

# The impact of oropharyngeal dysphagia and dysphonia on health-related quality of life in Parkinson's disease

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## Impact paragraph

Idiopathic Parkinson's disease (IPD) is with almost 10 million known cases worldwide the second most common neurodegenerative disease.<sup>34</sup> Oropharyngeal dysphagia (OD) and/or dysphonia will occur in more than 80% of the patients with IPD.<sup>5,14</sup> That means millions of people suffer from OD and dysphonia disturbances due to IPD.

In this paragraph we discuss the impact of the results and conclusions of this dissertation. We address the importance of the use of patient-reported outcome measures (PROMs) in the diagnosis and treatment of OD and dysphonia in patients with IPD. Also, we discuss the impact OD and dysphonia may have on patients, family, and friends. Finally, we show how we have shared our findings to create awareness, to give rise to new scientific studies to improve quality of care, and to support the update of clinical practice guidelines.

The aim of this thesis is to improve the diagnostic work-up and treatment of OD and dysphonia in patients with IPD. Unfortunately, we still cannot cure IPD nor the related OD and dysphonia. Therefore, optimizing a person's health-related quality of life (HR-QoL) should be one of the cornerstones of conventional swallowing and voice therapy in patients with IPD. In this thesis we validated the Dutch translation of the MD Anderson Dysphagia inventory (MDADI) for patients with a neurological disorder. It is an easy-to-use tool and relatively short compared to several other available questionnaires. HR-QoL questionnaires such as the MDADI are a vital part of diagnosing OD in IPD. Moreover, we compared common OD and dysphonia-specific PROMs to find a possible relationship between OD and dysphonia-specific HR-QoL. We found that both OD and dysphonia give a similar loss of HR-QoL when IPD progresses. This means health-care professionals should be aware of the coexistence of both OD and dysphonia, even when one of the two is not so apparent.

Using these HR-QoL questionnaires, we found that a patient's HR-QoL is not always in line with the severity of OD evaluated with flexible endoscopic evaluation of swallowing (FEES) or videofluoroscopic swallowing study (VFSS). Patients with severe OD may have a mild reduction in HR-QoL and vice versa. That means that we cannot tell the severity of OD solely based on the impact OD has on a patient's life. This thesis creates awareness about these sometimes hidden swallowing disturbances, so patients will seek help at an early stage of the disease.

Based on this thesis the existence of so-called phenotypes of OD seems plausible. The results of this thesis eliminate knowledge gaps on the existence of so-called phenotypes of OD. This is a first step towards a multidimensional phenotyping of OD in patients with IPD. The conclusion of this thesis marks the start of further research on the integration of PROM and investigator-reported outcome measures (IROM) outcomes of OD and

dysphonia in patients with IPD and hopefully supports the update of current national and international clinical practice guidelines for IPD. This thesis should also provide the foundation for future research to optimize this phenotyping or profiling of patients with IPD and OD or dysphonia and also inspire researchers to optimize the design of future randomized controlled trials on the effects of new treatments for OD and dysphonia by taking phenotypes into account.

Detection of subclinical OD and dysphonia, prevention of sequela and/or rehabilitation of OD and dysphonia will enable patients with IPD to participate in social activities and increase the chances of community reintegration and maintenance of employment in case of juvenile IPD. To find a possible treatment for dysphonia in IPD we added surface electrical stimulation (SES) of the neck to standard care with standard voice therapy. We found a positive therapeutic effect of standard voice therapy, but no additional effect of SES.

The results of this dissertation were published in high-impact scientific journals. For complete transparency and to target a broad audience the results were published in open access journals when possible. The results from this dissertation have also been communicated through presentations at international congresses targeting an interdisciplinary audience of health professionals working with patients with IPD, e.g. the Annual Meeting of the Dysphagia Research Society (2014, Nashville Tennessee USA), the Annual Meeting of the European Society for Swallowing Disorders (2017, Barcelona Spain), and the Annual Meeting of the Deutschen Gesellschaft für Neurologie (2016, Mannheim Germany). Also, results were presented at a regional ParkinsonNet<sup>33</sup> conference for health professionals involved in IPD and for patients and relatives in October 2023.