

# New insights into the diagnostic workup of oropharyngeal dysphagia in head and neck cancer patients

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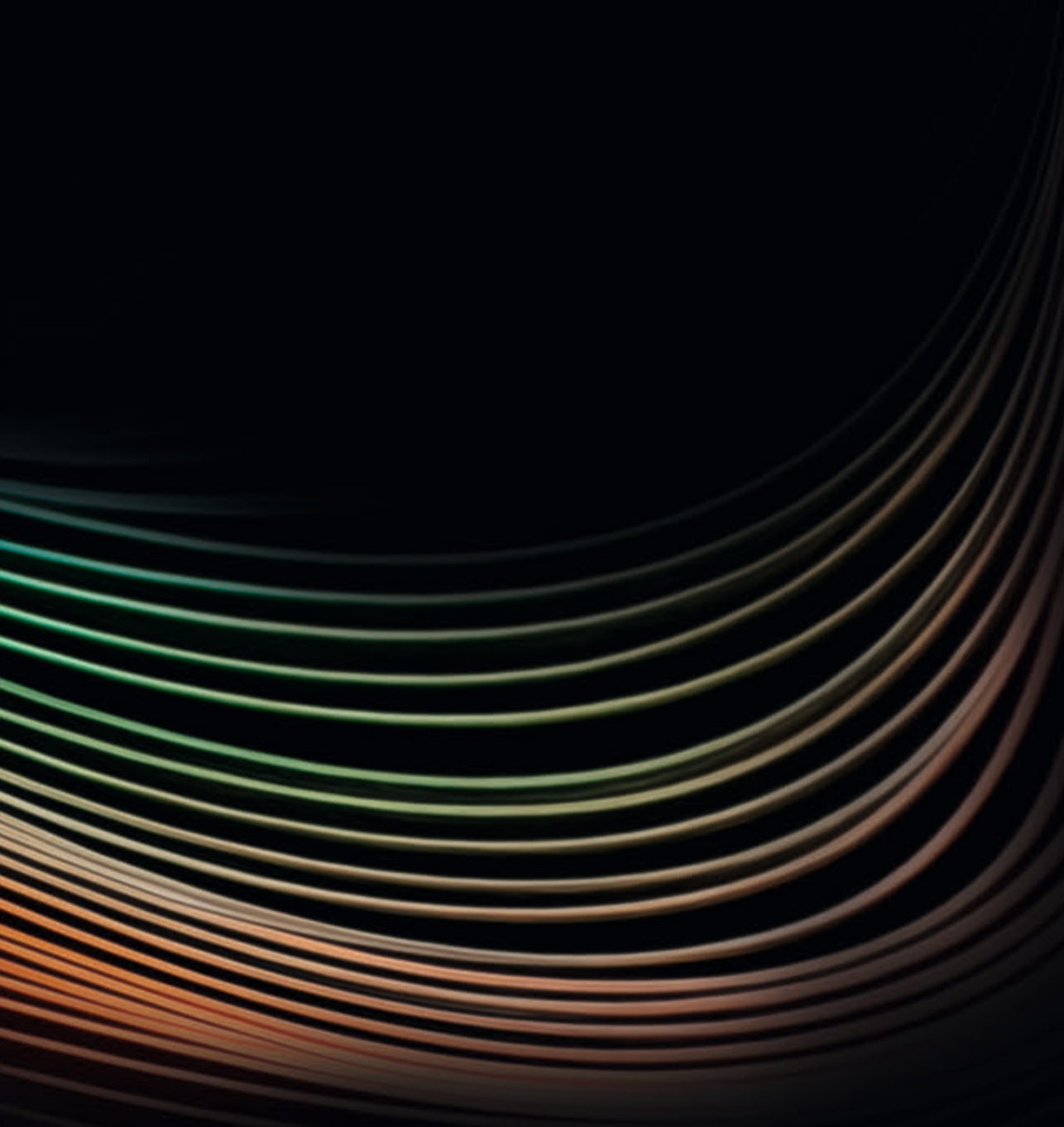
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# CHAPTER 9

IMPACT PARAGRAPH



Head and neck cancer (HNC) patients represent almost 900.000 new cases per year worldwide [1]. The proportion of elderly people with HNC and the average life expectancy are increasing. As a result, the number of people with swallowing disorders as a consequence of HNC is increasing. Despite being cancer-free, HNC survivors often suffer from swallowing impairment, i.e., oropharyngeal dysphagia (OD), which deeply affects one's life. Although clinical practice increases our understanding of HNC-related OD, only through research we can gather evidence that allows us to further develop this field. The outcomes of this thesis shed light on the interrelationship between the actual nature and severity of OD during instrumental imaging techniques for swallowing versus the patient's perspective on swallowing and on OD-related consequences. The knowledge obtained from this thesis has the potential to be implemented in clinical practice and may influence the way health professionals diagnose and treat OD, thereby improving patient care. Moreover, this knowledge can serve as a basis for future studies on OD (p)rehabilitation.

### ***Aims, most relevant findings, and conclusions of this dissertation***

Despite the growing attention in the literature on screening, diagnosis, and treatment of swallowing disorders in HNC, many aspects related to swallowing assessment remain underexplored in this patient population. Although OD assessment is performed worldwide, there is no consensus regarding the diagnostic workup of OD in HNC patients.

