

# Swallowing-related quality of life among oral-feeding Chinese patients with Parkinson's disease – a preliminary study using Chinese SWAL-QOL

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## ABSTRACT

**Purpose:** The objective of the present study is to evaluate swallowing-related quality of life in Chinese patients with Parkinson's disease (PD) using the validated Chinese version of the Swallowing Quality-of-Life Questionnaire (C-SWAL-QOL) and factors associated with swallowing-related quality of life, including age, disease duration, and severity of depression by 15-item Geriatric Depression Scale in Chinese version (GDS-C).

**Methods:** C-SWAL-QOL was administered to 67 Chinese patients with PD. Upon completion of C-SWAL-QOL, they completed the 15-item GDS-C. Spearman's Rho correlation analyses were performed to examine the relationship between the 10-subscale scores of C-SWAL-QOL and (1) age, (2) disease duration, and (3) depression.

**Results:** Among the subscales in C-SWAL-QOL, sleep, fatigue, eating duration, and communication were the most severely affected. Significant relationships existed between composite C-SWAL-QOL score, total C-SWAL-QOL score, Dysphagia Symptom Battery (DSB) core, and depression. Significant relationships were also observed between depression and the following subscales: communication, fear, mental health, social functioning, and fatigue. Yet, no relationships existed between score of C-SWAL-QOL and age or disease duration in PD.

**Conclusions:** Considering the goal of dysphagia intervention is to improve swallowing safety and efficiency and ultimately enhance patients' QOL, clinicians should consider using C-SWAL-QOL in clinical practice to measure swallowing outcomes and to better understand treatment effectiveness.

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## KEYWORDS

Chinese version of SWAL-QOL; deglutition; depression; dysphagia; Parkinson's disease; quality of life

## ► IMPLICATIONS FOR REHABILITATION

- Dysphagia-related patient-reported outcome (PRO) measures such as Swallowing Quality-of-Life Questionnaire (SWAL-QOL) are the cornerstone to systematically collecting patient-centered data and monitoring rehabilitation outcomes.
- Based on the scores of Chinese Parkinson's disease (PD) patients in an oral feeding population indicated in the current study, treatment goal and rehabilitation plan can be set.
- Chinese patients with Parkinson's disease might benefit from a rehabilitation program focusing on the most severely affected subscales in C-SWAL-QOL.

## Introduction

Parkinson's disease (PD) is the second most prevalent neurodegenerative disease in the world, with cardinal signs including tremor, bradykinesia, rigidity, and postural instability [1]. Through the course of the disease process, 90% of the PD patients develop dysphagia [2], and aspiration pneumonia is the leading cause of death [3]. It was estimated that there were 8 000 000 or more individuals in the world each year that have or will have swallowing and speech disorders during the course of PD [2]. Swallowing dysfunction, or dysphagia in PD can take place during any of the swallow phases and is usually caused by impairment of the affected bulbar structures. Common dysphagia symptoms observed in patients with PD may include repeated pumping tongue motion [4], lingual tremor [5], and excessive saliva in the oropharynx [6]. As such,

dysphagia manifests as an inability or difficulty swallowing, and affects the most fundamental functions of such sociobiological activity, the ability to drink and eat.

Swallowing function can be assessed directly by using instrumental testing including videofluoroscopic swallowing study (VFSS) and fiberoptic endoscopic evaluation of swallowing (FEES), or indirectly through patient self-report [7–9]. Patients' self-report represents the subjective experience of the patients regarding swallowing. It has been shown that attitudes and feelings toward eating, chewing, and swallowing of food in PD patients affect both their mental health and their eating habits [7,8]. The findings in the study of Miller et al. [8] showed that PD patients feel miserable due to the loss of mealtime enjoyment from slowness, altered diet, and dependence on a caregiver to cut food into

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small pieces. They might also have to mash, tenderize, or liquidize food before eating. In the study of Plowman-Prine et al. [7], dysphagic PD patients reported significant decreases in the mental health domain. The detrimental impact on the mental well-being was likely contributed by the inability to fully participate in society, mealtime anxiety, and feelings of frustration in the dysphagic PD patients.

