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Measurement and clinical evaluation of oropharyngeal dysphagia; a multidimensional approach

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7



Summary, general discussion and conclusions



OD is the disturbance in the process of transporting solids or liquids from the mouth to the esophagus. OD can cause major complications such as dehydration, malnutrition, aspiration pneumonia, and even death. Because OD is often a secondary expression of another primary cause, it is underdiagnosed, with consequences such as aspiration pneumonia and negative effects on FHS and HRQoL.

The effects of OD may impact domains such as a patient's health or FHS, HRQoL, and social functioning. Also the burden it places on the caregiver should not be underestimated.

Over the last two decades, there has been a huge increase in publications on OD, as objectified by electronic database searches. Recent studies on the reliability and validity of commonly used instruments show insufficient psychometric robustness. Despite the availability of FEES and VFS as the gold standard for the assessment of OD, in practice the screening and measuring of HRQoL and FHS show room for improvement. An analysis of studies reporting on OD revealed that outcomes are often not comparable due to substantial differences in measurement techniques and study designs. Despite the increase in publications and attempts to improve OD care, the low quality of the study designs and the use of measurement instruments with insufficient psychometric properties hamper the comparison of results between studies. When the tools are insufficiently robust, the interpretation of outcomes in all published studies using these instruments remains unclear and possibly flawed.

To improve their robustness, the questionnaires should be redesigned and re-evaluated. Until then, investigators should use only the best available ones, basing their choice on the psychometric properties of the tools. Despite known shortcomings, the questionnaires used in this thesis were the best ones available at the time they were administered.

The scope of this thesis spanned several issues in the measurement and evaluation of OD. The screening, assessment, and treatment effect for OD have been covered, with a special emphasis on patient self-evaluation. The need for further research is, however, evident.

When reviewing the literature on a specific clinical diagnosis, such as HNC, it was observed that the attention traditionally given to a primary disease or illness and its treatment, both in general practice and in research settings, has shifted in the course of the decade toward functional outcomes. Although reports on functional outcomes have appeared more frequently, their usability leaves much to be desired. One reason is that assessing functional outcomes is seldom the first priority of these studies but rather a secondary aspect. Another reason is that the outcomes are often uncomparable

due to methodological, measurement, and evaluation differences between the studies. Consequently, the amount of meta-data being generated is insufficient for meta-analysis, which makes it impossible to obtain outcomes for large cohorts or draw conclusions for functional outcomes of specific interventions. In line with the previous shortcomings the effects of speech language therapy, among others, would need to be studied and the results of those studies should be carefully reported.

In light of the literature review in chapter 2 and the gaps mentioned above, there is a clear need for consensus on methods and minimum requirements for research and reporting on functional outcomes. In particular, the following needs should be addressed:

- Consensus on which measurement or evaluation technique is appropriate for each functional outcome: e.g. voice, speech, swallowing, trismus, and HRQoL.
- Consensus on measurement moments, with a minimal requirement of measuring pre-therapy and preferably long-term post-therapy.

When shifting the focus of attention from HNC to a chronic disease, for instance Parkinson's disease (PD), with a wide variety of functional impairments, a review of the literature reveals an extensive range of treatment results. In contrast, there are fewer reports on the outcomes of swallowing therapy. Since dysphagia in PD can cause major complications, it would be important to evaluate existing, new, and additional therapies. In this thesis it was shown, in chapter 3, how to systematically evaluate the effect of a new treatment modality for dysphagia in PD. In a randomized clinical trial both pre- and post-therapy outcomes were taken into account when evaluating the participants' HRQoL and functional outcomes with reference to the dietary intake. Although all groups showed lasting improvement in HRQoL and severity scores after therapy, no correlation was found between those scores and dietary intake.

A large share of diagnostics in dysphagia care consists of determining whether a patient is at risk for dysphagia before deciding to subject that individual to further assessment. Although many screening tools are available to identify patients who need further dysphagia assessment, there is a need for short, fast, and easy screening options. A common starting point is just asking whether a patient has a swallowing complaint instead of using a questionnaire or screening instrument. Until now, to the best of our knowledge, no research has been done on the value of asking that straightforward question. Determining the sensitivity and specificity of a single question could make everyday clinical practice more evidence-based. Moreover, a simple technique could lead to time and cost savings without disrupting the course of activity or progress in the outpatient clinic. As mentioned in chapter 4, further research is necessary to

provide additional psychometric data on Functional Health Status (FHS) questionnaires, including the single question, and how the resulting information can be combined with the results from either fiberoptic endoscopic evaluation of swallowing (FEES) or videofluoroscopy (VFS) as the gold standard or reference test. With the knowledge of recent studies on the reliability and validity of commonly used instruments this study shows that the use of a simple question has also a potential share in screening for OD. The advantages of a screening questionnaire versus a screening question should be weighed up in order to determine the advantages and disadvantages e.g. burden for the patient or time consumption. Innovation requires looking at what is already there with different eyes. Thus, a single question can be as good as a questionnaire.

From the starting point of screening for dysphagia, it is usual to continue on to further assessment. At that point, QoL is considered an important outcome measurement, as it objectifies the current health status or therapy effects in patients with OD. Measuring HRQoL requires instruments that are reliable and valid, however. To that end this thesis assessed two questionnaires, the M.D. Anderson dysphagia inventory and the Deglutition Handicap Index, in terms of their reliability and validity. It was shown how to evaluate their reliability and validity in a structured and constructive manner in chapter 5.

Not every health professional has access to the gold standard procedures to evaluate the presence of aspiration in dysphagia. In most nursing homes, for example, there is absence of the equipment to execute FEES or VFS. To avoid unnecessary diagnostic procedures, innovative options should be given due consideration. These novel techniques should be easy to administer, put less burden on the patient and health professional, be reliable, and yield consistent results. In an attempt to fill that need, we built a prediction model to forecast aspiration in patients at risk for OD on the basis of common self-evaluation questionnaires and oral intake status. Using commonly available instruments, it was shown that it is possible to accurately predict aspiration in oropharyngeal dysphagia by a non-invasive and non-instrumental assessment protocol including oral intake status and self-report questionnaires on FHS and HRQoL. The performance of the final model was excellent. On the basis of findings in chapter 6, we conclude that every health professional can determine, after further evaluation of this technique, whether aspiration is present in a patient or not.

FUTURE STUDIES

The measurement and evaluation of OD may improve significantly when new FHS and HRQoL questionnaires are developed in line with item response theory (IRT) such as Rasch analysis. By departing from the classical approach to questionnaire development and applying newer methods, the methodological issues that have arisen over the past years can be resolved. Consequently, measurement and evaluation would become more accurate and informative, thereby improving the care for OD. Second, a more uniform way of evaluating OD and its treatment can facilitate quantitative and qualitative comparisons, which in turn could lead to better treatment choices and more pertinent outcome knowledge. There is still a need to raise awareness of underdiagnosed OD as a consequence of other more prominent diseases. Attention to comorbidity is warranted not only to manage the health-related consequences and their implications for the patient's FHS or HRQoL but also to reduce the carer's burden. All multi-dimensional aspects of OD should be taken into account when characterizing a patient.

With innovations and novel perspectives, new avenues may open to connect applied research and evidence-based clinical practice with the field providing dysphagia care. The first step in that direction is to make evidence-based methods of diagnosing OD more accessible to health professionals with no access to the gold standard. The outcomes and recommendations presented in this thesis may give some useful guidance for this development.