Oropharyngeal Dysphagia in Adults

Prevalence, professional practices, patient perspectives and treatment outcomes

Maribeth Caya Rivelsrud

Speech and Language Pathology Unit
Institute of Neuroscience and Physiology
Sahlgrenska Academy
University of Gothenburg

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UNIVERSITY OF GOTHENBURG

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maribeth.rivelsrud@gu.se

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In memory of my mom

One cannot think well, love well, sleep well,
if one has not dined well.
~Virginia Woolf

Abstract

Background: Oropharyngeal dysphagia (OD) is defined as any disruption in the transportation of food/liquids safely and efficiently from the mouth, through the pharynx and into the esophagus. The underlying causes of OD in adults are numerous and the consequences may have devastating effects on a person's health and quality of life.
Overall aim: Contribute to a stronger evidence base for the identification and treatment of OD in adults.
Results: Study I was a cultural adaptation and validation study resulting in the first valid and reliable dysphagia-specific health related quality of life questionnaire for the Norwegian population. Study II was a systematic review and meta-analyses that revealed considerable heterogeneity in the definition of OD and type and quality of outcome measures used to determine prevalence. Estimated pooled OD prevalence of 36.5%, 42.5% and 50.2% in the hospital, rehabilitation and nursing home settings, respectively. There were no eligible studies identified for OD prevalence in palliative care. In Study III survey results from 396 nurses, occupational therapists and speech-language pathologists in the Nordic countries showed notable professional role differences between countries, minimal education and practical training in OD, and limited use of evidence-based practice in screening, assessments and rehabilitative treatment for OD. Study IV was an exploratory randomised control study including 15 participants with Parkinson's disease or multiple sclerosis. Findings showed no change in swallowing function following expiratory muscle strength training, as assessed by flexible endoscopy, despite significantly improved maximal expiratory pressure and positive results from patient-reported outcome measures.
Conclusions: There is a high prevalence of OD in healthcare settings. Currently, education curriculums and use of existing evidence-based outcome measures and rehabilitative treatment in the management of adults with OD in the Nordic countries are minimal. The inclusion of patient-reported outcomes in the management of OD is needed along with continued research in the use of rehabilitative treatments of OD in people with Parkinson's disease or multiple sclerosis.

Keywords
Swallowing, assessment, rehabilitation, quality of life, evidence base

Sammanfattning på svenska

Bakgrund: Orofaryngeal dysfagi (OD) – sväljsvårigheter – definieras som en störning i transporten av föda/vätska på ett säkert och effektivt sätt från munnen, via svalget (farynx) och till matstrupen (esofagus). Det finns ett flertal orsaker till OD hos vuxna och konsekvenserna kan få förödande effekter på en persons hälsa och livskvalitet.
Syfte: Avhandlingens övergripande syfte är bidra till en starkare evidensbas för identifiering och behandling av OD hos vuxna.
Resultat: Studie I var en kulturell anpassnings- och valideringsstudie som resulterade i det första valida och reliabla dysfagispecifika hälsorelaterade livskvalitetsformuläret anpassat för den norska befolkningen. Studie II var en systematisk översikt med metaanalyser som visade på betydande heterogenitet när det gäller definitionen av OD, vilken typ av utfallsmått som används för att fastställa prevalens och vilken kvalitet dessa har. Beräknad sammanslagen förekomst av OD var 36,5 %, 42,5 % och 50,2 % för sjukhus, rehabilitering respektive vårdhem. Inga lämpliga studier av OD-prevalens inom palliativ vård kunde identifieras. I Studie III visade enkätresultat från 396 sjuksköterskor, arbetsterapeuter och logopeder i de nordiska länderna påtagliga yrkesrollskillnader mellan länder, minimal utbildning och praktisk träning i OD samt begränsad användning av evidensbaserad praktik vid screening, bedömningar och rehabiliterande behandling för OD. Studie IV var en explorativ randomiserad kontrollerad studie med 15 deltagare med Parkinsons sjukdom eller multipel skleros gällande effekterna av exspiratorisk muskelstyrketräning på sväljfunktionen mätt med flexibel endoskopisk undersökning av sväljningen (FUS). Effekten på sväljfunktionen var inte övertygande trots att det maximala utandningstrycket ökade signifikant och att patientrapporterade resultatmått (PROMs) var positiva.
Slutsatser: Förekomsten av OD i olika sjukvårdsmiljöer är hög. För närvarande är utbildningsplanerna och användningen av befintliga evidensbaserade resultatmått och rehabiliterande behandling minimal vid omhändertagande av vuxna med OD i de nordiska länderna. Patienternas självskattning av sina problem behöver inkluderas vid bedömning och utvärdering av behandling av OD och det behövs ökad forskning när det gäller rehabiliterande behandlingar för personer med Parkinsons sjukdom eller multipel skleros.

List of papers

This thesis is based on the following studies, referred to in the text by their Roman numerals.

I. Rivelsrud, M. C., Kirmess, M., & Hartelius, L. (2019). Cultural adaptation and validation of the Norwegian version of the swallowing quality of life questionnaire (SWAL-QOL). *Health and quality of life outcomes*, *17*(1), 179.

II. Rivelsrud, M. C., Hartelius, L., Bergström, L., Løvstad, M., & Speyer, R. (2023). Prevalence of oropharyngeal dysphagia in adults in different healthcare settings: a systematic review and meta-analyses. *Dysphagia*, *38*(1), 76–121.

III. Rivelsrud, M. C., Hartelius, L., Speyer, R., & Løvstad, M. (2023). Qualifications, professional roles and service practices of nurses, occupational therapists and speech-language pathologists in the management of adults with oropharyngeal dysphagia: a Nordic survey. *Logopedics, phoniatrics, vocology*, 1–13. Advance online publication.

IV. Rivelsrud, M.C., Antonsson, M., Løvstad, M., Speyer, R., Johansson, K., & Hartelius, L. Effects of expiratory muscle strength training on swallowing function in people with Parkinson's disease or multiple sclerosis as assessed by flexible endoscopic evaluation of swallowing. *Manuscript*

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Abbreviations

AXIS	Critical appraisal tool
CSA	Clinical swallowing assessment
EAT-10	Eating Assessment Tool-10
EBP	Evidence-based practice
ED	Esophageal dysphagia
EMST	Expiratory muscle strength training
EDSS	Expanded Disability Status Scale
FEES	Flexible endoscopic evaluation of swallowing
FHS	Functional Health Status
FOIS	Functional Oral Intake Scale
FOTT	Facial Oral Tract Therapy
GUSS	Gugging Swallowing Screen
H&Y	Hoehn & Yahr scale
HRQoL	Health-related Quality of Life
IDDSI	International Dysphagia Diet Standardisation Initiative
MASA	Mann Assessment of Swallowing Ability
MBS	Modified Barium Swallow
MDADI	MD Anderson Dysphagia Inventory
MDTP	McNeill Dysphagia Therapy Program
MEP	Maximum expiratory pressure
MMSE	Mini Mental State Examination
MS	Multiple sclerosis
Nor-SWAL-QOL	Norwegian Swallowing Quality of Life
OD	Oropharyngeal dysphagia
OT	Occupational therapist
PD	Parkinson's disease
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRO/PROM	Patient-reported outcome / Patient-reported outcome measure
PROSPERO	International prospective register of systematic reviews
SF-36	Short Form Health Survey
SLP	Speech-language pathologist
SWAL-QOL	Swallowing Quality of Life
SSQ	Sydney swallowing questionnaire
TOR-BSST	Toronto Bedside Swallowing Screening Test

VAS	Visual analogue scale
VFSS	Videofluoroscopic swallow study
V-VST	Volume-Viscosity Swallowing Test

Note: The abbreviations listed here are used in the running text. Some tables contain additional abbreviations, which are listed and explained below each table.

Introduction

Research in the field of oropharyngeal dysphagia (OD) is relatively new, with the first publications occurring in the mid 1960's and early 1970's. The first issue of the interdisciplinary journal, "Dysphagia", appeared in 1986 and the 1990's saw the formation of international dysphagia research societies in the United States of America, Europe and Japan. As a member of the multiple disciplinary team, speech-language pathologists (SLPs) involvement in the management and research of OD has been noteworthy from the beginning (Miller & Groher, 1993).

This is the background for this thesis, which originated from a SLPs plan to improve evidence-based practice in the assessment of adults with OD in a clinical rehabilitation setting. The original plan evolved into a doctoral project with the intention to lessen the knowledge gaps in key areas that influence the evidence-based practice in the management of adults with OD.

Deglutition /swallowing

Deglutition, or swallowing, is one of the most complex neuromuscular activities that humans perform hundreds of times a day without making a conscious effort. The act of swallowing is as natural as breathing; it is neurologically synchronised with respiration and involves many of the same structures and muscles as those used for respiration and speech (Martin-Harris et al., 2005). Swallowing is initiated in the brainstem, which is supplied with sensory and motor nerve fibers from cranial nerves (V, VII, IX, X, XI, XII), and can be modified by cortical and subcortical areas of the brain. Swallowing is a semiautomatic neurophysiologic process responsible for the transportation of food, liquid, and other substances from the mouth through the pharynx, past the laryngeal airway and through the esophagus. This highly complex, coordinated and continuous process can be divided into three overlapping phases: oral preparatory and oral, pharyngeal and esophageal (Sasegbon & Hamdy, 2017). Figure 1 illustrates the oropharyngeal phases of the swallow.

The oral phase involves the sensory recognition of the presence of touch, taste, temperature and viscosity of food/liquid in the oral cavity. There is a difference in the complexity required in the oral preparatory phase when swallowing liquid and food. When swallowing liquid, the oral preparatory phase is simple, requiring the collection and containment of the liquid in the oral cavity, followed by the initiation of the oral transit phase. The oral preparation of food, however, is more complex and requires mastication; using the teeth, lips, jaws, cheeks, tongue, hard and soft palate to mix food with saliva into an appropriate consistency (bolus) for swallowing. In the oral phase, the tongue presses upward, making a sweeping front to back movement pushing the bolus along the hard palate towards the back of the mouth (oropharynx) resulting in the elicitation of a pharyngeal swallow response (Sasegbon & Hamdy, 2017)

The initiation of the pharyngeal phase of the swallow results in a complex coordination of several events. The soft palate elevates to prevent food from going up into the nasal cavity, there is a brief cessation of respiration and the vocal folds adduct. The hyoid and larynx are pulled up and forward by the suprahyoid muscles resulting in a shortening of the pharynx and closure of the larynx. The base of tongue retraction and pharyngeal muscle contraction move the bolus downward through the pharynx. The pharyngeal phase ends with closure of the upper esophageal sphincter, return of pharyngeal structures to a resting position and the continuation of respiration. The oropharyngeal phase of swallowing lasts between 0.6-1 second (Sasegbon & Hamdy, 2017).