Over the past few years, a number of self-reported assessment scales have been developed to supplement the clinical assessment of swallowing ability [9,10]. It has now become common practice to evaluate the impact of dysphagia on one's quality of life through a questionnaire. Traditional instrumental assessments supplement with the patients' perception is a key part of a multi-dimensional swallowing evaluation. The use of questionnaire is not only convenient, but is also practical. It may help reveal subtle symptoms related to swallowing disorder that people have difficulty describing, such as impaired mastication and difficulty handling sticky food [11]. Due to the short duration of clinical swallowing evaluation or instrumental swallowing assessment, these observations could be missed. Early identification of dysphagia by using a swallowing-specific questionnaire could minimize the likelihood of developing pneumonia, aspiration and malnutrition.

One of the most widely known dysphagia-specific questionnaires in the field is the Swallowing Quality-of-Life Questionnaire (SWAL-QOL) [12–14], which was developed by McHorney et al. [12,13]. The SWAL-QOL has a wide range of applications thanks to its generic nature that caters patients with various causes of dysphagia. The SWAL-QOL allows us to differentiate patients with and without dysphagia (i.e., screening), as well as to determine the severity of swallowing impairment (i.e., severity rating) as measured by patient tolerance of various food textures and fluid consistencies [11]. SWAL-QOL assesses the symptoms reported by patients and their impact on swallowing-related quality of life. The SWAL-QOL can serve as an important tool in monitoring the patient's perspective on the efficacy of treatment. Currently, the SWAL-QOL questionnaire has been validated in an English-speaking [12–14] and German-speaking population [15], while the Chinese version of the Swallowing Quality-of-Life Questionnaire (C-SWAL-QOL) has also been validated for the Chinese-speaking population in Hong Kong [16]. The C-SWAL-QOL questionnaire has been reported to be a clinically valid and reliable tool for assessing swallowing-related quality of life in the Hong Kong Chinese population.

C-SWAL-QOL questionnaire has been used in previous studies investigating the long-term swallowing-related quality of life in stroke survivors in the post-acute phase [11] and laryngeal cancer patients [17]. In this preliminary study, we hope to identify self-perceived swallowing-related quality of life of PD patients in Hong Kong. As discussed previously, PD patients suffer a varying range of dysphagia. The relationship between swallowing function and self-perceived swallowing ability in Hong Kong community-dwelling PD patients is not available, specifically using C-SWAL-QOL. Since the patient-reported outcomes (PROs) of C-SWAL-QOL in a purely Chinese PD population have not been described, there is a knowledge gap of swallowing-related quality of life in Hong Kong PD patients. Knowing how dysphagia affects swallowing-related quality of life can help clinicians to understand PD patients' experience of living with dysphagia. Given the paucity of research about swallowing-related quality of life in patients with PD, this study attempted to examine the self-reported swallowing-related quality of life of Chinese PD patients in Hong Kong.

In a previous study [7], significant relationships were found between SWAL-QOL and depression. Yet, no relationship was

found between disease duration and SWAL-QOL. Since age, disease duration, and depression may play a significant role in influencing the score of C-SWAL-QOL, we included these variables when assessing the correlation with C-SWAL-QOL in the Chinese-speaking Hong Kong PD population.

The purpose of the current study was (1) to apply the validated C-SWAL-QOL on Hong Kong PD patients and (2) to investigate factors, including the socio-demographic variables and clinical variables, which were associated with swallowing-related quality of life by using C-SWAL-QOL. The study hypothesized that swallowing-related quality of life would be more severely impacted with increasing age, disease duration, and depression in patients with PD.

## Methods

Participants had no history of neurological disease, other than that related to PD. Due to the nature of this study, there were no restrictions on age, gender, education level, and marital status of the participants. The major inclusion criterion was that participants were all native Cantonese speakers who were residents of Hong Kong. For those who were illiterate, the researcher assistant was present to read aloud the survey questions to the participants, and record the answers provided.

