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Comparison of Patient-Reported and Caregiver-Reported Swallowing-Related Quality-of-Life in Parkinson's Disease

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ABSTRACT

Objectives: This pilot study explored agreement on swallowing-related quality-of-life scores reported by individuals with Parkinson's disease (PD) and their caregivers.

Methods: Thirty-six patient-caregiver pairs completed the Swallowing Quality of Life Questionnaire (SWAL-QOL) using an online survey format. Additional background and clinical information was ascertained. A Wilcoxon Signed-Rank test was completed to compare the means of scores between individuals with PD and caregivers. Factors potentially influencing SWAL-QOL scores (age, employment status, sex, ethnicity, race, previous history of swallowing evaluation or treatment, caregiver concern about patient cognition, caregiver burden, and time since onset of disease) were explored using Spearman Coefficient Correlation tests. The Holm-Bonferroni method was used to adjust for multiple comparisons.

Results: Results did not reveal significant differences in SWAL-QOL scores between individuals with PD and caregiver pairs. There was a moderate degree of reliability and agreement between paired patient and caregiver scores, with the average ICC measures being .598 (95% CI [358,.748]) ($F(71, 72)=2.451, p<.0001$). After adjusting for multiple comparisons, caregiver burden was found to be the only significant factor associated with caregivers' reported scores. No significant influential factor on reported scores by individuals with PD was found.

Conclusions: These pilot results suggest individuals with PD and their caregivers may report similar swallowing-related quality-of-life scores. Further, caregiver burden appears to be an influential factor for caregiver reported scores. Future studies should investigate the clinical benefits of including caregiver SWAL-QOL ratings in assessments, either as a supplement to patient scores to identify discrepancies across the dyad or in place of patient scores if needed.

Further, caregiver burden and its influence on dysphagia identification and management should be explored, with targeted interventions to manage caregiver burden.

Keywords: Parkinson's Disease; quality-of-life; Swallowing Quality of Life Questionnaire; dysphagia

Introduction

Nearly one million individuals in the United States and more than 10 million individuals worldwide are currently living with Parkinson's disease (PD) [1]. PD is a neurodegenerative disease caused by the loss of dopamine-producing neurons within the basal ganglia, leading to impairments in movement, muscle control, and balance [2]. An often under-recognized but highly prevalent impairment is dysphagia, with an estimated prevalence of more than 80% of individuals experiencing dysphagia during the course of their disease [3]. Individuals with PD may present with deficits across the swallowing continuum due to both muscular incoordination/weakness and sensory dysfunction. The most widely reported swallowing deficit in PD is lingual pumping, with other deficits including delayed initiation of the pharyngeal swallow, poor lip seal and oral containment, pharyngeal residue, and airway invasion [4]. Such impairments raise a serious concern since aspiration pneumonia is the leading cause of death in individuals with PD [5].

A diagnosis of PD often impacts swallowing-related quality-of-life. For example, Carneiro et al. [6] observed individuals with PD reported significantly lower Swallowing Quality of Life Questionnaire (SWAL-QOL) scores relative to an age-matched control group. Factors known to influence reported swallowing-related quality-of-life have also been previously reported, including age, cognitive function, presence of aspiration, and history of dysphagia [7-11] However, studies are incongruous in the PD literature on the relationship between PD severity/disability and its impact on swallowing-related quality of life [12-14]. A positive influence on swallowing-related quality-of-life previously reported is prior dysphagia treatment, likely due to improvement in swallowing function [10].

Despite the high prevalence of dysphagia and its related implications on health and quality-of-life in PD, Umemoto and Furuya [14] reported a poor association between individuals with PD's self-reported swallowing ability and observed impairments, which may be related to miscalibration between perceived and actual function. Previous research supports a miscalibration and misperception of loudness of speech in individuals with PD that results in hypophonia (i.e., low volume) without awareness by the patient [15]. If individuals with PD suffer from sensory and perception deficits, they may be unaware of swallowing difficulty and/or they may overestimate their swallowing ability when asked to report on swallowing function and its impact on quality-of-life. Delayed management of dysphagia in individuals with PD may be of consequence. Hiseman and Fackrell [16] suggested that when symptoms of apathy, depression, and cognitive impairment are present in individuals with PD, caregivers may be in a better position to appraise symptoms and its effects of treatment. There is the potential then to suggest that caregivers may be an appropriate proxy for reporting dysphagia-related symptoms and quality-of-life on behalf of the individual with PD and warrants further investigation.

Previous studies have investigated the use of proxy for measures related to quality-of-life. For example, Oszkowski and O'Donnell observed "moderate to substantial" reliability for caregiver response related to impact of daily tasks on quality-of-life for patients post-stroke [17]. Balash and colleagues [18] reported that caregivers perceived greater embarrassment and shame compared to what patients with PD reported, although there were no significant differences in total scores on general quality-of-life measures validated in PD. However, proxies may be more reliable reporters for more observable symptoms experienced, such as pain, and less reliable for more subjective symptoms [18].

Caregiver report of problems are increasingly beneficial if impaired insight is present in the patient. As aforementioned, since patients with PD may not only have sensory deficits but also impaired cognitive function, a discrepancy may exist for reported swallowing-related quality-of-life between the individual with PD and the caregiver. The SWAL-QOL's administration guidelines state it can be completed by a proxy, such as a caregiver [19], although to date, no research has specifically compared SWAL-QOL scores reported by the individual with PD and the caregiver. Therefore, the primary purpose of this pilot study was to compare patient experience and caregiver's perception of swallowing-related quality-of-life in Parkinson's disease (PD). Additionally, potential factors which may be associated with reported scores were also explored. Based on previous reports of sensory and perceptual deficits frequently observed in individuals with PD [15, 17], it was hypothesized caregivers of patients with PD would report lower SWAL-QOL scores, suggesting greater swallowing detriment compared to patient-reported scores. Further, based on outcomes reported in previous studies [7-10], we expected that age, cognitive function, and history of dysphagia treatment would be significant influential factors on reported SWAL-QOL scores. Lower age, intact cognition, and history of dysphagia treatment have been previously reported to positively impact swallowing-related quality-of-life [8-10].