The esophageal phase includes movement of the bolus downward via peristaltic waves, through the lower esophageal sphincter and into the stomach (Sasegbon & Hamdy, 2017). A thorough understanding of the sequencing, coordination and variations in the normal swallow is essential prior to the diagnosis of an abnormal swallow and implementation of adequate intervention.

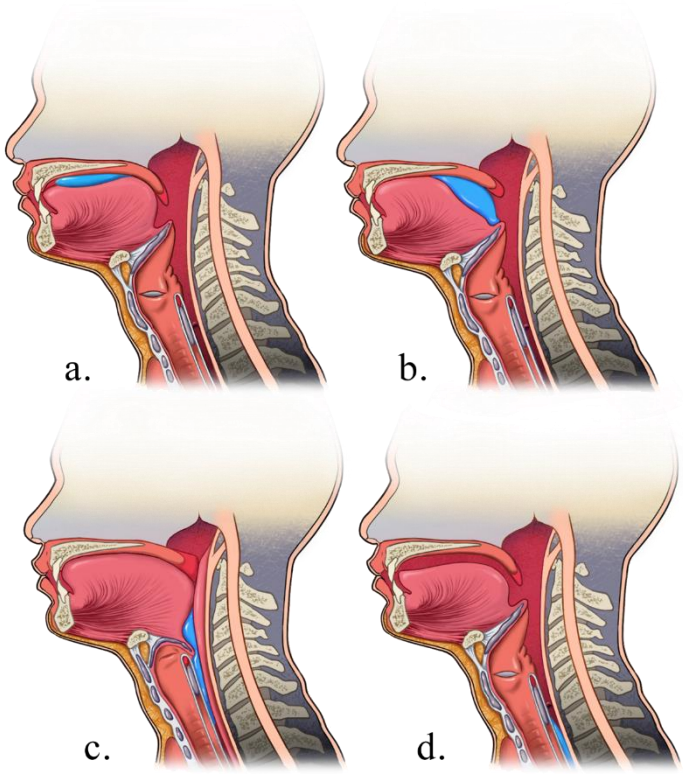

Figure 1. *Schematic of swallowing phases. a) bolus hold in the oral cavity-oral preparatory phase; b) oral phase sweeping tongue movement pushes bolus back towards the oropharynx; c) pharyngeal phase initiation of the pharyngeal swallow response and bolus movement through the pharynx and; d) passage of the bolus through the upper esophageal sphincter in to the esophagus.*

Illustrations by Mariel Rivelsrud

Oropharyngeal dysphagia in adults

Definition

The terms deglutition disorders, swallowing disorders and dysphagia have been used interchangeably in the literature and generally refer to structural or mechanical disturbances in the transportation of food or liquid from the mouth to the stomach. Oropharyngeal dysphagia (OD) is included in the International Classification of Diseases (ICD-10, R13.12) of the World Health Organisation (WHO) (WHO, 2019). Dysphagia is generally divided into oropharyngeal dysphagia (OD) and esophageal dysphagia (ED). OD pertains to the difficulties in the oral and pharyngeal phases of swallowing and ED concerns the esophageal phase of swallowing. OD is not an illness in and of itself, but is characterised as a subjective symptom or collection of symptoms of an underlying medical disease or injury (Speyer et al., 2021).

Causes and prevalence

OD in adults is common and has been observed in individuals with neurological disorders (e.g. stroke, traumatic brain injury, brain tumour) and neurodegenerative diseases (e.g. Parkinson's disease, multiple sclerosis). OD can also be a result of injury, surgery or radiation to areas involving the oral cavity, larynx and/or pharynx. Furthermore, changes in swallowing physiology, such as reduced sensitivity and slowed movements are a part of the natural aging process in healthy adults (presbyphagia). These natural changes combined with age-related decline in muscle mass and strength (sarcopenia) in the elderly can exacerbate the severity of OD that may occur with disease or injury that become more prevalent in the aged (Sasegbon & Hamdy, 2017). The European Society for Swallowing Disorders (ESSD) has described OD as a geriatric syndrome (Baijens et al., 2016). With an increase in life span follows an increase in prevalence of persons living with chronic disease and an increased risk of OD. The literature on the prevalence for OD has focused largely on age or medical diagnosis (Madhavan et al., 2016; Takizawa et al., 2016).

Prevalence refers to the proportion of people in a certain population presenting with OD (new and pre-existing cases) within a certain point in time or period. The knowledge of prevalence is of importance because it gives an indication of the scope of OD and supports planning of OD management, such as establishing

procedures for early identification and treatment in populations where the risk of OD is known (Takizawa et al., 2016).

Prevalence of OD in adults is varied and dependent on the terminology used to define dysphagia, the population sampled, disease severity at the time of assessment, type of assessment and other variables. Determining pure OD prevalence from larger, general population-based studies is difficult. This may be partially due to use of self-report questionnaires that often include general questions about swallowing that relate to both OD and ED (e.g., "Do you have difficulty swallowing solid foods?") (Speyer et al., 2021). Studies reporting on estimated prevalence may be comprised of data from studies including ED or feeding problems, if not specified in the inclusion/exclusion criteria (Table 1).

The accuracy and frequency of reported OD prevalence in a population may also depend on the underlying diagnosis. Prevalence of OD following acute stroke is highly reported, which is understandable considering the medical urgency, access to highly qualified medical personnel and equipment. Many countries have national stroke guidelines for acute care management and there are several published screening tools validated for the acute stroke population. Conversely, determining accurate OD prevalence in populations with degenerative disease, such as Parkinson's disease or multiple sclerosis may be more difficult. Guidelines for screening or assessment of OD in these populations are scarce and many prevalence results are based on self-report. Symptoms of OD in degenerative disorders appear gradually and may remain unidentified by the people themselves or caregiver(s) (Suttrup & Warnecke, 2016). Thus, OD may not be identified before complications arise from OD, such as weight loss or respiratory infection, requiring attention from health care professionals and possible hospitalisation.

Table 1. *Prevalence of dysphagia*

Population	Prevalence & test type	Author
Adults in USA	4% self-report	[a] (Bhattacharyya, 2014)
Community dwelling elderly	5% interview, 11% swallow questionnaire 72% 3oz water swallow test 12% water swallow test 17% questionnaire 30% screening	[a] (Madhavan et al., 2016)* (Doan et al., 2022)*
Dementia	13-57% bedside or instrumental	(Alagiakrishnan et al., 2013)*
Stroke	29-57% water swallow test 8-55% bedside assessment 35-67% videofluoroscopy	(Takizawa et al., 2016)*
Traumatic brain injury	30% videofluoroscopy	(Takizawa et al., 2016)*
Parkinson's disease	26% rating score/interview 34% water swallow 43% swallow questionnaire 57% instrumental	[a] (Gong et al., 2022)*
Multiple sclerosis	36% self-report 81% clinical or instrumental	(Guan et al., 2015)*
Head and neck cancer	83% flexible endoscopy	(Jensen et al., 2007)
Acute cervical spinal cord injury	80% flexible endoscopy	(Wolf & Meiners, 2003)

[a] *Possible inclusion of esophageal dysphagia, *Systematic review*

Symptoms and consequences

The presence of OD can be identified with subjective symptoms that provide an indication of unsafe and/or ineffective swallowing. Coughing and choking are often associated with unsafe swallowing; meaning some substance (e.g. food, liquid, saliva, or medications) has entered the airway. However, in some instances neurological damage results in a weakened or absent cough reflex, resulting in an unprotected airway and silent aspiration. Symptoms such as food remaining in the mouth, complaints of food sticking in the throat or the need to swallow several times on one bolus, are associated with ineffective swallowing. These difficulties can lead to prolonged mealtimes, the need for diet modification and/or a loss of appetite due to the amount of effort required to complete a meal. Consequently, people with OD often have difficulty maintaining adequate nutrition and hydration. In addition, individuals identified with an inefficient swallowing have an increased association with aspiration (Leonard et al., 2023).

Unfortunately, an increase in risk for aspiration can result in respiratory complications such as aspiration pneumonia (Martino et al., 2005). Aspiration pneumonia is a frequent cause of death in populations with neurological disease such as Parkinson's disease (PD) or multiple sclerosis (MS) (Muller et al., 2001; Sumelahti et al., 2010).

OD is a negative predictor of rehabilitation outcomes and associated with increased healthcare costs. People with dysphagia are in the hospital on average 4 days longer, have more re-admissions, and are more likely to be discharged to rehabilitation units or nursing homes rather than home compared to those without OD. Overall inpatient costs are 33% higher for patients with OD than without (Arnold et al., 2016; Patel et al., 2017). The severity of OD can range from the need for minor adjustments, such as reducing the amount swallowed per mouthful, to profound changes such as dependency of nourishment through a percutaneous gastrostomy tube. OD may be temporary, lasting weeks to a few months or chronic, lasting from months, to years, or life-long. Thus, consequences of OD can have devastating and long-lasting effects on the health and psychosocial aspects of an individual's quality of life and the lives of those who care for them (Howells et al., 2021).

Safe and efficient swallowing is not only essential for maintaining nutrition and hydration to sustain life, but is also a fundamental function that is influential on a person's ability or choice to partake in social and cultural gatherings whether at home, work or out with friends. Individuals with OD have expressed feeling embarrassed and anxious in association with mealtimes, which can lead to social isolation and depression (Ekberg et al., 2002; Helldén et al., 2018; Verdonschot et al., 2017). Considering the possible devastating complications and consequences of OD, early and optimal assessment and treatment of OD is of great importance.

Screening and assessment

The identification and assessment of OD is generally in the form of a swallow screen, non-instrumental clinical swallowing assessment, self-report, and/or instrumental assessment. The choice of screening or assessment method and timing is often dependent on the type of underlying disorder (acute, progressive), clini-

cal setting (e.g. acute care, outpatient clinic, nursing home) and available expertise. Accurate identification and assessment of OD is dependent on outcome measures with sufficient diagnostic performance and psychometric properties (Speyer et al., 2021).