To avoid the possible confounding factor of mechanical causes of dysphagia, other exclusion criteria for subjects included a self-reported pulmonary disease, and history of head and/or neck injury or surgery. Potential participants who were on antitussive medication for colds, coughs, and hay fever allergies were also excluded, as were those with a current upper/lower respiratory tract infection. In the present study, a total of 70 subjects were recruited through online advertisement and a self-help group of PD patients in Hong Kong from January 2017 to December 2017. The recruited subjects ate orally and did not rely on tube-feeding. All participants continued their anti-Parkinsonian medication during the test. Among them, one participant refused to consent while two others were excluded due to the presence of confounding factors. In the end, the C-SWAL-QOL was administered to a total of 67 (40 male and 27 female) subjects with idiopathic PD. Age ranged from 38 to 82 years, with a mean (SD) age of 60.84 (8.30) years. The average disease duration was 9.35 years, ranging from 0.5 to 24 years. Demographic information of participants is shown in Table 1.

Ethics of the present study was approved by the Yonsei University Institutional Review Board (IRB#: 7001988-201708-HR-235-03) and informed consent was obtained from all participants.

## Outcome measures

Two validated survey tools, C-SWAL-QOL and the Chinese version of 15-item Geriatric Depression Scale (GDS-C), were used to evaluate swallowing-related quality of life and depression, respectively. C-SWAL-QOL is a patient-based and disease-specific dysphagia

Table 1. Demographic information and GDS-C scores of the participants in the present study.

	N (n = 67)	Mean	SD	Range
Age (years)	67	60.84	8.30	38–82
Gender				
Male	40 (59.70%)			
Female	27 (40.30%)			
Disease duration (years)	67	9.35	5.72	0.5–24
15-item GDS-C (maximum = 15 points)	67	3.52	3.56	0–14

SD: standard deviation.

tool used to assess the swallowing-related quality of life [16]. C-SWAL-QOL consists of 44-items related to swallowing, two questions about modification of food textures, and one question about patients' overall health. According to the instrument's developers of SWAL-QOL [12–14], the items are grouped into 10 subscales: including burden (two items), eating duration (two items), eating desire (three items), food selection (two items), communication (two items), mental health (five items), social functioning (five items), sleep (two items), and fear (four items). According to previous studies [18,19], seven subscales were regarded as dysphagia-specific scales, while three (communication, sleep, and fatigue) of the subscales were regarded as generic QOL scales. It is worth mentioning that communication subscale is not regarded as dysphagia-specific. Previous studies [18,19] pointed out that the communication subscale focuses on speech and intelligibility, instead of dysphagia per se. Thus, when deriving the total score of SWAL-QOL, the communication subscale was excluded as it was not regarded as dysphagia-specific.

C-SWAL-QOL consists of 10 scales with 30 items and the Dysphagia Symptom Battery (DSB) with 14 items. DSB is an individual battery to assess the severity of dysphagia symptoms [19]. DSB shows a list of dysphagia symptoms that can be divided into three main types of symptoms, including saliva symptoms, oral symptoms, and pharyngeal symptoms, as described by the developers of SWAL-QOL [12–14]. Items such as "having thick saliva or phlegm" and "having excess saliva or phlegm" are regarded as saliva symptoms. Items such as "throat clearing", "coughing," and "food sticking in the throat" are regarded as pharyngeal symptoms. Items such as "drooling", "problems chewing," and "food dribbling" are examples of oral symptoms.

Participants were asked to answer each item based on their experience during the past month. A C-SWAL-QOL composite score and a 14-item DSB score can be calculated respectively. "Composite score" is an average of the 10-subscale scores. By adding up the score of each domain and dividing it by 10, a composite score of C-SWAL-QOL that ranges between 0 and 100 can be derived. The score of DSB is calculated separately since DSB is not considered a scale by the SWAL-QOL developers [12–14]. In previous studies [7,19], DSB was used to index dysphagia status rather than using a physiologic measure of dysphagia.

Possible responses in C-SWAL-QOL are "always" (0 points), "many times" (25 points), "sometimes" (50 points), "seldom" (75 points), and "never" (100 points). The score for each domain is calculated by adding the points of the responses to the questions in the domain and dividing the total by the number of questions in the domain. The score for each domain may vary from 0 (worse) to 100 (best).

The results of SWAL-QOL were linearly transformed from a five-point Likert scale to ratings between 0 and 100 in accordance with the validation by McHorney et al. [12–14]. The Likert scale assumes that each item correlates substantially with the scale it is hypothesized to represent. The least favorable score is 0, and the most favorable score is 100. A decrease of 14 points from the maximum SWAL-QOL total score (100 points) has been suggested as a cut-off [18] so that a SWAL-QOL total score of 86 points or less is considered to indicate presence of clinically relevant swallowing problems.