Methods

Prior to participation in study procedures, all study participants provided informed consent. This study received approval by the Institutional Review Board (IRB) at the University of South Alabama.

Study Participants

Participants included both individuals who had been diagnosed with PD and their identified primary caregivers. Participants were included in the project if they met one of the following criteria: 1) diagnosis of PD; or 2) were the primary caregiver of someone who had been diagnosed with PD. Individuals with PD were excluded if they had a diagnosis of a cognitive impairment/dementia since deficits in executive function and attention can influence safe and efficient feeding/swallowing [7]. Further, a patient with PD was excluded if they had an additional diagnosis of another neurologic disease/condition, such as myasthenia gravis or stroke. Lastly, caregivers were excluded if they had been diagnosed with a neurological disease/condition. Since this was a pilot study and we wanted to capture the full range of potential scores, swallow function or current oral intake status was not included as part of the eligibility criteria. Members of approximately 25 PD support groups and Rock Steady Boxing groups from across the United States of America were contacted via email and social media and invited to participate. The online survey was available for approximately three months (July 2019 until October 2019).

Questionnaires

All eligible participants were asked to complete background, demographic, and SWAL-QOL questionnaires online using Google Forms. Participants were instructed to identify themselves as either the patient or the caregiver and were then directed to complete either the caregiver or participant survey. Specific instructions for the individual with PD and caregiver to independently complete the survey were also provided. Participant-caregiver pairs were matched according to the first two letters of the patient's last name followed by the first two letters of the patient's first name reported.

Each survey collected general demographic and clinical information. The demographic and background clinical questions aimed to assess potential influential factors on swallowing-related quality-of-life, including time since onset of the disease, previous history of swallowing evaluation or treatment, caregiver burden, caregiver's concern about patient level of cognition, and caregiver level of care. For participants who identified themselves as the primary caregiver, questions were designed to identify the level of support given and burden felt by each caregiver in order to better define the caregiver-patient relationship (e.g., Do you live with the patient? What level of care do you provide for the patient related to eating meals? Do you find caregiving burdensome (and if so, in what way(s)?) What is your relationship to the patient?). Each participant was then requested to complete the SWAL-QOL.

The SWAL-QOL was selected to measure swallowing-related quality-of-life due to its previous use in the PD literature and its comprehensive intake across multiple domains. Each item on the SWAL-QOL was scored on a scale of 1 to 5, with 1 indicating strongly agree and 5 indicating strongly disagree. Each item was equally weighed and summed into an overall score. All scales were linearly transformed to a 0-100 metric using a rubric, and only 10 of the 11 domains were totaled (physical scale omitted) [20]. Psychometric properties of the SWAL-QOL are published and available online [20]. Caregivers were instructed to answer SWAL-QOL questions from the perspective of the individual with PD. Digital ascertainment of the SWAL-QOL responses have been previously encouraged [21].

Data Analysis

Of the 123 total individual online responses submitted, 50 responses were excluded due to lack of partner response or an inability to match patient-caregiver responses and 1 was excluded due to self-reported cognitive impairment (Figure 1). No paper forms were completed.

Thus, a total of 36 patient-caregiver pairs were available for analysis. All analyses were performed with *Statistical Package for Social Sciences*® (SPSS), v.24 [22]. Descriptive measures, including means, standard deviations, medians, and ranges were reported for both individuals with PD and caregivers. A Wilcoxon Signed-Rank test was completed to compare the means of scores between individuals with PD and their caregivers and to compare the means of scores between respondents included in the study and respondents who were excluded. Further, an intraclass correlation coefficient was run to determine reliability and agreement between patient and caregiver scores. Factors potentially influencing scores (age, employment status, sex, ethnicity and race, previous history of swallowing evaluation or treatment, caregiver concern about patient cognition, caregiver burden, and time since onset of disease) were explored using Spearman Coefficient Correlation tests. The Holm-Bonferroni method was used to adjust for multiple comparisons.

Results

Participant Characteristics

The majority of individuals with PD were Caucasian, Non-Hispanic males who were retired and living at home. The majority of individuals with PD (70%) denied assessment of swallowing function, although over half of respondents reported assessment for cognitive-communication function. Complete participant demographic information is provided in Table 1. Information collected pertaining to previous SLP services and oral intake is provided in Table 2. The majority of caregivers were Caucasian, Non-Hispanic females that were retired. Most caregivers (89%) were spouses and lived with the patient. The most common challenge reported by the caregiver was related to emotional burden; twelve caregivers reported an emotional

burden. Table 3 details the caregiver's relationship to the individual with PD and their reported level and burden of care.

SWAL-QOL Scores

The mean (standard deviation) SWAL-QOL score, excluding the physical scale, reported by individuals with PD and caregivers were 78.47 (± 15.5) and 78.53 (± 13.9), respectively.

Further descriptive statistics are provided in Table 4. Table 5 provides mean scores across each domain. Patient-caregiver paired scores for the majority of subtests (63.6%; 7/11) were within 3 points of one another. The fatigue subtest revealed the biggest difference in patient-caregiver scores (mean difference of 5.32). The subtest with the smallest difference in patient-caregiver scores were food selection and mental health (mean differences of .35 and .14, respectively).