Screening

A screening is used to determine the risk of aspiration and/or OD. The content of a screening may vary from a simple yes/no question (e.g. "do you have trouble swallowing?") to completion of a standardised screening procedure. However, use of formal screening protocols is associated with better adherence of health care professionals' use of swallow screens and significantly decreases risk of pneumonia (Hinchey et al., 2005). Much of the literature describes the use of swallow screenings designed as a simple pass/fail tests, with the goal of determining: 1) the likelihood of dysphagia and aspiration risk, 2) if oral intake is recommended, and 3) the need for referral to more comprehensive diagnostic assessments (Donovan et al., 2013; European Society for Swallowing Disorders (ESSD), 2012; Speyer et al., 2021). Swallow screening tools are meant to be feasible, time and cost effective, easy to administer and require minimal training. A wide range of screening tools have been developed in the past three decades; many were developed particularly for use with the acute stroke population and intended to be administered by other health care professionals such as nurses.

Several systematic reviews have been published investigating the diagnostic performance and psychometric properties of dysphagia screening tools for the neurogenic populations. Although no one screening tool has shown 100% sensitivity and specificity, in addition to good methodological quality, there are several that have met suggested minimum diagnostic performance criteria of high sensitivity (≥70%) and moderate specificity (≥60%) (Speyer et al., 2021). Some of these screenings include swallow trials using only water Toronto Bedside Swallowing Screening Test (TOR-BSST) (Martino et al., 2009), while others use a variation of amounts and consistencies such as the Gugging Swallowing Screen (GUSS) (Trapl et al., 2007) and the Volume-Viscosity Swallowing Test (V-VST) (Clavé et al., 2008).

The use of standardised swallow screening protocols have be shown to reduce aspiration pneumonia. Nonetheless, absence of a cough response to aspiration (silent aspiration) renders clinical identification of aspiration unreliable for many screening tests (Perry et al., 2019) and recommendations on oral intake should be supported by further assessments (Speyer et al., 2021).

Non-instrumental clinical swallowing assessment (CSA)

The non-instrumental clinical swallowing assessment (CSA) is an assessment that enables the clinician to get a baseline impression of swallowing function. The non-instrumental CSA is often used as the next step after screening, as the only assessment to determine OD and/or as a precursor to an instrumental assessment (e.g. videofluoroscopic swallow study or flexible endoscopic evaluation of swallowing) (Garand et al., 2020; Speyer, 2013). As with the screening, the non-instrumental CSA can be administered bedside and in different settings (e.g. outpatient clinic, home) and is usually administered by a dysphagia specialist, such as a speech-language pathologist (SLP). Unlike the screening, the CSA is not a pass/fail test, but a comprehensive assessment typically including an interview with the patient/caregiver and medical history taking, a cranial nerve examination via the assessment of oral and laryngeal function and observation of cognitive and communicative abilities (Speyer, 2013; Speyer et al., 2021). The Mann Assessment of Swallowing Ability (MASA) (Mann, 2002) is a non-instrumental clinical swallowing assessment developed and validated for use with the acute stroke population. A cancer specific MASA has also been developed (MASA-C)(Carnaby & Crary, 2014). If deemed safe and beneficial, the CSA includes observation of swallow trials using different foods and liquids (Garand et al., 2020; Suiter et al., 2020).

Results from the non-instrumental CSA helps the clinician form diagnostic impressions of the severity of OD, possible causes, prognosis for improvement, hypotheses on the safety and efficiency of the swallow that warrant possible restrictions or assistance, and determine need for further assessment. Although the non-instrumental can help identify information related to overall severity of OD, no significant information can be determined about the pathophysiology of the pharyngeal phase of swallowing. Therefore, the presence of symptoms or signs of pharyngeal dysphagia necessitate the use of an instrumental assessment (Rangarathnam & McCullough, 2016).

Instrumental assessment

Instrumental swallowing assessments for OD such as videofluoroscopic swallow study (VFSS), also known as the modified barium swallow (MBS), and flexible

endoscopic evaluation of swallowing (FEES) have been considered "gold standards" for the assessment of OD. Both assessments have advantages and disadvantages, and are considered as complementary to one another (Langmore, 2003; Miller et al., 2020). The VFSS is completed with the patient seated upright, or standing if preferred. Video-recordings of all phases of the swallowing process are taken in the lateral and anterior-posterior (AP) view. Barium contrast is added to all food and liquid in order be able to visualise the movement of the bolus in relation to the structures within the oral cavity, through the pharynx and esophagus. While watching the movement of the bolus through the pharynx, it is possible to determine if penetration and aspiration occurs before, during or after swallow. The penetration-aspiration scale (PAS) was originally developed for use with the VFSS (Rosenbek et al., 1996). The PAS is an 8-point ordinal scale that describes the eventual location of material in the airway and also the patients response to eventual penetration or aspiration (e.g. zero means 'no material in the airway'; 8 means 'material enters the airway, passes below the vocal folds, and no effort is made to eject').

The VFSS is beneficial in providing objective measures for the timing of events (e.g. hyolaryngeal excursion, airway closure and aspiration), range of structural movements, and degree of bolus clearance and efficiency (Martin-Harris & Jones, 2008). The VFSS protocol may conclude with trial swallows to determine the effect of using compensatory treatment techniques such as a change in posture or swallow manoeuvres (Martin-Harris et al., 2000).

The FEES is also completed with the patient seated upright. It is an invasive examination with the passage of a flexible endoscope transnasally and positioned between the velum and posterior pharyngeal wall. The FEES provides a birds-eye view of structural movements including the base of tongue, pharynx and larynx. This view allows for the assessment of pharyngeal swallow phase, with the exception of a brief interruption or "white-out" when the airway cannot be visualised due the velopharyngeal constriction. Food colouring is added to food and liquid to aid in localising and differentiating between consistencies (Miller et al., 2020). The PAS has also been determined reliable for use in determining level of swallowing safety with the FEES (Colodny, 2002). Ordinal scales have also been developed for use with FEES to determine level of swallowing efficiency by looking at placement and amount of pharyngeal residue following the swallow. The Yale Pharyngeal Residue Severity Rating Scale (YPRSRS) is a validated and reliable ordinal scale that provides a visual image of differing levels of residue in the valleculae and pyriform sinuses. This scale has five levels of severity

for both the valleculae and pyriform sinuses ranging from 1 'none' (0%, no residue) to severe (>50%; filled vallecular or pyriform sinuses) (Neubauer et al., 2016).

Particular advantages of the FEES is that it can be used bedside, has no radiation exposure in contrast to VFSS, provides direct visualisations of the larynx and can be used as biofeedback during treatment (Pisegna & Murray, 2018). Unfortunately, assessments with FEES are mostly subjective as current technology has yet to be developed that allows the examiner to quantify results such as amount of residue (Pisegna et al., 2020).

Both the VFSS and FEES require specialised personnel such as radiologist, radiology technician, otolaryngologist and SLP, whose roles vary by institution and country. Standardised protocols for the VFSS (Martin-Harris et al., 2008) and FEES (Langmore, 2017) are available, however, the quality of the psychometric properties for the visuoperceptual measures used to interpret VFSS and FEES are insufficient (Swan et al., 2019). Nonetheless, the pathophysiology of the swallow cannot be determined by the naked eye and thus the use of VFSS and/or FEES is necessary to diagnose and determine appropriate evidence-based intervention, particularly for pharyngeal phase OD (Baijens et al., 2021).

Patient-report outcome measure (PROM)

Previous mentioned examples of screening and assessment have centred on clinically observable manifestations of OD (e.g. coughing, weight loss). However, patient and clinician perspectives often differ (Martino et al., 2010). Therefore, an essential part of the assessment is the inclusion of the unobservable elements (e.g. anxiety, fear of choking, embarrassment), hence, the patients' perspective on how OD affects their health-related quality of life (HRQoL). Patient reported outcome (PRO) is defined as any health-related information that comes directly from the patient without modification by health care professions or anyone else (Food and Drug Adminstration (FDA), 2009). PROMs may be comprised of two different aspects, Functional Health Status (FHS) and Health Related Quality of Life (HRQoL). FHS refers to a person's ability to fulfill usual roles and perform daily activities required to meet basic needs and maintain health and well-being, while HRQoL pertains to the impact that FHS has on a persons' perceived physical, mental and social functioning (Jones et al., 2018). This valuable information

directly from the patient is a primary element in the provision of evidence-based practice. The main advantage with PROMs is the focus on the patients' viewpoint on how their symptoms and disease are affecting daily life while avoiding input or bias from an outside source. Although dysphagia-specific PROMs provide important information from the patients' experience, results may not fully reflect the severity of the physiologic swallowing impairment. Therefore, it is not uncommon for OD prevalence from PROMs (subjective measures) to result in lower prevalence than more objective measures (e.g. instrumental assessment). Nevertheless, to promote OD as a multidimensional phenomenon, PROMs have become recognised as an integral part in planning intervention and the evaluation of the effectiveness of treatment approaches (Moloney et al., 2023).

Two examples of PROMs that were developed for oropharyngeal dysphagia are the Swallowing Quality of Life questionnaire (SWAL-QOL) and Sydney Swallowing Questionnaire (SSQ). McHorney and colleagues developed and validated the SWAL-QOL as one of the first dysphagia specific health-related quality of life assessments, recognising that "physiologic function is not synonymous patient functioning and well-being" (McHorney, Bricker, Kramer, et al., 2000). The SWAL-QOL consists of 44 items scored on an five-point ordinal (Likert) scale, has been widely used in research and considered a "gold standard" within PROMs (Keage et al., 2015). The SSQ was also developed in early 2000 and was designed to assess the severity of OD from the patient's perspective. This questionnaire includes 17 questions; developed to reflect an individual's perception of their swallowing performance focusing on symptoms in relation to the anatomical area (e.g. oral, pharyngeal), the type of dysfunction (swallow, cough) and the consistency (thin liquids, hard food). The SSQ uses a visual analogue scale (VAS) ranging from 0-100 per question with the highest possible total score of 1700. A higher score indicates a higher degree of perceived impairment (Wallace et al., 2000).