The 15-item Geriatric Depression Scale [20] is a commonly used self-report assessment for the screening of depression among older adults. It is brief, non-somatically focused, and can be either observer- or self-administered. Scores cover a range of 0–15, with higher scores indicating more severe depression. Although the 15-item Geriatric Depression Scale was originally

developed and validated in the elderly population, preliminary evidence showed that it has high sensitivity and specificity for ages below 65 in individuals with PD [21]. In the present study, participants were asked to complete a validated GDS-C after they filled out C-SWAL-QOL. There was no time limit imposed to complete the questionnaires. Later results were dichotomized into depressed and non-depressed groups using a cutoff of 5, as suggested by previous study [22].

### Statistical analyses

All statistical analyses were performed using SPSS version 24.0 software (IBM-SPSS Inc., Chicago, IL). A significance level (alpha level) was set at 0.05 for all statistical analyses.

A series of non-parametric Spearman's Rho correlation analyses were performed to examine the relationship between the 10-subscale scores in C-SWAL-QOL and (1) age, (2) disease duration, (3) depression, and (4) the 14-item DSB. Following a previous study [19], correlations were regarded as weak if  $|r| < 0.3$ , moderate if  $0.3 \leq |r| < 0.5$ , strong if  $0.5 \leq |r| < 0.7$ , and very strong if  $|r| \geq 0.7$ .

### Results

Table 1 shows the demographic information of the participants, as well as clinical characteristics as depicted by GDS-C, which assessed their possible depressive symptoms. As shown in Table 1, the scores of 15-item GDS-C ranged from 0 to 14, with a mean score of 3.52 (SD = 3.56). Using a cutoff score of 5, 21 (31.34%) subjects in the current study were considered as "depressed" by the 15-item GDS-C.

The mean score of the 10 subscales in the C-SWAL-QOL is presented in Table 2. As shown in Table 2, the 14-item DSB served to assess the severity of dysphagia symptoms. Based on the average of the 10-subscale (30 items) scores, a composite score of 82.26 was derived. Following the method of Rinkel et al. [18], a total score indicated by the average of the seven dysphagia-specific subscales (23 items) was also derived. Relatively low mean scores were observed in scales including sleep (66.42), fatigue (71.40), and eating duration (75.19). A prior study [23] classified scores according to the following standard: mild or no impairment in QOL (71–100), moderate impairment (50–70), and severe impairment (0–49). Following the above standard, results showed a mild to moderate impairment in the swallowing-related quality of life in participants.

Table 2. Mean and standard deviation (SD) of scores in C-SWAL-QOL.

	No. of items	Mean	SD
10 subscales (max = 100 each)			
1. Burden	2	91.42	13.80
2. Eating duration	2	75.19	27.65
3. Eating desire	3	82.84	19.19
4. Food selection	2	82.46	18.98
5. Communication	2	76.87	20.90
6. Fear	4	92.83	10.94
7. Mental health	5	93.36	15.56
8. Social functioning	5	89.85	17.36
9. Sleep	2	66.42	25.49
10. Fatigue	3	71.40	21.68
DSB score <sup>a</sup> (max = 100)	14	86.19	8.47
Composite score <sup>b</sup> (max = 100)	30	82.26	10.21
Total score <sup>c</sup> (max = 100)	23	86.85	10.84

<sup>a</sup>DSB: 14-item Dysphagia Symptom Battery.

<sup>b</sup>Composite score: an average of the 10-subscale scores, excluding the score of DSB.

<sup>c</sup>Total score: an average score of the seven dysphagia-specific subscales, excluding the score of DSB, communication, sleep and fatigue subscales.