In terms of SWAL-QOL total score, no consistent pattern was identified in terms of the individuals with PD or caregivers reporting higher scores. Approximately 40% of paired responses had the individuals with PD reporting higher quality of life, while over 50% of caregivers reported higher scores. Further, approximately 10% of the patient-caregiver pairs were within 1-point. Caregivers reported higher scores (higher quality of life) (mean rank = 19.83) than individuals with PD (mean rank = 17.00), although this was not significant ($Z = -0.691$, $p = 0.498$). Caregivers also reported higher physical scores (mean rank = 18.69) than individuals with PD (mean rank = 18.23), but again, this did not reach statistical significance ($Z = -0.935$, $p = 0.350$). There was a moderate degree of reliability and agreement between patient and caregiver scores, with the average ICC measures being .598 (95% CI [358,.748]) ($F(71, 72) = 2.451$, $p < .0001$).

Post-Hoc Analysis

Since approximately 40% of total respondents did not have a matched pair, descriptive statistics and Wilcoxon Sign Ranks test were performed to determine if differences existed between respondents included in study analyses and respondents who were excluded. The mean (standard deviation) SWAL-QOL score, excluding the physical scale, reported by individuals with PD included and individuals with PD excluded was 78.47 (± 15.5) and 73.43 (± 16.92), respectively ($Z = -0.991, p = 0.322$) (Table 6). The mean (standard deviation) SWAL-QOL score, excluding the physical scale, reported by caregivers included and caregivers excluded was 78.53 (± 13.9) and 69.71 (± 18.81), respectively ($Z = -1.328, p = 0.184$) (Table 7). No statistically significant differences were observed for reported swallowing-related quality-of-life between patient and caregiver respondents included and excluded in the current study.

Influencing Factors

Patient Scores. Eight variables were tested to assess association with SWAL-QOL scores (Table 7). These included age, employment status, sex, ethnicity and race, previous history of swallowing evaluation or treatment, caregiver concern about patient cognition, and time since the onset of disease. When adjusting for multiple comparisons, all factors failed to reach statistical significance.

Caregiver Scores. Nine variables were tested to assess influence on SWAL-QOL scores (Table 9). These included age, employment status, sex, ethnicity and race, previous history of swallowing evaluation or treatment, caregiver concern about patient cognition, time since the onset of disease, and caregiver burden. Researchers were unable to determine if a relationship existed between SWAL-QOL scores and patient/caregiver relationship status since the majority of pairs (89%) were spousal. After adjusting for multiple comparisons, only caregiver burden

remained statistically significant ($p = .001$), with emotional burden being the most frequent burden reported by caregivers. When caregiver burden was reported, the caregiver reported lower SWAL-QOL scores.

Discussion

The primary purpose of this pilot study was to compare caregiver perception and patient experience of swallowing-related quality-of-life in Parkinson's disease (PD). Additionally, potential factors that may be associated with the reported scores of both individuals with PD and caregivers were explored. Results did not reveal significant differences in SWAL-QOL scores between patient and caregiver pairs, and there was moderate agreement in their total scores. After adjusting for multiple comparisons, caregiver burden was found to be the only significant influential factors on caregiver scores; no factor was found to be statistically significant for influencing on patient score.

Comparison of Patient and Caregiver Scores

Balash and colleagues [18] explored agreements on general quality-of-life between individuals with PD and caregivers, reporting similar results with no significant differences observed. The original hypothesis in the present study stated caregivers would report lower SWAL-QOL scores, associated with lower swallowing-related quality of life, based on the assumption that the individuals with PD would have a discrepancy between their perceived and actual swallowing function. Researchers in the current study, rather, found caregivers and patients reported similar swallowing-related quality-of-life, and that previous dysphagia evaluation or treatment did not statistically impact SWAL-QOL scores. With this being said, there are potential clinical benefits of knowing the responses of caregivers and individuals with PD are similar. The lack of difference in SWAL-QOL scores between pairs could suggest

support for the use of proxy SWAL-QOL scores in PD when an individual with PD is unable to respond and/or as a supplement to patient-reported scores as caregivers may accurately report similar swallowing-related quality-of-life scores for their loved one. However, this would need to be investigated further. Additionally, potential discrepancies in scores between the caregiver and the individual with PD could suggest an increased risk for caregiver burden, as it was found that caregiver burden is the only statistically significant factor associated with SWAL-QOL scores.

Factors Affecting Swallowing-Related Quality-of-Life

Balash et al. [18] suggested influential variables, such as caregiver burden, patient's level of cognition, and the type of relationship between caregiver-patient pairs, may influence general quality-of-life. In this current study, we explored if such potential factors affect swallowing-related quality-of-life scores in PD. Concern about cognitive function, history of prior swallowing evaluation or treatment, and time since onset of disease did not reach statistical significance when adjusting for multiple comparisons. Our results might have differed from Balash et al. due to both an inability to determine the effect of patient/caregiver relationship status (the majority of our pairs were spousal) and due to respondent bias, such as faulty recall or demand bias.

