

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

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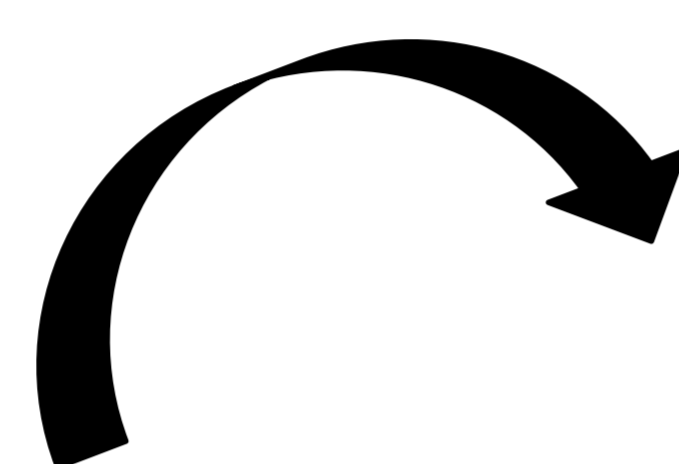
Introduction

- Dysphagia is an often under-recognized but highly prevalent impairment in Parkinson's disease (PD), with an estimated prevalence of >80% of individuals.¹
- Dysphagia **adversely affects quality-of-life** in patients with PD.
- Due to cognitive/behavioral and sensory impairments in individuals with PD, **caregivers may be an appropriate proxy** for dysphagia-related concerns.
- **Purpose: To compare patient experience and caregiver's perception of swallowing-related quality-of-life** in PD. **To explore potential factors** which may be associated with reported scores.
- **Hypothesis:** Based on previous reports, it was hypothesized **caregivers of patients with PD would report lower SWAL-QOL scores.**²⁻⁴ We anticipated that age, cognitive function, presence of aspiration, and history of dysphagia treatment would be significant factors for SWAL-QOL scores.⁵⁻⁸

Methods

- **Inclusion criteria:** diagnosis of PD or the primary caregiver of someone who had been diagnosed with PD.
- **Exclusion criteria:** diagnosis of cognitive impairment and/or diagnosis of another neurologic condition other than PD.
- Members of ~25 PD support groups and Rock Steady Boxing groups in the USA were invited to participate.
- All eligible participants were asked to complete an online survey, including questions related to **demographic and clinical information, and the SWAL-QOL questionnaire.**⁹ For caregivers, additional questions related to **caregiver burden** were included.

Methods



Access participant survey here!

- **Statistical analysis:**
 - Wilcoxon Signed-Rank test **compared the means of scores** between individuals with PD and their caregivers.
 - **Factors** potentially influencing reported SWAL-QOL scores (age, employment status, sex, ethnicity, race, previous history of swallowing evaluation or treatment, caregiver concern about cognition, caregiver burden, time since onset of disease) were explored using Spearman Coefficient Correlation tests.
 - The Holm-Bonferroni method was used to adjust for multiple comparisons.

Results

- **Participants with PD:**
 - Majority were Caucasian, Non-Hispanic males who were retired and living at home.
 - 70% denied assessment of swallowing function.
 - >60% reported eating a full normal diet.
- **Caregivers:**
 - Most caregivers (89%) were **spouses** and lived with the patient.
 - The most common challenge reported by the caregiver was related to **emotional burden.**

Results

Table 1. SWAL-QOL scores for individuals with PD and caregivers.

Variable	PD (N=36)	Caregivers (N=36)
Mean ± SD	78.5 ± 15.5	78.5 ± 13.9
(95% CI)	(83.4, 83.5)	(73.9, 83)
Range	50 – 98	39 – 99

- **Agreement between patient-caregiver pairs:**
 - In general, **no consistent pattern was identified** in terms of the individual with PD or caregivers reporting higher scores.
 - Approximately 10% of the patient-caregiver pairs were within 1-point.
 - **Moderate degree of reliability and agreement** between the individual with PD score and the caregiver score, with the average ICC measures being .598 (95% CI [358,.748]) ($F(71, 72)=2.451, p<.0001$).
- **Influential factors:**
 - **All factors failed to reach statistical significance** for individuals with PD.
 - Only **caregiver burden was statistically significant** ($p=.001$) for caregivers.

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Conclusions

- Lack of difference in SWAL-QOL scores between pairs could suggest support for the **use of the caregiver as a proxy** when using the SWAL-QOL.
- **Caregiver burden may contribute to poorer dyadic management and/or illness appraisal** resulting in lower SWAL-QOL scores reported by the caregiver.
- There exists a need to **appropriately identify and manage caregiver burden**, as it is also important to identify and manage dysphagia in PD.
- Caregivers with low burden are likely better equipped to identify and manage patient's needs.

Selected References

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