The aim of this thesis is to improve the diagnostic workup of OD including the integration of clinician-reported outcome measures (CROMs) and patient-reported outcome measures (PROMs) in HNC patients with OD. We show that methylene blue is the preferred food dye for evaluation of swallowing using fiberoptic endoscopic evaluation of swallowing (FEES). In addition, a commonly used HNC-specific overall severity scale for pharyngeal dysphagia (DIGEST) appears to be a reproducible measurement for FEES in terms of observer agreement. We also underline the importance of integrating visuoperceptual FEES measures of impaired swallowing safety and efficiency as this may help us better understand the underlying pathophysiology causing the swallowing disorder.

As mentioned, OD can have a substantial impact on a patient's life as it can affect several domains of health. While CROMs applied during FEES provide valuable information about the actual nature and severity of OD, the patient's perspective on swallowing and on OD-related consequences must also be integrated into the diagnostic workup. Our findings indicate that OD and risk of malnutrition remain an ongoing concern in HNC survivors, and we emphasize the need for early nutritional risk screening of HNC patients with OD. In addition to malnutrition, the importance of early screening of clinically relevant affective symptoms in all HNC survivors with OD is emphasized. While health professionals mainly focus on quality of care and survival, the patient's perspective almost self-evidently focuses on quality of life. Unfortunately, for the majority of HNC patients, there is no cure for their swallowing disorders. Therefore, optimizing a person's health-related quality of life (HRQoL) should be one of the cornerstones of conventional swallowing therapy in HNC patients with OD. This means that

PROMs should not be missing in a diagnostic workup aimed at person-centered OD care that matters to the patient. This can even mean that, based on the integration of CROMs and PROMs, more attention and help is needed for the psychosocial aspects of OD than for somatic consequences of swallowing disorders. Therefore, this thesis makes an important contribution to the knowledge about the integration of information that is essential in an interdisciplinary multidimensional care pathway for OD. This knowledge will support shared decision-making, based on a more holistic view of the extent and impact of OD, further optimizing person-centered (p)rehabilitation of OD. The results of our studies can also be implemented in patient care and clinical practice guidelines.

### ***Scientific relevance***

The high incidence of OD in HNC patients, resulting in a significant societal impact of swallowing disorders, calls for a vision for the future, both in terms of scientific research and in patient care.

This thesis has great scientific relevance. The findings of our studies increase the body of evidence on HNC-related OD and lay the foundations for future studies. We show that integration of visuoperceptual outcome measures during instrumental imaging techniques for swallowing improves our understanding of the underlying pathophysiology of OD. In addition, we underline the importance of studying the reproducibility of pharyngeal dysphagia scales. We also stress the relevance of repeated nutritional risk and OD screening in all HNC survivors, as well as the importance of early screening of clinically relevant affective symptoms in HNC survivors with OD. Our findings can, among others, contribute to the development of new protocols on OD diagnosis.

The personal impact of OD on patients and their families should not be underestimated. Eating is one of the most basic human needs and eating together connects people in social interaction. Because they cannot eat or drink, or may choke while eating or drinking, HNC patients avoid social interactions involving food. This takes its toll on their well-being, as social interactions provide emotional and social support. Improving the diagnostic workup of OD in HNC patients may lead to early identification and more effective treatment, allowing HNC patients to participate in social interactions involving food without the embarrassment of choking or coughing while eating.

### ***Target audience and societal impact***

The conclusions of this dissertation are relevant for a wide audience. HNC patients with OD can benefit from improved accuracy and alignment of diagnostic tests for OD. Our findings will enable national and international patient associations for HNC patients to provide up-to-date information on HNC-related OD. Additionally, this thesis aims to expand the knowledge of health professionals involved in the care of HNC patients with OD, creating opportunities for improved integrated patient care. National and international professional associations within the field of both HNC and OD can also benefit from the insights unraveled in our

dissertation. For example, our findings may support the update of current clinical practice guidelines for HNC patients with OD [2]. The results of our thesis may also be relevant for policymakers, politicians, and insurance companies involved in healthcare. In view of the remaining knowledge gaps, scientific research groups are encouraged to continue research within the field of HNC-related OD, as the results of this thesis lead to new studies to improve quality of care for HNC patients with OD.

### ***Knowledge transfer***

The findings of this thesis have been published in peer-reviewed journals, and several studies have been made freely and permanently accessible to everyone through open access publishing. Open access publishing also encourages optimal reproducibility of our studies. The studies in this thesis have been presented at multiple national and international conferences in the field of dysphagia and otolaryngology, including the General Meeting of the Dutch Association of Otorhinolaryngology and Head and Neck Surgery (2017 and 2018, Nieuwegein, The Netherlands), The Annual Meeting of the Dysphagia Research Society (2018, Baltimore, Maryland, United States; 2021, Virtual Meeting), The Annual Congress of European Society for Swallowing Disorders, (2018, Dublin, Ireland), and The Congress of The Confederation of the European Otorhinolaryngology and Head and Neck Surgery (2019, Brussels, Belgium). Participation in these conferences provided many opportunities to interact with colleagues from around the world and discuss research ideas and projects.

The clinical relevance of our research was also recognized by receiving the following rewards: the Pélerin Prize for Senior Year Medical Master Students (2017, Maastricht, The Netherlands), the Springer Publishing Travel Scholarship (Under-Represented in Discipline Award) (2018, The Annual Meeting of the Dysphagia Research Society, Baltimore, United States), and the Dr. Catharine van Tussenbroek Foundation Travel Grant (2018).

The valuable input of the patients in the research processes and in disseminating the results of this thesis is acknowledged. The Dutch patient society for HNC (PVHH - Patiëntenvereniging Hoofd-Hals) will be asked for help to disseminate the results to their members.

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