Caregiver burden and level of care provided. Caregiver burden was observed to be a statistically significant factor associated with caregiver SWAL-QOL score, even after adjusting for multiple comparisons. The current study found that caregiver burden was highly associated with lower SWAL-QOL scores by caregivers. Caregivers of individuals with PD have reported emotional stress, frustration, worry, economic burden, role conflict, and feelings of being manipulated [23]. Caregiver burden in PD is exacerbated when the patient experiences depression, anxiety, sleep disorders, cognitive decline, and apathy [24]. One can extrapolate that,

similar to apathy, unawareness of deficits by the individual with PD may also likely exacerbate caregiver burden, as apathy does, given that caregivers are more likely to be responsible for identifying changes in function and employing care plans to treat impairments. Dysphagia may also contribute to caregiver burden, which can further exacerbate psychosocial consequences of increasing burden and further impacting the patient-caregiver relationship. According to Shune and Namasivayam-MacDonald [25], caregivers of individuals with dysphagia were significantly more likely to experience psychological and emotional burdens of caregiving. Dysphagia in elderly adults leads to caregiver fears of choking, nutritional concerns, grieving over the prospect of changing feeding-behaviors or feeding tubes, and anxiety over the responsibility of caretaking [26-27]. Thus, increased caregiver burden might be associated with decreased perceived quality-of-life by the caregiver. Relatedly, given the relationship between patient and caregiver SWAL-QOL scores, poorer patient swallow-related functioning (as suggested by a lower SWAL-QOL score) may also contribute to increased caregiver burden.

According to the Theory of Dyadic Illness Management, the health of both members of the dyad are interdependent and dyadic health is reliant on the chronic illness being appraised and managed in a balanced manner across dyad (i.e., patient and caregiver) [28]. This theory not only supports the necessity of examining both patient and caregiver perceptions of the illness, or dysphagia, but encourages to also explore *how* the dyad is managing the condition together, supporting the use of both patient and caregiver SWAL-QOL ratings. The results from this present study indicated that lower caregiver SWAL-QOL scores were reported for caregivers experiencing general burden. According to the Theory of Dyadic Illness Management, the health of the patient relies on the health of the caregiver; they should be in balance for maximal dyadic health. When caregivers have worse mental quality-of-life and caregiver burden, they may have

a more difficult time identifying and treating patient symptoms [28]. Caregivers with higher levels of caregiver burden may have more difficulty accurately identifying symptoms in individuals with PD than caregivers who do not experience high levels of burden. The caregivers in the present study who reported higher caregiver burden and level of care may be experiencing poorer dyadic illness management and poorer symptoms identification, resulting in lower reported SWAL-QOL scores on behalf of the individual with PD. It would be beneficial for future work to specifically target those dyads that did demonstrate incongruence in SWAL-QOL scores in order to further explore their levels of caregiver burden and illness management skills.

Limitations

Several limitations should be considered when interpreting current study findings. First, participants were contacted via email and asked to complete the online survey, with email distribution primarily through PD support groups. Although 123 participants responded to the survey, only 72 (36 patient-caregiver pairs) were included in the study. Therefore, 51 participants were excluded due to lack of partner response or due to an inability to match patient-caregiver responses. However, when comparing included and excluded respondents, no significant differences in SWAL-QOL scores were observed. Additionally, there was no way to ascertain how many partially completed/abandoned the survey. Data related to which support group disseminated the email or which geographic region from which patient-caregiver pairs responded was also not ascertained. Further, because this used a survey approach, the influence of response bias should also be considered which may result in an over- or under-estimate of true population parameters. For example, volunteer participants were recruited specifically from PD groups and would have had computer/internet access to complete the survey. It is, therefore, not known whether those who chose not to participate in this study are inherently differently from those

who did. Lastly, cognitive and swallow function were not formally screened or assessed. We relied on patient and/or caregiver report of cognitive impairment as part of our exclusionary criteria and collected information on diet restrictiveness and SWAL-QOL as the only measures of swallowing function.

To address aforementioned limitations, future studies could use in-person specialized PD clinics, where both individuals with PD and their caregivers are present and formal cognitive screening measures can take place. Instrumental assessment of swallowing function can then be performed to determine relationships with reported swallowing difficulty and objective measures of oropharyngeal swallowing physiology. Fifty-one participants were excluded from analysis due to inability to match patient-caregiver responses. Therefore, providing compensation for participation may motivate participants to participate to increase sample size. Lastly, additional quality-of-life measures could also be employed as well as examination of other potential influential factors on reported scores. Despite such limitations, these findings and preliminary information contribute meaningful and preliminary information to existing literature regarding patient experience and caregiver perception of swallowing-related quality-of-life in PD.

Conclusions

This pilot study provides information regarding patient-caregiver agreement about swallowing-related quality-of-life (SWAL-QOL scores) in individuals with PD. Although no previous studies have explored patient-caregiver agreement regarding swallowing-related quality-of-life, previous studies have investigated general quality-of-life agreements between patient-caregiver pairs. The current study findings failed to observe a statistically significant difference in SWAL-QOL scores between patient-caregiver pairs. Caregivers, who are in direct

contact with the patient frequently, may provide valuable information related to swallowing and swallowing-related quality-of-life to health care professionals. This can be either in addition to patient report or if there are concerns related to validity of patient report, such as poor insight or awareness is of concern. The lack of difference in SWAL-QOL scores suggest the need for further investigation regarding the use of proxy SWAL-QOL scores in PD. Also of clinical importance, caregiver burden was found to be a statistically significant influential factor on caregiver ratings of swallowing-related quality-of-life. Caregiver burden may contribute to poorer dyadic management and/or illness appraisal resulting in lower SWAL-QOL scores on behalf of the caregiver in this current study; caregivers with low burden are likely better equipped to identify and manage patient's needs. There exists a need, then, to appropriately identify and manage caregiver burden, as it is also important to identify and manage dysphagia in PD. Future investigations should incorporate larger sample sizes and diversify their patient-caregiver profile, as our sample consisted of homogenous participants (e.g., majority of individuals with PD were Caucasian males over the age of 60 and the majority of patient-caregiver pairs were spousal). Such findings will further contribute to the literature regarding differences in how individuals with PD and their caregivers report swallowing-related quality-of-life and how to best support these patients and caregivers.