**Table 3.** Correlations of C-SWAL-QOL with personal and clinical characteristics ( $n = 67$ ).

SWAL-QOL domain	Age		Disease duration		Severity of depression by 15-item GDS-C	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
1. Burden	-0.262*	0.032	-0.108	0.385	-0.296*	.015
2. Eating duration	0.010	0.933	-0.047	0.709	0.027	.826
3. Eating desire	0.005	0.970	-0.013	0.915	0.001	.993
4. Food selection	-0.057	0.649	-0.027	0.826	-0.182	.141
5. Communication	-0.015	0.906	-0.139	0.260	-0.379**	.002
6. Fear	-0.103	0.408	-0.085	0.493	-0.446**	.000
7. Mental health	-0.093	0.454	-0.050	0.688	-0.347**	.004
8. Social functioning	-0.104	0.401	0.130	0.295	-0.388**	.001
9. Sleep	0.104	0.404	-0.133	0.282	-0.254*	.038
10. Fatigue	0.007	0.956	-0.138	0.265	-0.567**	.000
DSB score <sup>a</sup>	-0.177	0.151	-0.057	0.647	-0.287*	0.019
Composite score <sup>b</sup>	-0.068	0.584	-0.071	0.570	-0.433**	0.000
Total score <sup>c</sup>	-0.077	0.534	-0.039	0.756	-0.248*	0.043

\* $p < 0.05$ .\*\* $p < 0.01$ .<sup>a</sup>DSB: 14-item Dysphagia Symptom Battery.<sup>b</sup>Composite score: an average of the 10-subscale scores, excluding the score of DSB.<sup>c</sup>Total score: an average score of the seven dysphagia-specific subscales, excluding the score of DSB, communication, sleep and fatigue subscales.

Correlations of subscales with age, disease duration, and severity of depression are depicted in Table 3. It can be observed that age had a weak negative correlation with the burden scale. Note that a lower burden score indicates a higher burden to eat. Besides burden scale, age did not show any significant correlation with other subscales. Disease duration failed to correlate significantly with any other subscales. However, correlation analysis revealed a significant correlation between depression and the following scores in C-SWAL-QOL: composite C-SWAL-QOL score ( $\rho = -.433$ ,  $p < 0.0001$ ), total C-SWAL-QOL score ( $\rho = -.248$ ,  $p = 0.043 < 0.05$ ), and DSB score ( $\rho = -.287$ ,  $p = 0.019 < 0.05$ ). As C-SWAL-QOL and 15-item GDS-C are scored on an opposite scale, therefore, the worse the depression (e.g., higher the GDS-C score), the worse the swallowing-related quality of life (e.g., lower the C-SWAL-QOL score). Significant relationships were also observed between depression and seven subscales, including burden ( $\rho = -.296$ ,  $p = 0.015 < 0.05$ ), communication ( $\rho = -.379$ ,  $p = 0.002 < 0.01$ ), fear ( $\rho = -.446$ ,  $p < 0.0001$ ), mental health ( $\rho = -.347$ ,  $p = 0.004 < 0.01$ ), social functioning ( $\rho = -.388$ ,  $p = 0.001 < 0.01$ ), and fatigue ( $\rho = -.567$ ,  $p < 0.0001$ ).

Table 4 shows the mean value of the 14-item symptoms in DSB. When reporting the frequency of symptoms in DSB, possible responses are "almost always" (0 points), "often" (25 points), "sometimes" (50 points), "hardly ever" (75 points), and "never" (100 points). As indicated in Table 4, the symptom with the lowest mean score was "drooling". The second and third lowest mean scores in DSB were "having to clear your throat" and "having excess saliva or phlegm," respectively. The least frequent symptoms reported by participants were "food or liquid coming out your nose" and "gagging".

## Discussion

The present investigation was the first Chinese study to evaluate the swallowing-related quality of life among the Chinese-speaking PD population by using the C-SWAL-QOL questionnaire. The Chinese version of SWAL-QOL was validated based on the Chinese-speaking population in Hong Kong [16]. The rationale to apply C-SWAL-QOL on Hong Kong community-dwelling PD patients is to be consistent with the linguistic and cultural adaptation of C-SWAL-QOL, which was validated in the Hong Kong Chinese-speaking population.