There are other types of scales used to document different levels of eating and swallowing function for people with OD. One example is the Functional Oral Intake Scale (FOIS) (Crary et al., 2005). The FOIS is an ordinal scale that describes the amount of oral intake and bolus modifications/viscosities ranging from 1- 'no oral intake', to 7-total 'total oral intake with no restrictions'. This scale helps health care personnel in documenting the degree of oral intake a patient has at any time in the course of their disease or injury and like the SWAL-QOL and SSQ, FOIS has been used in research to assess treatment outcome.

Treatment

The results from the non-instrumental and instrumental assessments help determine an evidence-based treatment plan. The most common treatment goal for OD is to ensure sufficient oral intake of food and liquids to meet nutritional needs, while at the same time promoting airway safety and minimising complications. Intervention for OD may be classified as compensatory and/or rehabilitative.

Compensatory treatment is typically used in the acute stage of disease or injury or with severe disorders, in order to compensate for loss of swallowing function. Common compensatory strategies to improve bolus flow and airway safety include the use of posture adjustment (e.g. chin tuck), modification of bolus consistency (e.g. thick liquid, puree) and swallow maneuvers (e.g. supraglottic swallow). Although these strategies may result in a change in bolus flow or physiologic change at the time of execution, this change is often temporary. Research showing long-term effects of these strategies on restoring swallowing physiology is lacking (Zimmerman et al., 2020). In addition, continued use of learned compensatory strategies may limit possible improvement in motor function and swallowing performance (Zimmerman et al., 2020).

Although compensatory strategies may be the only option for some people with chronic or severe dysphagia, the ultimate goal in treatment is to gradually reduce or remove the reliance on compensatory techniques and prioritise behavioural rehabilitative approaches to retrain the swallowing mechanism. Behavioral rehabilitative treatments aim to re-train or restore swallowing physiology through skill- and/or exercise-based training. Strengthening exercises based on exercise physiology guidelines have shown positive results in the literature (Zimmerman et al., 2020). Some training programs may focus on improving lip and tongue muscle strength to improve the oral phase of swallowing, such as the Iowa Oral Performance Instrument (Franciotti et al., 2022), while others may target a combination of muscle groups important to the pharyngeal swallow, such as EMST. EMST targets respiratory and submental (suprahyoid) muscles important for airway safety and opening of the upper esophageal sphincter important for swallow efficiency (Wheeler et al., 2007). Further still some training incorporates both skill and strength based approaches such as the McNeill Dysphagia Training Program (MDTP) (Carnaby-Mann & Crary, 2010). This training program uses swallowing

as an exercise incorporating the use of a hard swallow in combination of a specific hierarchy of food /liquid consistencies to improve the patient's functional swallowing. Providing the patient with biofeedback on the swallowing function during rehabilitative training where applicable has also been shown to be beneficial (Bogaardt et al., 2009; Zimmerman et al., 2020).

Eventual change or improvement in swallowing impairment as a result of treatment can be assessed with clinical non-instrumental and instrumental assessments (Rangarathnam & McCullough, 2016). However, there is a shortage of evidence in the literature from quality randomised control studies examining the effects of rehabilitative treatment methods (Speyer et al., 2010). Likewise, knowledge on the amount of training (frequency, intensity) needed to improve and/or maintain swallowing function is unclear (Langmore & Pisegna, 2015).

Considering the wide variation in underlying diagnosis for OD and the complexities of OD and its comorbidities, the management of OD requires a multiple disciplinary approach. A collaboration of allied health professionals, including speech-language pathologists (SLP), nurses, occupational therapists (OTs), physical therapists, dieticians, respiratory therapists, and diverse physicians is essential in providing optimal OD management. The availability and access to the different medical and allied health professionals will vary depending on the clinical setting (acute care, outpatient clinic, home care), as will the level of knowledge and skills.

In many countries, the SLP has been identified as the "primary" dysphagia clinician and several studies have investigated the level of knowledge, skills and service practices of SLPs (Archer et al., 2013; Carnaby & Harenberg, 2013; Rumbach et al., 2018). Nevertheless, the amount of SLP resources are often less than other professions and the SLP must work closely with other team members. Therefore, the roles may vary and overlap, demanding close communication for optimal and effective treatment planning (McGinnis, 2019). Nurses and OTs are team members that often have a more direct and daily involvement in the management of OD (e.g. monitoring oral intake, helping with oral care, mealtimes, positioning, assistive feeding). However, little is known about the education or training of other health care professions such and nurses and OTs in the field of OD.

Evidence-based practice

Evidence-based practice (EBP) is a decision making approach in clinical practice guided and justified by a combination of current high quality research evidence, clinical expertise/expert opinion and patient preferences (Greenwell & Walsh, 2021). Inclusion of these three main elements in decision making provide clinicians with a scientific foundation for their work. However, evidence-base practice arises from the foundation of ethical practice and professionalism. Thus, although clinical decisions are guided by the research evidence, it is the clinicians' professional ethical standards and expertise in the field of question that will support the decision for each individual patient (Chabon et al., 2011). In 2004, the American Speech-Language-Hearing Association (ASHA) establish a position statement regarding EBP requiring the incorporation of the principles of EBP into the SLPs graduate level education and clinical practice prior to clinical certification (Greenwell & Walsh, 2021). Other countries such as Canada, the United Kingdom and Australia have implemented similar requirements.

Rationale for the studies in the present thesis

Knowledge on the aetiology of a disease or disorder provides fundamental information of the scope or burden of the problem. A considerable amount of the prevalence literature centres on populations according to age or medical diagnosis. However, people with oropharyngeal dysphagia often require institutionalisation due to complications such as pulmonary infection or weight loss. Consequently, healthcare institutions have patients or residents admitted of all ages and with a multitude of diagnosis. There are individual studies presenting data on OD prevalence in some clinical settings, however, overall prevalence of OD in adults admitted to different healthcare settings is unknown.

Access to and use of evidence-based clinical assessment tools are necessary to provide a valid and reliable representation of the scope and severity of OD. This information is essential with regard to many aspects in the rehabilitation of OD; to advocacy for distribution of finances and resources, development of policies and procedures, research, guidance in clinical decision-making and the inclusion of patient perspectives and preferences. In Norway, access to evidence-based tools for the clinical assessment of patients' dysphagia-specific quality of life is non-existent. Hence, there is a need to provide a valid and reliable, culturally

adapted PROM, for the Norwegian population. Additionally, the management of OD requires a multidimensional approach, involving multiple disciplines providing different services. Currently, the professional knowledge base and service practices provided for adults with OD in Norway and other Nordic countries is unexplored.

Treatment for OD aims to improve the safety and efficiency of swallowing by means of compensatory and rehabilitative methods. The use of compensatory strategies to improve the symptoms of OD has been a major focus of OD management, while evidence supporting the efficacy of rehabilitative methods is needed. Rehabilitative methods that alter the physiology of the swallow, such as EMST have shown promising results in populations such as Parkinson's disease and multiple sclerosis (Claus et al., 2021; Silverman et al., 2017; Troche et al., 2010).

Aims and research questions

The overall aim of this doctoral thesis is to contribute to a stronger evidence base for the identification and treatment of adults with OD. The aims and research questions, respectively, for each study were as follows:

I. Aim: Translate and validate the Norwegian version of the Swallowing Quality of Life questionnaire (Nor-SWAL-QOL).

   Research question: Is the Norwegian version of the Swallowing Quality of Life questionnaire reliable and valid?

II. Aim: Establish new epidemiological knowledge in OD through a systematic literature review.

   Research question: What is the prevalence of OD in adults in different healthcare settings?

III. Aim: Investigate interdisciplinary training and clinical practices in the identification and management of OD.

   Research question: What are the general qualifications, clinical competencies and service practices for nurses, OTs and SLPs working with adults with OD in the Nordic countries?

IV. Aim: Examine the effects of treatment with expiratory muscle strength training on swallowing function in people with Parkinson's disease (PD) or multiple sclerosis (MS) as assessed by flexible endoscopic evaluation of swallowing.

   Research question: Is there a change in swallowing safety and/or efficiency, and self-perceived swallowing difficulties following EMST in people with PD or MS?

Materials and Methods

This thesis includes four studies with three different study designs.

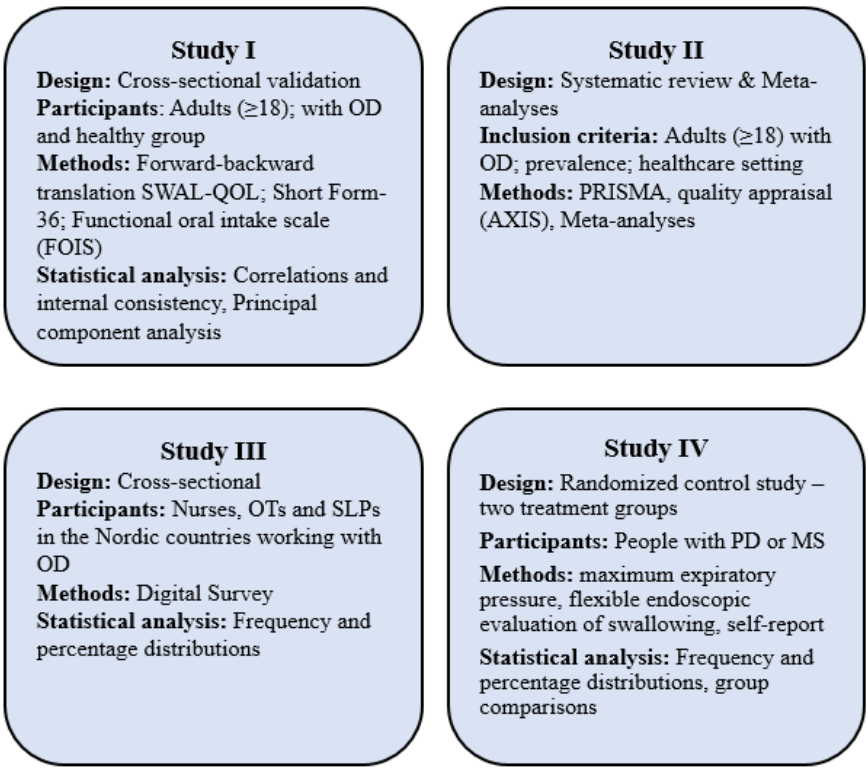

Figure 2*.Overview of the design, participants, methods and statistical analyses of the four thesis papers.*

Study I

The first study, a cultural adaptation and validation of a Norwegian version of the Swallowing quality of life (SWAL-QOL) questionnaire, was completed to provide clinicians and researchers access to a valid and reliable patient-report outcome measure for an adult Norwegian population.

