification System which was developed for adults with CP [33].

Hand Function and SWAL-QOL

In this study, MACS level was found to be an independent predictor of SWAL-QOL score, which was significant both on univariate analysis and multiple linear regression analysis. Self-care skills such as eating, bathing, and dressing are reduced in adults with CP [34]. A qualitative study reported that hand mobility had an effect on mealtime experience [16]. The need to employ assistive devices or receive assistance from a caregiver during mealtime arises from the lack of coordination or weakness of the upper extremities and leads to prolonged meal duration, which increases burden and affects SWAL-QOL. While there are efforts to improve hand function in adults with CP [35, 36], manual mobility might not be a modifiable factor in some individuals, especially in the adult population. Rather than implementing additional training for meal preparation and feeding, a more effective intervention might be to focus on improving environmental factors including increasing the awareness of adults with CP and their families through education about swallowing disorders and potential impact.

Age and SWAL-QOL

Multiple linear regression analysis revealed that, in adults with CP, the SWAL-QOL score decreased with age, which is in agreement with previous findings that, in adults with CP aged > 35 years, the number and severity of health problems increase, whereas mobility, self-care performance, and walking performance decrease with age [37]. Another study reported that the deterioration of gross motor function and health-related QOL is more severe among adults with CP aged 33–42 years than among those aged 23–27 years [38]. Similar to findings from a qualitative study on the effects of aging on mealtime experience, which concluded that adults with CP experience gradual changes in their swallowing capabilities from as early as age 30 [16], our results found age to be a factor affecting dysphagia-related QOL; our study population had a mean age of 38.1 years, and a range from 20 to 79 years.

In this study of adults with CP, participants with GMFCS levels I–III were somewhat older (mean age 41.2 years; SD 12.52 years; range 20–79 years) than those with GMFCS level V (mean age 33.0 years; SD 9.44 years; range 20–58 years). In a study of the survival rate of individuals at 19 years of age [15], GMFCS V and gastrostomy feeding were reported as risk factors for mortality during childhood. It should also be considered that older adults with CP at GMFCS level V would likely not be able to attend the community center and thus would not have been included in the population we surveyed. Selection bias might thus explain why age was not identified as a significant factor affecting SWAL-QOL on univariate analysis. However, on multiple linear regression corrected for MACS level and FOIS level, age was an independent factor affecting the SWAL-QOL composite score.

Study Limitations

The sample of this study is not fully representative of the general CP population because we recruited adults with CP who attended the community center. Older individuals or those with severe CP, who might be unable to travel, were not well represented in our sample because in our setting such individuals do not attend community centers specialized for persons with a disability. Additionally, because this was a cross-sectional study, longitudinal changes in dysphagia symptoms and their impact on QOL were not investigated. Future longitudinal studies should be conducted to clarify these issues in adults with CP.

Conclusions

In adults with CP, dysphagia symptoms are frequent and can have a profound effect on swallowing-related QOL. Thus, when working with adults with CP, an evaluation can help establish swallowing function and assist in developing an active intervention plan for those on oral diets. 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). Given that adults with CP who took more than 45 min to complete meals had a significantly lower BMI than those with mealtime durations of less than 15 min, it is necessary to closely examine adults with CP for average time taken to eat one's meal and the reasons for extended meal durations.

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Compliance with Ethical Standards

Conflict of interest The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Ethical approval was obtained from the Seoul National University Hospital Institutional Review Board (IRB) No. 1712-013-903.

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