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Figures

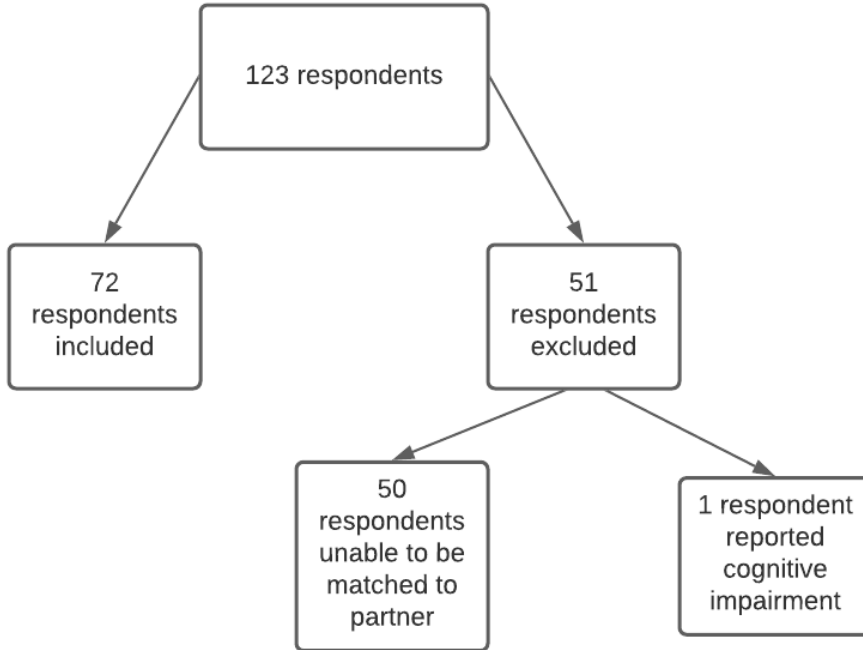


Figure 1 Flow diagram of inclusion/exclusion criteria

Table 1.

Participant demographics. Data reported as frequency (percentage).

<i>Variable</i>		<i>Individual with PD (N=36)</i>	<i>Caregiver (N=36)</i>
Age	Mean \pm SD	70.8 \pm 7.3	65.9 \pm 7.7
Sex	Females	12 (33.3)	27 (75.0)
	Males	24 (66.7)	9 (25.0)
Race	White/Caucasian	34 (94.4)	33 (91.7)
	African American	0 (0)	1 (2.8)
	Mixed/Other	2 (5.6)	2 (5.6)
Ethnicity	Hispanic/Latino	0	0
	Non-Hispanic/Latino	22 (61.1)	25 (69.4)
	Other	3 (8.3)	2 (5.6)
	Did not report	11 (30.6)	9 (25.0)

Education	Less than high school	0	0
	High school degree	3 (8.3)	2 (5.6)
	Some college	6 (16.7)	8 (22.2)
	Associate degree	4 (11.1)	2 (5.6)
	Bachelor's degree	6 (16.7)	13 (36.1)
	Master's degree	6 (16.7)	2 (5.6)
	Doctorate	3 (8.3)	2 (5.6)
	Did not report	8 (22.2)	8 (22.2)
Employment	Employed	1 (2.8)	11 (30.6)
	Homemaker	1 (2.8)	1 (2.8)
	Unable to work	3 (8.3)	0
	Retired	31 (86.1)	24 (66.7)
Residence	Home	34 (94.4)	-
	Independent Living	1 (2.8)	-
	Assisted Living	0 (0)	-
	Living w/ family	1 (2.8)	-
Do you live with the individual with PD?	Yes	-	35 (97.2)
	No	-	1 (2.8)

Table 2.

Individuals with PD demographics related to speech and swallowing. Data reported as frequency (percentage).

<i>Variable</i>	<i>Total (N=36)</i>
Has your swallowing been evaluated by an SLP?	No 25 (69.4)
	Yes 9 (25.0)
	I don't know 2 (5.6)
Have you received swallowing therapy by an SLP?	No 29 (80.6)
	Yes 7 (19.4)
Has your speech, language, or cognition been evaluated by an SLP?	No 19 (52.8)
	Yes 16 (44.4)
	I don't know 2 (5.6)
Have you received speech, language, or cognition therapy by an SLP?	No 19 (52.8)
	Yes 14 (38.9)
	I don't know 3 (8.3)
Do you use a feeding tube for nourishment?	No 36 (100.0)
	Yes 0 (0)
What consistency or texture of food have you been eating most often within the last week?	Eating a full normal diet 22 (61.1)
	Eating soft, easy to chew foods 5 (13.9)
	Eating food that is blended/ pureed 0 (0)
	Do not eat solids 1 (2.8)

	No answer	8 (22.2)
What consistency of liquids have you been drinking most often within the last week?	Thin liquids	33 (91.7)
	Naturally thick liquids (tomato juice)	0 (0)
	Moderately thick liquids (milkshakes, smoothies)	3 (8.3)
	Very thick liquids (pudding)	0 (0)
	No liquids by mouth	0 (0)

Table 3

Caregiver relationship and level and burden of care. Data reported as frequency (percentage).