Dysphagia-specific health-related quality of life

There are several dysphagia-specific health-related quality of life (HRQoL) measurement tools available in the literature. Some have been developed to assess the quality of life for specific diagnoses such as the MD Anderson Dysphagia Inventory (MDADI) developed for people with head and neck cancer (Chen et al., 2001). While others, such as the Eating Assessment Tool (EAT-10), are symptom-specific outcome tools for people with either oropharyngeal or esophageal dysphagia (Belafsky et al., 2008). The SWAL-QOL questionnaire underwent a rigorous development process, was found to have adequate psychometric properties and was applicable to a diverse adult patient population (McHorney, Bricker, Kramer, et al., 2000; McHorney, Bricker, Robbins, et al., 2000; McHorney et al., 2002). The SWAL-QOL has been considered a "gold standard" and used as a reference tool in determining the psychometric properties of other dysphagia specific quality of life questionnaires (Speyer et al., 2011). The questionnaire consists of 44 items including 10 concepts (burden, food selection, eating desire, eating duration, fear, sleep, fatigue, mental health, social and communication) and a 14-item symptom scale. Items were written in a simple, conversational language and comparable to a fifth-grade reading level. The administration time of the SWAL-QOL was estimated to be 15 -20 minutes and it was designed to either be self-administered, administered by an interviewer or completed by a proxy such as a family member or assistant. The later characteristics were considered important for the inclusion of populations with communication disorders.

Translation and cultural adaptation

The translation of an assessment tool is an extensive and time-consuming process. In addition, there is no clear evidence base for the best method for completing this process. The methodological approach to translation and adaptation was based on international guidelines by Beaton and colleagues (Beaton et al., 2000). Figure 3 provides a description of the translation process.

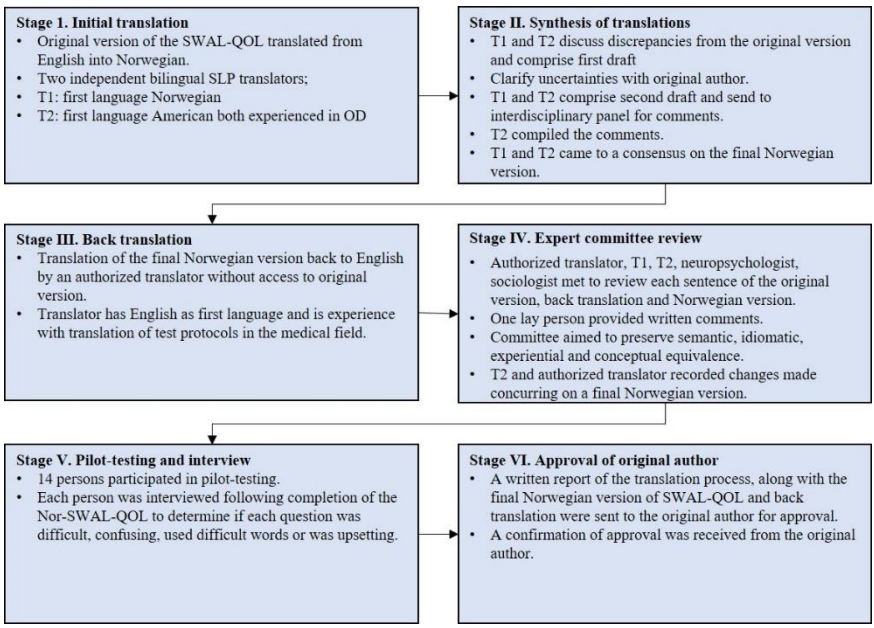

***Figure 3**. Description of the contents in each stage in the translation process in Study I.*

Participants

Finding a clear evidence base on how to determine sample size for validation studies was difficult. It was decided to use the "rule of thumb" recommendation of 12-15 observations per concept (Campbell, 2008). The SWAL-QOL has 10 domains, thus, the goal was to include 120-150 participants.

An inspection of medical records at Sunnaas Rehabilitation was completed, encompassing a four-year period from January 2014 to February 2018. Identification of possible participants through medical records was limited to the key word "videofluoroscopy" because physician coding of OD (ICD-10, R.13) was not

common practice. Included participants were at least 18 years of age and had undergone the Mann Assessment of Swallowing Ability (MASA) and videofluoroscopic swallow study (VFSS). Potential participants were excluded if they were unable to provide informed consent, were unable to understand written or spoken Norwegian, denied having OD or had evidence of pure esophageal dysphagia. Following a check for duplicates (i.e. re-admissions) and deceased, the search identified 305 adults with OD that were considered eligible for inclusion in this study. Each of the 305 potential participants with OD were sent a cover letter providing information on the purpose and contents of the envelope; an ethically approved consent letter, and two questionnaires (SF-36 and Nor-SWAL-QOL). Instructions were provided on how to complete and return the enclosed forms using a stamped addressed envelope. Individuals that did not wish to participate in the study were encouraged to indicate why by choosing one of two options for non-participation: 1) no swallowing difficulties or 2) other reasons, and return the cover letter with this information. Information on reason for non-participation allowed us to determine non-response percentage. Of the 305 potential participants, 231 persons responded to the survey. One hundred and three respondents declined participation and seven persons did not meet inclusion criteria, resulting in 121 participants. To determine test-retest reliability, thirty-four participants with OD completed and returned the SWAL-QOL a second time after 2-3 weeks.

A group of 123 healthy adults were recruited as a control group. Recruitment was completed via hanging flyers in public areas (i.e. shopping malls, food stores), announcements posted on social media (Facebook, LinkedIn, Norwegian SLP network) and snowballing. In addition, the doctoral candidate gave oral presentations at patient/caregiver association meetings and written project announcements in two patient membership magazines (Stroke, Head and Neck Cancer). Potential participants denied having neurological illness/injury or subjective oropharyngeal or esophageal dysphagia.

The Short Form-36 (SF-36), a patient-report survey for general health status, was used for validity testing. This form has 36 questions covering eight health concepts: physical functioning, role limitations due to emotional problems and social functional functioning, emotional well-being, energy/fatigue, pain and general health perceptions. The FOIS was administered via telephone interview with each participant or family member when appropriate.

User participation

Collaboration with the Norwegian Association for Stroke Survivors was established early in the planning of this study. Two members of local patient organisations: The Norwegian Association for Stroke Survivors (NFS) and The Head and Neck Cancer Association (MHKF) were involved in the translation and cultural adaptation of the SWAL-QOL. These associations also assisted in spreading information about this study with its members.

Statistical analysis

Construct validity: Convergent and discriminant validity were determined by correlation analysis (Spearman rho test) of data from the OD group from the Nor-SWAL-QOL and the Norwegian version of SF-36. Bonferroni-correction was used given the existence of multiple correlations. Known-groups validity was tested by comparing Nor-SWAL-QOL scores for healthy controls and study group with OD using the Mann-Whitney *U* test. A principle component analysis (PCA) was completed. The Functional Oral Intake Scale (FOIS) was used to document eventual solid/liquid restrictions and amount of oral intake vs enteral feeding for each participant with OD.

Reliability: Reliability analysis for internal consistency, test-retest and intra-class correlations coefficient (ICC) were completed.

Study II

In study II, a systematic literature review and meta-analyses were performed to determine the estimated OD prevalence of adults with OD in the hospital, rehabilitation, nursing home and palliative care settings.

The protocol for this systematic review and meta-analyses was registered with the international prospective register of systematic reviews (PROSPERO) in August of 2019. The findings were reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Liberati et al., 2009).

Study inclusion and exclusion criteria

To be eligible for inclusion in this systematic review, studies needed to report on persons with OD, provide data on prevalence, frequency or incidence, include adults at least 18 years of age and refer to healthcare settings such as hospital, rehabilitation, nursing homes or palliative care. Only studies in English were included. In order to minimize selection bias, studies that had prevalence estimates based on preselected groups (e.g. selection of adults by previous OD screening, specific comorbidity or surgical procedures) were excluded. Lastly, studies with sample sizes ≤30 participants were excluded in order to improve the level of precision in prevalence estimation.

Information sources and search strategy

A literature search of two electronic databases, Embase and PubMed was completed on March 30, 2021. All publications dates up to the search date were included. Three main categories of the terms dysphagia, prevalence and clinical settings (hospital, rehabilitation, nursing home and palliative care) were used in combination. Search strategies were performed in both electronic databases using subheadings (i.e. MeSH and Thesaurus terms). In addition, free text terms were included in combination with field searches (Title/Abstract) and truncation (i.e., wildcards). In order to identify additional eligible articles, a search of the reference lists of each eligible full-text article was completed.

Two independent reviewers completed two training sessions on a total sample of 200 abstracts. The purpose of this was to establish a consensus on the interpretation of the eligibility criteria. These two reviewers independently screened all titles and abstracts for eligibility, after which the two same reviewers independently reviewed and assessed the eligibility of the identified full-text articles. Any unresolved discrepancies on inclusion between reviewers was resolved by consensus consultation with a third reviewer, having extensive experience in systematic review methodology.

Systematic Review

Methodological quality and risk of bias

Two independent reviewers used the AXIS critical appraisal tool (Downes et al., 2016) to assess and provide a consensus-based rating on the methodological quality of the included articles. The AXIS includes 20 question checklist that follows the general outline and addresses common methodological issues of a cross sectional paper. Questions were answered "yes" (score of 1), "no" (score of 0) or "do not know". A maximum AXIS score of 20, reflecting good methodological quality, was possible; however not all questions were applicable to each study. Thus, total scores were converted into percentage scores; total score divided by the maximum score possible and multiplied by one hundred (Speyer et al., 2019).

Data extraction

The following information was extracted from the included articles in the systematic review: author and journal, study design and AXIS score, study setting, country and study period, underlying medical diagnosis, recruitment criteria and time of screening/assessment, age and gender of the sample population, OD terminology used, OD screening and assessment methods used and test administrator(s), and OD prevalence data.