**Table 4.** Mean scores in 14-item Dysphagia Symptom Battery (DSB).

14 dysphagia symptoms (max = 100 points each)		Mean
1.	Coughing	79.48
2.	Choking when you eat food	85.45
3.	Choking when you take liquids	83.21
4.	Having thick saliva or phlegm	79.85
5.	Gagging	96.27
6.	Drooling	72.26
7.	Problems chewing	89.55
8.	Having excess saliva or phlegm	77.99
9.	Having to clear your throat	77.61
10.	Food sticking in your throat	89.93
11.	Food sticking in your mouth	91.42
12.	Food or liquid dribbling out of your mouth	94.78
13.	Food or liquid coming out your nose	98.51
14.	Coughing food or liquid out of your mouth when it gets stuck	89.93

This study found that sleep, fatigue, eating duration and communication were the most severely affected subscales of C-SWAL-QOL incurred by PD. These findings are consistent with the central dopaminergic effects of PD that lead to various non-motor symptoms [24], such as sleep dysfunction and depression. Previous studies [24,25] have pointed out that disturbed sleep is common among PD patients due to various causes, such as rapid eye movement (REM), nocturia, and restless legs syndrome. This echoes with the present findings that our PD participants had the lowest score in the sleep subscale. Decrease in sleep quality might also contribute to fatigue, in which PD subjects scored the second lowest score in the subscales of C-SWAL-QOL. Fatigue is not only a frequent complaint of PD patients, but also an important contributor to the reduced quality of life. These non-motor symptoms collectively cause the deterioration of swallowing-related quality of life. In addition, prolonged mealtime in PD patients is likely to be a result of their motor symptoms [24], such as rigidity, postural instability, and bradykinesia. In fact, taking more time to eat or drink can be a compensation for PD patients with mild dysphagia [26]. PD participants also showed a low score in the communication subscale, which is likely related to hypokinetic dysarthria, a speech disorder resulting in reduced speech intelligibility, that is often associated with PD [27]. Increased speech rate and other prosodic abnormalities [28] tend to limit the communication ability of PD patients.

SWAL-QOL has been administered to PD participants in different cultural settings [7,29,30]. Plowman-Prine et al. [7] administered SWAL-QOL to 36 PD subjects from the USA. It was reported

that the four most severely affected subscales in SWAL-QOL incurred by overall PD participants were sleep, fatigue, communication, and eating duration. Compared to these findings, the current study showed higher mean scores in all 10 subscales of SWAL-QOL overall. The current study results showed higher mean scores of swallowing-related quality of life in eight subscales, except for food selection and sleep subscales, compared to the results reported by Carneiro et al. [29] who investigated 62 PD subjects in Brazil. The fact that all subjects in the current study ate orally and did not rely on tube-feeding may have contributed to the generally higher C-SWAL-QOL scores found. In the study by Plowman-Prine et al. [7], a quarter of the PD participants included in the sample were reported to be on a restricted diet such as mechanical soft diet, puree diet or using thickened liquids. This might explain the higher C-SWAL-QOL score in this study than that of other cultural studies.

In the study, C-SWAL-QOL score was not significantly correlated with age and disease duration. In line with the current results, Plowman-Prine et al. [7] also reported no relationship between SWAL-QOL and PD duration. These findings suggest that clinicians need to be aware when assessing swallowing-related quality of life in PD through all ages and not specifically on those that are elderly or with longer duration of disease. Most of the patients in the current study were elderly and later-onset PD, only a very few patients were young and early-onset PD patients. Since the number of young and early-onset PD were not sufficient for a comparison with the later-onset PD, we did not perform a comparison here. Further prospective studies could investigate if there are any significant differences between the early-onset PD patients and the later-onset PD patients.

Previous research [18] has suggested a clinical cut-off score of a decrease of 14 points from the SWAL-QOL total score (100 points) to identify individuals with relevant swallowing dysfunction. Based on this cut-off score, 41.79% of PD participants in this study showed a total score below 86, which was a cut-off for clinically significant dysphagia. Using this cut-off score, the results of this study may indicate the use of C-SWAL-QOL as a screener to identify PD patients who may require further swallowing assessment.

A previous study [26] pointed out that participants with PD tended to underreport their swallowing difficulties in questions related to their swallowing function. In our conversation with the participants, most elderly PD patients tended to believe their swallowing problems and symptoms were due to aging, without realizing the fact that their swallowing problems could be a result of PD. Some of the older PD patients might also fail to recognize their swallowing problems may be related to deteriorating cognitive function. The underreporting or lack of awareness of swallowing changes could affect the results of a patient-rated questionnaire such as SWAL-QOL. This underestimation of dysphagic symptom highlights the need for a more proactive approach in educating PD patients and the use of instrumental assessment, such as VFSS and FEES. In addition to a patient-rated questionnaire, clinician-rated measurements should also be used to identify dysphagia in PD patients.