Variable		Total (N=36)
What is your relationship to the patient?	Spouse	32 (88.9)
	Child	3 (8.3)
	Friend	1 (2.8)
What level of care do you provide related to meals?	I do not provide assistance.	7 (19.4)
	I prepare meals but the patient self-feeds.	11 (30.6)
	I prepare meals, set up plate but the patient self feeds.	8 (22.2)
	I prepare the meals, set up the plate, and feed the patient.	1 (2.8)
	Did not report	8 (22.2)
Do you find caregiving challenging?	Physically challenging	2 (5.6)
	Emotionally challenging	12 (33.3)
	Financially challenging	0 (0)
	Physically and emotionally challenging	5 (13.9)
	Physically, emotionally, and financially challenging	3 (8.3)
	No burden	6 (16.7)
Do you have concerns about the patient's cognitive function?	Did not report	8 (22.2)
	Yes	14 (38.8)
	No	14 (38.9)

Table 4.

SWAL-QOL scores for individuals with PD and caregivers.

<i>Variables</i>	<i>PD (N=36)</i>	<i>Caregivers (N = 36)</i>
Mean ± SD	78.5 ± 15.5	78.5 ± 13.9
Range	50 – 98	39 – 99
Median	83.5	80.4
95% CI	73.4, 83.5	73.9, 83.0

Table 5.

Mean ± SD and range of scores across SWAL-QOL domains by patients and caregivers.

<i>Domain</i>	<i>Mean ± SD patient score (N=36)</i>	<i>Mean ± SD caregiver score (N = 36)</i>	<i>Range of patient score (N=36)</i>	<i>Range of caregiver score (N=36)</i>
Burden	78.8 ± 23.2	81.9 ± 20.4	25 – 100	25 – 100
Eating Desire	90.7 ± 12.9	93.1 ± 18.4	58.3 – 100	25 – 100
Eating Duration	66.3 ± 31.3	67.9 ± 33.9	0 – 100	0 – 100
Physical Scale	73.5 ± 19.9	78.0 ± 18.4	32.1 – 98.2	37.5 – 100
Food Selection	87.2 ± 19.8	87.5 ± 22.4	25 – 100	12.5 – 100
Communication	70.5 ± 30.5	69.4 ± 29.5	0 – 100	0 – 100
Fear	82.1 ± 22.1	85.9 ± 21.1	18.8 – 100	0 – 100
Mental Health	84.4 ± 23.8	84.3 ± 22.8	5 – 100	20 – 100
Social	92.4 ± 16.1	93.9 ± 16.5	30 – 100	20 – 100
Fatigue	61.6 ± 24.8	56.2 ± 24.8	16.7 – 100	0 – 100
Sleep	69.1 ± 28.6	65.6 ± 27.8	12.5 – 100	0 – 100

Table 6.

Comparison of respondents included and respondents excluded.

<i>Variables</i>	<i>Patients (N=36)</i>	<i>Patients excluded (N = 33)</i>	<i>Caregivers (N = 36)</i>	<i>Caregivers excluded (N = 18)</i>
Mean ± SD	78.5 ± 15.5	73.4 ± 16.9	78.5 ± 13.9	69.7 ± 18.8
Range	50 – 98	36.4 – 97.1	39.0 – 99.0	38.4 – 95.0

Table 7.

Factors associated with PD SWAL-QOL score.

<i>Influencing Factor</i>	<i>p-value</i>	<i>Correlation Coefficient</i>
Time since onset of disease	.020	-.387
Prior swallow therapy or evaluation	.034	.355
Concern about cognition	.045	-.337
Prior speech therapy or evaluation	.176	.230
Sex	.663	.075
Education	.716	-.063
Employment	.860	-.030
Age	.920	.017

Note: p-values reported are after adjustment for multiple comparisons

Table 8.

Factors associated with caregiver SWAL-QOL scores.

<i>Influencing Factor</i>	<i>p-value</i>	<i>Correlation Coefficient</i>
Caregiver burden	.001*	-.527
Level of care provided	.016	-.398
Concern about cognition	.017	-.397
Employment	.085	-.291
Sex	.112	-.269
Education	.125	-.261
Time since onset	.125	-.261
Age	.258	.194

Note: p-values reported are after adjustment for multiple comparisons

Appendix

Appendix 1: Online Survey Sent to Participants

Appendix I: Online Survey Sent to Participants

1. Are you the patient of caregiver?
 - a. Patient (skip to question 2)
 - b. Caregiver (skip to question 19)

Patient Questionnaire

2. Please enter the following lab code: first 2 letters of patient's last name, first 2 letters of patient's first name (e.g. John Smith = SMJO).
3. How old are you?
4. What is your gender?
 - a. Female
 - b. Male
 - c. Prefer not to say
 - d. Other
5. What is your race?
 - a. African American or Black
 - b. American Indian or Alaskan Native
 - c. Asian
 - d. Caucasian
 - e. Native Hawaiian or other Pacific Islander
 - f. More than one
6. What is your ethnicity?