Data synthesis and risk of bias

The information and data were entered into data extraction forms. Risk of bias assessment were completed for the included articles using AXIS. Two reviewers independently assessed abstracts, full-text eligibility and methodological quality of included articles. Eventual discrepancies were settled by consensus between the two reviewers. A third reviewer was consulted for additional consensus when needed.

Meta-Analyses

Studies that raised concerns regarding data completeness, quality, validity, reliability and possible selection or recall bias were excluded from the meta-analyses in order to reduce heterogeneity. Subsampling was completed to determine

within-group OD prevalence for the different clinical settings (hospital, rehabilitation and nursing home). In addition, subsampling for between-group prevalence was performed to detect confounding variables for type of assessment method, diagnosis group and type of hospital ward for each setting when applicable. The software program Comprehensive Meta-Analysis, Version 3.0 was used to provide estimated pooled prevalence and forest plots. A random-effects model was used due to the heterogeneity of the included articles. Heterogeneity was estimated using the Q statistic to determine the spread of effect sizes about the mean and I^2 to estimate the ratio of true variance to total variance. Assessment of publication bias was determined by the classic fail-safe N test.

Study III

The third study aimed to provide insight into the qualifications, professional roles and service practices that nurses, occupational therapists (OTs) and speech-language pathologists (SLPs) had in the management of adults with OD in the Nordic countries (Denmark, Finland, Iceland, Norway and Sweden).

Survey development

A self-administered digital survey was developed with close assistance of co-supervisor (R.S.) and was based on earlier survey studies in the literature as well as experience from clinical practice. Six allied health professionals, from Australia, Denmark, Sweden and Norway, assisted in piloting the survey. All were experienced in working with adults with OD, research and survey development. Suggestions from the piloting phase were implemented in the final survey where appropriate and possible. Adjustments were made included: simplified sentence formulation, use of terminology clarifications, consistency in terminology use, reduction in the use of abbreviations and in the number of multiple choice options. There were comments from the piloting professionals on the limitations in the digital format of the survey, particularly regarding the lack of branching logic, which allows the survey to jump over irrelevant questions depending on the respondents' choices.

Survey items included matrix and multiple choice questions, ordinal scales and text boxes for additional comments. There were 14 survey questions pertaining to

demographic information (e.g. age group, gender, profession) for participants that did not work with adults with OD. Participants that had worked with adults with OD within the past 12 months answered the same questions pertaining to demographic information, in addition to 36 more detailed questions pertaining to type of workplace and professional practices in screening, assessment and treatment of adults with OD. The short survey was expected to take 5-10 minutes, while the entire survey was expected to take approximately 30 minutes. Participants were required to answer each question in order to continue the survey and it was not possible to save the survey to continue later.

The survey was in English for the sake of using one familiar language for all participants and allow for consistent interpretation of the data. Short terminology definitions were provided, (e.g. management=screening, assessment and/or treatment). In addition, italics, underlining and bold print were used in order to provide emphasis on important aspects of the instructions.

Participants

All currently employed nurses, occupational therapists (OTs) and speech-language pathologists (SLPs) working in the Nordic countries were eligible to participate in this survey.

Recruitment

This digital survey collected data via convenience and snowball sampling. First, a collaboration via email was established with contact persons listed for professional associations for each country identified through internet searches. Some associations had restrictions for global distributions to its members, but supplied contact information for regional associations and professional subgroups (e.g. network for rehabilitation nursing). The email included an invitation to participate in a research project, explained the purpose of the survey and asked permission to send a digital link to the survey via email on a predetermined date. An invitation to participate and information about the study, with a link to the digital survey, was also distributed on social media (e.g. Facebook, LinkedIn), via online professional and dysphagia networks and snowballing. Three reminders were sent to collaborating professional associations, subgroups, networks and social media. Each professional association was asked to give an estimate of current members including a percent of which were “active” or practicing professionals. These estimates were used to provide an estimate of the prevalence of

nurses, OTs and SLPs per capita in the Nordic countries published as supplementary material in *Study III*. The recruitment period was from April 1, 2018 to September 15, 2019.

Data analysis

The digital survey data was downloaded onto a Microsoft Excel spreadsheet from the University of Oslo Central IT department (USIT). Data were analysed using IBM SPSS Statistics version 26 (IBM SPSS Statistics for Windows, 2019). The data was organised into frequency and percentage distributions.

Study IV

The purpose of the fourth and final study of this thesis was to explore the effects of expiratory muscle strength training (EMST) on swallowing function in people with Parkinson's disease (PD) or multiple sclerosis (MS) as assessed by flexible endoscopic evaluation of swallowing (FEES).

Recruitment and participants

This study originated from a collaboration between two Swedish hospital clinics. People with PD or MS were invited to participate in this study between March and August 2019. Potential participants were provided with both verbal and written information about the study.

The study included participants that reported experiencing a change in speech and swallowing function due to PD or MS and felt like they ran out of breath while speaking. Other inclusion criteria was a score of four or less on the modified Hoehn & Yahr scale (H&Y) for PD (Goetz et al., 2004) and five or less on the Expanded Disability Status Scale (EDSS) for MS (Kurtzke, 1983). A neurologist assessed the level of disease severity. Neurologist assessments of participants with MS was inevitably delayed until after study intervention had begun. At this time, it was discovered that all eligible participants with MS scored higher on the EDSS than the original criteria, thus this criteria was changed. All eligible participants with MS had EDSS scores of 5-8. Further, participants with

a history of other neurological illness affecting swallowing, respiratory illness, smoking the past five years or high blood pressure were excluded from the study. Eligible patients that agreed to participate provided written consent and underwent additional assessments for inclusion: a score of ≥25 on the Mini Mental State Examination (MMSE) (Folstein et al., 1975) and achieve a minimum resistance level of 30 cm H_2O when blowing into the EMST150 device.

All eligible participants were randomised into two groups and informed that they would receive EMST, with or without resistance (sham). Participants were blinded (not informed) to which group would receive EMST or sham. Figure 4 gives an overview of the study design. There were two licensed SLPs at each hospital clinic that were responsible for randomization, weekly calibration of MEP target threshold, administration of FEES and SSQ, thus they were not blinded for the participants stage of treatment.

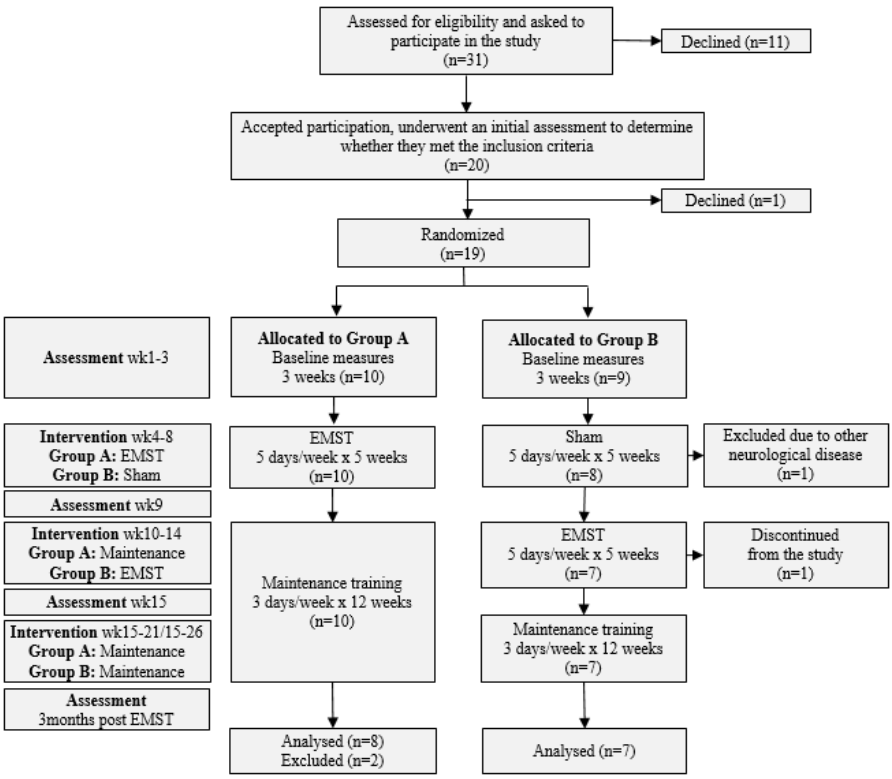

Figure 4. *Overview of study design for study IV.*

Procedures

EMST

The participants were instructed on how to use EMST150 device and to train five days per week for 5 weeks. The participants were instructed to take a deep breath and blow forcefully into the EMST150 device, rest 15-20 seconds, then repeat five times. After each set of five repetitions, the participant took a longer rest (1 min.). One training session consisted of five sets of five repetitions, totalling 25 repetitions. Participants trained independently in their homes, received written instructions on how to perform EMST and asked to keep a training log throughout the study.

Group A participants began with EMST while those in Group B completed sham training for five weeks. Sham participants followed the same procedure for training, but their EMST device consisted only of the mouthpiece, thus, providing no resistance. After group B completed five weeks of sham training, they complete five weeks of EMST. Following the five-weeks of EMST each group completed 12 weeks of maintenance training with EMST. Target thresholds for the maintenance period were set at the level that was achieved during the final week of the EMST period.

Assessments

Participants were assessed at baseline and following each stage of treatment. Measurement of maximum expiratory pressure was done with a digital manometer (MicroRPM) that measures expiratory pressure in cm H_2O. Participants were instructed to take a large breath (inhale) and then blow out (exhale) as forcefully as possible into the manometer. This was repeated up to ten times and the three highest MEP values within 10% of variance from each other were averaged to provide a mean MEP. The patients met once weekly with the SLP to adjust the level of resistance on the EMST device. The target threshold was set at 75% of maximum when possible, but adjusted down for participants that were unable to perform at 75% MEP.

The structure of the FEES examination was based on the standardised Langmore protocol; an initial anatomic and physiologic inspection followed by swallowing of food and liquid. Each participant was given the same amounts and types of food/liquid, in the same order of presentation. Food and liquid consistencies were defined based on the International Dysphagia Diet Standardisation Initiative (IDDSI) (Cichero et al., 2017). A different food colouring was used for each consistency. Participants were encouraged to feed themselves during the assessment; otherwise, help was available if needed. Outcome measures used to interpret swallow safety and efficiency from the FEES were the PAS and YPRSRS. FEES examinations were recorded and later scored by an independent SLP, who was blinded to participant's stage of intervention.