As for the dysphagia symptoms reported in the DSB, several patient-reported symptoms were highly prevalent among the PD participants, such as drooling, coughing and having excess saliva or phlegm. In this study, participants scored the lowest mean value for drooling (mean = 72.76), suggesting that drooling is the most frequent dysphagic symptom in PD. Drooling, known as "sialorrhoea", refers to the inability to control oral secretions, leading to excessive saliva in the oropharynx [6]. Studies [31,32]

reported that over 70% of PD patients suffer from drooling or wetting of pillow during sleeping. Chou et al. [6] pointed out that drooling in PD is more likely to be caused by flexed head posture and infrequent or impaired swallowing. Having excessive saliva or phlegm in the mouth may become a source of aspiration, leading to choking and pneumonia [6]. The present findings emphasize the need for clinicians to work closely in the treatment of drooling in PD patients, in order to prevent aspiration pneumonia.

A relatively low score was also observed for another dysphagic symptom: coughing (mean = 79.48). Biologically, coughing protects the airway from the entrance of foreign material into the airway [33]. Previous research has pointed out that cough may be an indicator of swallowing dysfunction [34]. Since cough may indicate a risk for penetration or aspiration [34], it is important for clinicians in neurology, otolaryngology and speech-language pathology to monitor any signs of change of cough pattern among PD patients.

Consistent with results reported by other studies [7,35], a significant correlation was found between depression and swallowing. In the present study, the worse the depression was (higher GDS-C score), the lower the swallowing-related quality of life and C-SWAL-QOL score, especially in the subscales of communication, fear, mental health, social functioning, and fatigue. Interestingly, other researchers have also observed a link between dysphagia and depression in PD. Plowman-Prine et al. [7] reported a significant relationship between the score of SWAL-QOL and the Beck Depression Inventory (BDI). These exploratory findings highlighted the psychosocial sequelae of dysphagia in PD patients and suggested a possible relationship between depression and swallowing. Yet, one should note that the correlation between the two does not imply causation and conclusions about that cannot be drawn. These current findings call attention to the need for clinicians such as speech-language pathologists, to work jointly with mental health clinicians on intervention for PD patients with swallowing disorder. Further studies concerning the psychosocial impact of swallowing disorder in PD deserve attention to better guide PD intervention.

### Limitations and future direction

The major limitation of this study is its relatively small and specific sample size of PD participants, as only a very specific population of Hong Kong community-dwelling PD subjects were included in the present study. The results derived from this study should be interpreted with caution due to the possibly low statistical power and narrow population. Second, none of our PD participants relied on tube-feeding, implying that they were relatively healthy. It would be interesting to investigate the swallowing-related quality of life, using the C-SWAL-QOL, of those Chinese PD patients who were reliant on tube feeding to maintain nutrition. Also, our participants were all living in the community and did not include any hospitalized PD patients. The prevalence of dysphagia would possibly be higher if institutionalized and hospitalized subjects were included. Third, since the current study is cross-sectional, we could not measure the responsiveness of the C-SWAL-QOL to change with stage of disease over time. Lastly, participants in the current study were not asked if they had undergone treatment for swallowing disorders.

In the future, studies involving more representative and larger sample size of PD patients of different severities are recommended. Further studies using the Hoehn and Yahr staging or Unified Parkinson's Disease Rating Scale (UPDRS) to compare the

responsiveness of C-SWAL-QOL in Chinese PD patients at different disease stages are also recommended.

## Conclusions

The current study is the first to apply C-SWAL-QOL on Chinese PD patients. The findings of this study can help clinicians to identify the area which is most impacted in the swallowing-related quality of life in PD, as rated by the patients. The goal of dysphagia intervention is to improve swallowing safety and efficiency and ultimately to enhance patients' QOL, clinicians should consider the use of C-SWAL-QOL in clinical practice to help measure outcomes related to QOL for PD patients.

## 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. (IRB#: 7001988-201708-HR-235-03, Seoul, Korea). *Informed consent* was obtained from all individual participants included in the study.

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