- a. Hispanic or Latino
 - b. Non-Hispanic or Non-Latino
 - c. Other
7. What is your highest level of education?
- a. Less than a high school degree
 - b. High school degree or equivalent
 - c. Some college but no degree
 - d. Associate degree
 - e. Bachelor's degree
 - f. Master's degree
 - g. Doctorate
8. What is your current relationship status?
- a. Single, never married
 - b. Married or domestic partnership
 - c. Widowed
 - d. Divorced or separated
 - e. In and relationship or engaged to be married
9. What is your current employment status?
- a. Employed or self-employed
 - b. Out of work and looking for work
 - c. Homemaker
 - d. Military
 - e. Student

- f. Retired
 - g. Unable to work
 - h. Other:
10. Where do you currently reside?
- a. Home
 - b. Independent living (e.g., retirement community)
 - c. Assisted living
 - d. Nursing home
 - e. Other:
11. What year were you diagnosed with Parkinson's disease?
12. Do you have concerns about your swallowing? If so, what are these concerns?
13. Have any of your family/friends expressed concerns about your swallowing? If so, please explain.
14. Has your swallowing ever been evaluated by a speech-language pathologist?
- a. Yes
 - b. No
 - c. I don't know
15. Have you ever received treatment for swallowing problems from a speech-language pathologist? If so, please explain.
16. Have you ever received a speech, language, or cognitive (thinking) evaluation from a speech-language pathologist?
- a. Yes
 - b. No

- c. I don't know
17. Have you ever received treatment for speech, language, or cognitive problems from a speech-language pathologist? If yes, please explain.
18. Do you have any of the following diagnoses other than Parkinson's disease? If so, please check all that apply.
- a. Diabetes
 - b. Hypertension (high blood pressure)
 - c. Cognitive impairment, such as Dementia
 - d. Arthritis
 - e. Sleep disorder
 - f. Other cardiovascular disease, such as heart failure
 - g. Anxiety, depression, or other mood disturbance
 - h. Gastrointestinal issues, such as reflux or constipation
 - i. Cancer
 - j. Other neurologic condition/disease, such as Multiple Sclerosis, stroke, brain tumor, etc.
 - k. High cholesterol (hyperlipidemia)
 - l. Pulmonary disease, such as emphysema, chronic obstructive pulmonary disease (COPD), etc.
 - m. Other:

Individual with PD, skip to question 39

Caregiver Questionnaire

19. Please enter the following lab code: first 2 letters of patient's last name, first 2 letters of patient's first name (e.g. John Smith = SMJO).

20. How old are you?

21. What is your gender?

- a. Female
- b. Male
- c. Prefer not to say
- d. Other

22. What is your race?

- a. African American or Black
- b. American Indian or Alaskan Native
- c. Asian
- d. Caucasian
- e. Native Hawaiian or other Pacific Islander
- f. More than one

23. What is your ethnicity?

- a. Hispanic or Latino
- b. Non-Hispanic or Non-Latino
- c. Other

24. What is your highest level of education?

- a. Less than a high school degree
- b. High school degree or equivalent
- c. Some college but no degree

- d. Associate degree
- e. Bachelor's degree
- f. Master's degree
- g. Doctorate

25. What is your current relationship status?

- a. Single, never married
- b. Married or domestic partnership
- c. Widowed
- d. Divorced or separated
- e. In and relationship or engaged to be married

26. What is your current employment status?

- a. Employed or self-employed
- b. Out of work and looking for work
- c. Homemaker
- d. Military
- e. Student
- f. Retired
- g. Unable to work
- h. Other:

27. What is your relationship to the individual with Parkinson's disease?

- a. Spouse
- b. Child
- c. Sibling

- d. Distant family member (e.g., aunt, uncle, grandchild, etc.)
 - e. Friend
 - f. Parent
 - g. Other:
28. Do you live with the individual with PD?
- a. Yes
 - b. No
29. What year did you meet the individual with PD? (If you are the child, please put your birth year)
30. Do you have a concern about the individual with PD's swallowing? If yes, please explain.
31. Has the individual with PD ever voiced concerns about his/her swallowing? If yes, please explain.
32. Has the individual with PD ever received a swallowing evaluation from a speech-language pathologist?
- a. Yes
 - b. No
 - c. I don't know
33. Has the patient ever received treatment for swallowing from a speech-language pathologist? If yes, please explain.
34. Has the individual with PD ever received a speech, language, or cognitive (thinking) evaluation from a speech-language pathologist?
- a. Yes
 - b. No

- c. I don't know
35. Has the individual with PD ever received treatment for speech, language, or cognitive problems from a speech-language pathologist? If yes, please explain.
36. What level of care for the individual with PD do you provide related to eating meals?
- a. I do not provide any assistance.
 - b. I prepare meals but the individual with PD self-feeds.
 - c. I prepare meals and set up the individual's plate (e.g., cut up food), but the individual self-feeds.
 - d. I prepare meals, set up the individual's plate, and feed him/her.
 - e. Other:
37. As a caregiver, do you find caregiving for the individual with PD is any of the following?
(Check all that apply)
- a. Physically challenging
 - b. Emotionally challenging
 - c. Financially challenging
 - d. Other:
38. Do you have concerns about the individual with PD's cognitive (thinking) functioning?
For example, do you have any concerns related to memory, problem-solving, reasoning, etc.?
- a. Yes
 - b. No

Caregiver, skip to question 39.

Swallowing Quality of Life Questionnaire (SWAL-QOL)

Below are some general statements that people with swallowing problems mention. In the last month, how true have the following statements been for you?

39. Dealing with my swallowing problem is very difficult.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
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40. My swallowing problem is a major distraction in my life.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
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Below are aspects of day-to-day eating that people with swallowing problems sometimes talk about. In the last month, how true have the following statements been for you?

41. Most days, I don't care if I eat or not.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
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42. It takes me longer to eat than other people.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

43. I'm rarely hungry anymore.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

44. It takes me forever to eat a meal.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

45. I don't enjoy eating anymore.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

Below are some physical problems that people with swallowing problems sometimes experience. In the last month, how often have you experienced each problem as a result of your swallowing problem?