Each participant filled out the SSQ prior to the FEES assessment. The purpose of this was to capture the patient's perspective following the intervention period without the influence from the FEES results.

Intra-rater reliability

In order to determine an intra-rater reliability, ten percent (6/52) of the FEES recordings were scored two times with a two-three week time-lapse in-between. A point-by-point absolute agreement determined intra-rater reliability. Determining an intra-class correlation coefficient was not possible due to the small sample and low variability in PAS and YPRSRS scores.

Statistical analysis

In order to simplify the results, the worst score for three 10ml swallows of each consistency (thick liquid, thin liquid, puree and ½ cracker) were used in the analysis for the PAS and YPRSRS. A decrease in PAS score by at least one level of severity was considered a clinically relevant improvement. A clinically relevant improvement on the YPRSRS was a decrease in two or more levels of severity. The non-parametric Mann-Whitney Rank Sum test was used for baseline group comparisons. The mean rank differences in MEP values and SSQ total scores between treatment phases from baseline to 3-months post-EMST were determined with the Wilcoxon signed-rank test. Level of significance was set at $p<0.05$ for all comparisons. Statistical analysis were performed using IBM SPSS Statistics for Windows, version 28 (IBM Corp. Armonk, N.Y., USA).

Ethical considerations

Study I was approved by the Regional Committees for Medical and Health Research Ethics (2017/356 REK). All participants provided written agreement to participate in this study. *Study II* was a systematic review and meta-analyses based on published papers. *Study III* was a survey questionnaire for health care professionals and did not require ethical approval as there was no intent to register health information from participants; however, approval was acquired from the Norwegian Centre for Research Data AS (NSD). The Swedish Ethical Review Authority (Dnr 2019-01402) gave permission for *Study IV*.

Results

Study I

Cultural adaptation and validation of the Norwegian version of the swallowing quality of life questionnaire (SWAL-QOL).

The research question for *Study I* was:

> Is the Norwegian version of the Swallowing Quality of Life questionnaire (SWAL-QOL) reliable and valid?

Participants

The study sample included 102 participants with a ratio of men/women of 6:4, and ages ranging from 24-87 years. Nearly 60% had a neurological diagnosis, 15% head and neck cancer, 18% had other diagnosis and the remaining had diagnosis of unknown origin. Ninety percent of the study group had chronic OD (>12months) and over 60% required diet modifications or were tube fed. Results from the FOIS revealed that only about one-quarter (26%) of the study group were able to eat and drink what they wanted, without restrictions. Age and gender differences were significant between the OD and control groups; however, a weighted adjustment revealed that the differences would not affect the results of the analysis.

Reliability

Table 2 shows the reliability results for the Norwegian version of the SWAL-QOL. The internal consistency, extent for which the items in the questionnaire are measuring the same concept, was acceptable for all 10 subscales and the symptom frequency scale (Cronbach's α >0.70). All but two of the subscales (eating duration and eating desire) met the recommended Cronbach's α >0.80 for group level research (McHorney et al., 2002). A test-retest analysis revealed moderate to strong reliability (0.68–0.90) supporting the questionnaires' ability to provide consistent results over time. Intraclass correlation coefficient values showed moderate (0.67; 95% CI 0.43–0.82) to good (0.89; 95% CI 0.79–0.95) reliability (Koo & Li, 2016).

Table 2. *Reliability estimates for Norwegian version of the Swallowing Quality of Life (Nor-SWAL-QOL) in Study I.*

Nor-SWAL-QOL	Internal consistency (Cronbach's α)	*n*=	Test-retest[a] (Spearman's r_s)	*n*=	Intraclass correlation
Burden	0.85	101	0.68*	34	0.67
Food selection	0.85	102	0.83*	34	0.81
Eating duration	0.73	102	0.74*	34	0.74
Eating desire	0.73	100	0.73*	33	0.75
Fear	0.80	101	0.66*	33	0.67
Sleep	0.82	101	0.82*	34	0.82
Fatigue	0.89	98	0.84*	34	0.85
Communication	0.95	99	0.85*	33	0.88
Mental health	0.91	101	0.77*	34	0.79
Social functioning	0.91	98	0.85*	34	0.84
Symptom frequency battery	0.87	89	0.90*	33	0.89

[a]*Test-retest average time interval 18.5 days; *Correlation is significant at p<0.01*

Validity

Construct validity was determined by assessing convergent, discriminant and known-groups validity. Convergent validity was evident by the significant correlations found between the Nor-SWAL-QOL subscales (burden, food selection, sleep, fatigue, mental health and social functioning) and several of the SF-36 domains (role physical, general health, vitality, social functioning and mental health).

Discriminant validity was demonstrated by non-significant correlations occurring between the Nor-SWAL-QOL subscales eating duration, fear of eating and communication and any of the SF-36 domains. Eating desire and symptom frequency battery had low but significant correlation with only one domain in the SF-36. There was also no significant correlation between SF-36 domains physical functioning and role emotional with any of the Nor-SWAL-QOL subscales.
The Mann-Whitney *U* test revealed statistically significant differences between the OD and control group mean scores on all Nor-SWAL-QOL subscales. In addition, large effect sizes for all subscales, except for the sleep subscale, show clinical relevance for group comparisons. Statistically significant differences and large effect sizes were found between the OD and control groups for all items on

the symptom frequency battery. Table 3 displays the results supporting known-groups validity of the Nor-SWAL-QOL. Mean scores on all Nor-SWAL-QOL subscales were significantly lower (worse) for participants with OD than the control group. Effect sizes were large (0.62-0.91) for all subscales except the sleep subscale (Field, 2013).

Table 3. *Construct validity; differences on the Nor-SWAL-QOL between OD and control group (known-groups validity) from Study I.*

Nor-SWAL-QOL	OD group		Control group		Mann-Whitney *U*	Effect size *r*
	n	Mean (SD)	*n*	Mean (SD)	Sign. (two-tailed)	
Burden	101	44.6 (28.2)	123	99.9 (1.1)	*p<0.001*	0.91
Food selection	102	57.3 (31.7)	123	99.4 (3.9)	*p<0.001*	0.81
Eating duration	102	40.0 (29.7)	122	98.9 (4.4)	*p<0.001*	0.87
Eating desire	102	65.6 (28.9)	122	97.5 (8.8)	*p<0.001*	0.73
Fear of eating	102	62.3 (27.6)	123	99.5 (2.3)	*p<0.001*	0.83
Sleep	102	60.0 (31.0)	123	86.5 (18.5)	*p<0.001*	0.45
Fatigue	101	52.9 (28.2)	123	87.5 (16.5)	*p<0.001*	0.62
Communication	102	61.9 (33.0)	123	99.7 (2.5)	*p<0.001*	0.76
Mental Health	102	46.3 (28.2)	123	99.9 (.902)	*p<0.001*	0.91
Social functioning	102	54.4 (31.4)	123	100 (.000)	*p<0.001*	0.85
Symptom frequency battery	99	55.6 (19.4)	123	97.5 (4.2)	*p<0.001*	0.86

Results from the principle components analysis indicated that the Nor-SWAL-QOL was different from the original in that three components had an eigenvalue greater than one, rather than two.

Further analysis to assess validity and test the hypotheses about the Nor-SWAL-QOL's sensitivity to severity were completed with the Kruskal-Wallis test. Nor-SWAL-QOL scores for within the OD group were stratified according to necessary bolus modifications and if they were dependent on a feeding tube for nutrition or not. Results showed that OD participants that ate pureed/blended food, no liquids and/or thickened liquids showed statistically significantly lower scores than those that ate regular food, thickened liquids and/or thin liquids on subscales food selection, eating duration, eating desire, communication and social functioning. Similar results were found for participants that were tube fed and those that were not tube fed. Statistically significant lower scores were also found on symptom battery scores for participants that ate pureed/blended food, than for those that ate regular consistency food, and for those that were tube fed compared to those that were not tube fed. Thus, the Nor-SWAL-QOL has shown that it is sensitive to severity, as lower scores correspond to more severe difficulty.

Study II

Prevalence of oropharyngeal dysphagia in adults in different healthcare settings: a systematic review and meta-analyses

The research question for *Study II* was:
What is the prevalence of OD in adults in different healthcare settings?

There were 256 full-text articles assessed for eligibility, resulting in 44 papers that met inclusion criteria for final review. Figure 5 shows the flow diagram of study identification.

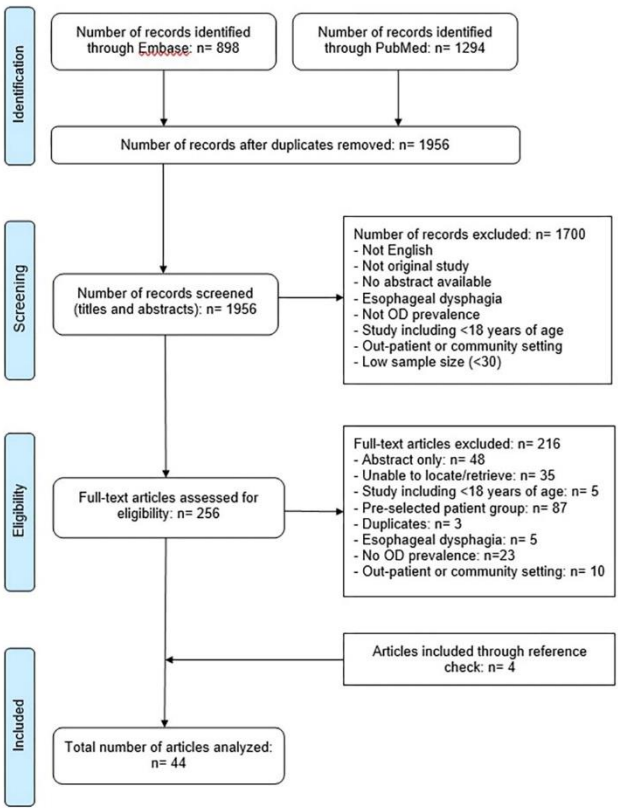

Figure 5. *PRISMA flow diagram for Study II.*

Methodological quality

The mean total AXIS score and percentage for included articles was 15.3 (SD2.2; range 10-19) and 77% (SD 11; range 50-95), respectively. Just over half of the articles (24/44) scored above 75% and 18/44 scored above 50% and below or equal to 75%. The remaining two articles scored 50% or lower.