46. Coughing

1	2	3	4	5
Almost always				Never

47. Choking when you eat

1	2	3	4	5
Almost always				Never

48. Choking when you take liquids

1	2	3	4	5
Almost always				Never

49. Having thick saliva or phlegm

1	2	3	4	5
Almost always				Never

50. Gagging

1	2	3	4	5
Almost always				Never

51. Drooling

1	2	3	4	5
Almost always				Never

52. Problems chewing

1	2	3	4	5
Almost always				Never

53. Having excess saliva or phlegm

1	2	3	4	5
Almost always				Never

54. Having to clear your throat

1	2	3	4	5
Almost always				Never

55. Food sticking in your throat

1 Almost always	2	3	4	5 Never
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56. Food sticking in your mouth

1 Almost always	2	3	4	5 Never
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57. Food or liquid dribbling out of your mouth

1 Almost always	2	3	4	5 Never
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58. Food or liquid coming out your nose

1 Almost always	2	3	4	5 Never
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59. Coughing food or liquid out of your mouth when it gets stuck

1 Almost always	2	3	4	5 Never
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Next, please answer a few questions about how your swallowing has affected your diet and eating in the last month

60. Figuring out what I can and can't eat is a problem for me.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

61. It is difficult to find foods I both like and can eat.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

In the last month, how often have the following statements about communication applied to you?

62. People have a hard time understanding me.

1 Almost always	2	3	4	5 Never
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63. It is difficult for me to speak clearly.

1 Almost always	2	3	4	5 Never
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Below are some concerns that people with swallowing problems sometimes mention. In the last month, how often you experienced each feeling?

64. I fear I may start choking when I eat food.

1	2	3	4	5
Almost always				Never

65. I worry about getting pneumonia.

1	2	3	4	5
Almost always				Never

66. I am afraid of choking when I drink liquids.

1	2	3	4	5
Almost always				Never

67. I never know when I am going to choke.

1	2	3	4	5
Almost always				Never

In the last month, how often have the following statements been true for you because of your swallowing problem?

68. My swallowing problem depresses me.

1	2	3	4	5
Strongly Agree	Agree	Neither Or N/A	Disagree	Strongly Disagree

69. Having to be so careful when I eat or drink annoys me.

1	2	3	4	5
Strongly Agree	Agree	Neither Or N/A	Disagree	Strongly Disagree

70. I've been discouraged by my swallowing problem.

1	2	3	4	5
Strongly Agree	Agree	Neither Or N/A	Disagree	Strongly Disagree

71. My swallowing problem frustrates me.

1	2	3	4	5
Strongly Agree	Agree	Neither Or N/A	Disagree	Strongly Disagree

72. I get impatient when dealing with my swallowing problem.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

Think about your social life in the last month. How strongly would you agree or disagree with the following statements.

73. I do not go out to eat because of my swallowing problem.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

74. My swallowing problem makes it hard to have a social life.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

75. My usual work or leisure activities have changed because of my swallowing problem.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
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76. Social gatherings (like holidays or get-togethers) are noy enjoyable because of my swallowing problem.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

77. My role with family and friends has changed because of my swallowing problem.

1 Strongly Agree	2 Agree	3 Neither Or N/A	4 Disagree	5 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

78. In the last month, how often do you feel weak?

1 Almost always	2	3	4	5 Never
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79. In the last month, how often do you have trouble falling asleep?

1 Almost always	2	3	4	5 Never
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80. In the last month, how often do you feel tired?

1	2	3	4	5
Almost always				Never

81. In the last month, how often do you have trouble staying asleep?

1	2	3	4	5
Almost always				Never

82. In the last month, how often do you feel exhausted?

1	2	3	4	5
Almost always				Never

83. Do you use a feeding tube for nourishment?

- a. Yes
- b. No

84. If you use a feeding tube, how often is it used?

- a. Not at all. Water flushes only.
- b. Use feeding tube as supplement but mostly get nourishment by eating and drinking.
- c. Use as primary means of nourishment but will also eat and drink by mouth for nourishment.
- d. Use a feeding tube for nourishment but may eat or drink for pleasure.
- e. I do not have a feeling tube .

85. Please choose the one description below that best describes the consistency or texture of the food you have been eating most often within the last week.

- a. Eating a full normal diet which would include a wide variety of foods, including hard to chew foods like steak, chips, bread, salad, popcorn, etc.
- b. Eating soft, easy to chew foods like pasta, canned fruits, soft-cooked vegetables, ground meat, or cream soups.
- c. Eating food that is blended (using a blender or food processor(, where solids are pureed or smooth in texture
- d. I do not eat solids.

86. Please choose the one description below that best describes the consistency of liquids you have been drinking most often within the last week.

- a. Thin liquids (e.g., water, milk, tea, juice, soda, coffee)
- b. Majority of liquids you drink are naturally thick, like tomato juice or apricot nectar.
- c. Liquids are moderately thick, like a thick milkshake or smoothie. Such moderately thick liquids are difficult to suck through a straw or drip off your spoon slowly drop by drop when you turn it upside down, such as honey.
- d. Liquids are very thick, like pudding. Such very thick liquids will stick to a spoon when you turn it upside down, such as pudding.

- e. Do not take any liquids by mouth or only have ice chips/water
87. In general, would you say your health is:
- a. Poor
 - b. Fair
 - c. Good
 - d. Very good
 - e. Excellent
88. Did anybody help you complete this survey?
- a. No, I did it myself.
 - b. Yes, someone helped me.
89. If someone helped you fill out this questionnaire, how did they help you? (Check all that apply)
- a. Read you the questions and/or wrote down the answers you gave.
 - b. Answered the questions for you.