Study Characteristics

All extracted data are summarised and presented in Table 2 in the published article. The large majority of included articles were published after 2010. The articles originated from 23 countries, representing 5 continents and over half were from Europe. Thirty-two articles presented OD prevalence from hospitals, four from rehabilitation and 12 from the nursing home settings. Two studies had datasets from two different settings and one study had datasets for all three settings, resulting in the inclusion of 48 datasets for OD prevalence. There were no articles identified from the palliative care setting that met the inclusion criteria. The mean age from the 42 out of 44 studies that reported age, was 75 years (SD10; range 54-106 years). Nineteen studies included stroke, 15/44 included diverse diagnoses (e.g. geriatrics, fractures, head and neck cancer), one study included only dementia and the remaining nine studies had no specific diagnosis.

Type and timing of screening or assessment method

The type of screenings and assessment formats used varied in all settings, including chart review, survey, PROM, screening, non-instrumental CSA and instrumental assessment. Nearly 60% of the studies used screening or non-instrumental CSA that were designed or adapted for the purpose of the study, therefore, not providing information on diagnostic performance and psychometric properties. The most frequently used screening, non-instrumental CSA and PROM were the Volume-Viscosity Swallow Test (V-VST), Mann Assessment of Swallowing Ability (MASA) and Eating Assessment Tool-10 (EAT-10), respectively. The timing of screening administration was primarily reported from the hospital setting (21/24) as time post-stroke (7/21) or post-admission (14/21). Time of screen or assessment were reported in three studies from the rehabilitation setting, distinguished by the number of hours or days from admission. There was no specified timing of screen or assessment from the nursing home setting.

Meta-analyses

Twenty-two studies met the pre-defined criteria for inclusion in the meta-analyses: 17 from the hospital, two from rehabilitation and three from nursing home settings. Included studies used screenings, non-instrumental clinical swallowing assessments, PROM, instrumental assessments or a combination of these.

Prevalence per healthcare setting

Hospital

OD prevalence data from 17 hospitals studies are shown in Figure 6. Random effects meta-analysis revealed an overall pooled OD prevalence estimate of 36.5% (95% confidence interval [CI] 29.9-43.6). Between-group analysis for type of assessment (screening vs non-instrumental CSA), diagnosis and type of ward were performed. Twelve studies used screening and four used non-instrumental CSA resulting in pooled OD prevalence estimates of 35.6% (95% CI 27.6 − 44.5) and 41.8% (95% CI 27.4 − 57.7), respectively. Between-group analysis for stroke (11/17) and mixed diagnosis (5/17) resulted in pooled OD prevalence estimates of 37.5% (95% CI 28.7–47.2) and 34.4% (95% CI 22.5–48.6), respectively. Type of ward in the hospital setting revealed the highest estimated OD pooled prevalence for geriatric wards (3/17) 51.1% (95% CI 35.0–67.0), followed by 35.3% (95% CI 27.2–44.2) for general or non-specified wards (10/17), and 29.1% (95% CI 18.5–42.6) for stroke wards (4/17). None of the between-group differences were significant. This meta-analysis included data from 17 studies, which yielded a z-value of -12.00171 and corresponding 2-tailed p-value <0.001. The fail-safe N is 621. This means that we would need to locate and include 621 "null" studies in order for the combined 2-tailed p-value to exceed 0.050.

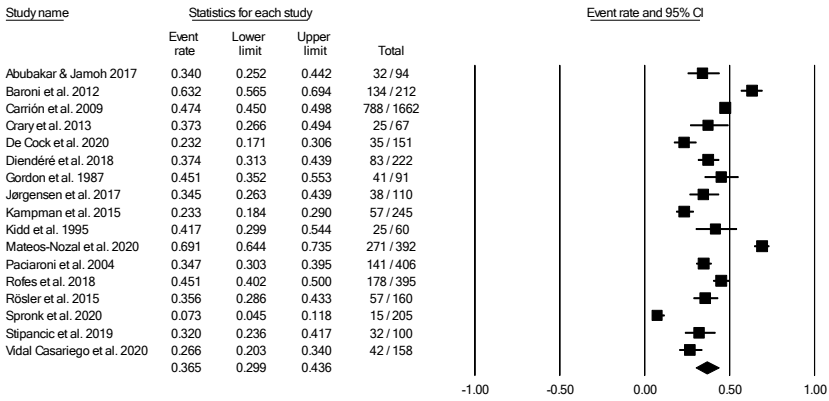

Figure 6. *Random effects forest plot for overall pooled OD prevalence estimate in the hospital setting from Study II. Note: Event rates (prevalence) reported with lower and upper limit (95% CI). The total refers to the ratio of persons with OD versus total group. Heterogeneity:* $Q^2=322$, $df=16$, $p<0.001$, $I^2=95\%$

Rehabilitation

Results for the meta-analysis of two studies in the rehabilitation setting are displayed in Figure 7. Findings revealed an estimated overall pooled OD prevalence of 42.5% (95% CI 35.8–49.5). Both studies used non-instrumental CSA. As there were only two studies included in this meta-analysis, a fail-safe N analysis for publication bias was not available.

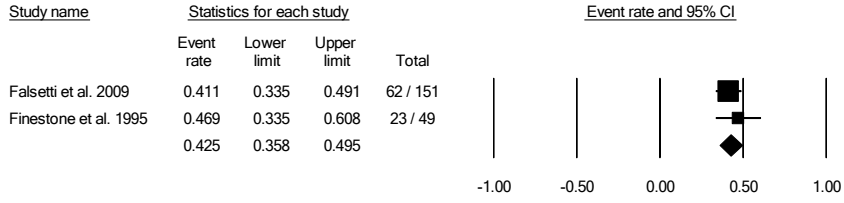

Figure 7. *Random-effects forest plot for overall pooled OD prevalence estimate in the rehabilitation setting from Study II. Note: Event rates (prevalence) reported with lower and upper limit (95% CI). The total refers to the ratio of persons with OD versus total group. Heterogeneity:* $Q^2=0.5$, $df=1$, $p=0.470$, $I^2=0\%$.

Nursing home

Figure 8 reveals an overall pooled OD prevalence estimate from three studies from the nursing home setting of 50.2% (95%CI 33.3–67.2). Two studies used screening and one used a PROM, resulting in estimated pooled OD prevalence of 58.1% (95% CI 47.3–68.2) and 35.0% (95% CI 22.8–49.5), respectively. These between-group estimates were significantly different (p = 0.012). This meta-analysis incorporates data from three studies, which yield a z-value of − 1.11840 and corresponding 2-tailed p-value of 0.263. Since the combined result is not statistically significant, the fail-safe N (which addresses the concern that the observed significance may be spurious) is not relevant.

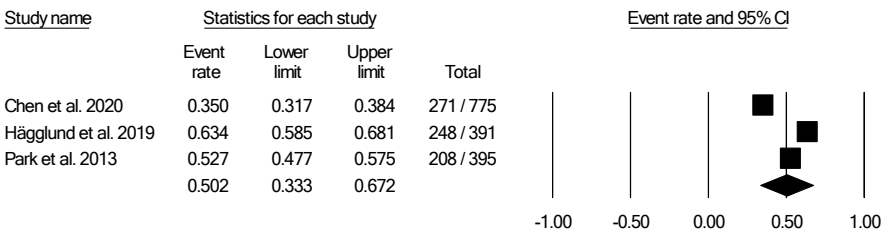

Figure 8. *Random-effects forest plot overall OD prevalence estimate in the nursing home setting from Study II. Note: Event rates (prevalence) reported with lower and upper limit (95% CI). The total refers to the ratio of persons with OD versus total group. Heterogeneity:* $Q^2=90$, $df=2$, $p<0.001$, $I^2=98\%$.

Study III

Qualifications, professional roles and service practices of nurses, occupational therapists and speech-language pathologists in the management of adults with oropharyngeal dysphagia: A Nordic survey

The research question for *Study III* was:

> What are the general qualifications, clinical competencies and service practices for nurses, OTs and SLPs working with adults with OD in the Nordic countries?

The survey data allowed us to address the following questions:

1. What is the level of education and self-reported expertise in OD management for Nordic nurses, OTs and SLPs?
2. Which professionals usually perform the OD screening and non-instrumental clinical assessments, and what tools are used to identify and diagnose OD?
3. What is the availability and use of instrumental clinical assessment procedures and what instrumental measurement tools are used for OD diagnosis in the Nordic countries?
4. What interventions do nurses, OTs and SLPs use for OD and how often do they participate in multidisciplinary meetings?
5. How do the roles for nurses, OTs and SLPs in OD management differ between countries?

Participant demographics, workplace and level of experience working with adults with OD

There was a total of 1023 respondent to the survey, 12 respondents were exclude due to not currently practicing in their profession (n=8) and having an "other" profession (n=4) than the target professions. The demographics for the sample of respondents working with adults with OD are presented in Table 4.

Table 4. *Study III demographics for respondents (n=396).*

Characteristics	*n* (%)
Gender (female)	(*n*=396)
	364 (91.9)
Age (years)	(*n*=396)
21-25	14 (3.5)
26-35	138 (34.8)
36-45	132 (33.3)
46-55	74 (18.7)
>55	38 (9.6)
Profession	(*n*=396)
Nurse	50 (12.6)
Occupational Therapist	224 (56.6)
Speech-Language Pathologist	122 (30.8)
Country of employment	(*n*=396)
Denmark	217 (54.8)
Finland	34 (8.6)
Iceland	14 (3.5)
Norway	70 (17.7)
Sweden	61 (15.4)
Level of education	(*n*=393)
Bachelor	276 (70.2)
Masters	107 (27.3)
Doctorate	10 (2.6)
Years in profession	(*n*=396)
<1 year	32 (8.1)
1-2 years	38 (9.6)
3-5 years	63 (15.9)
6-10 years	75 (18.9)
11-15 years	66 (16.7)
16-25 years	83 (21.0)
>25 years	39 (9.8)

The majority of the respondents were OTs (*n*=224; 56%) mostly from Denmark, while 31% were SLPs (*n*=122) and 13% were nurses (*n*=50). Most respondents worked in urban/metropolitan areas (350/396; 88%). Distribution of work settings were inpatient rehabilitation (*n*=110), acute care settings (*n*=143), outpatient clinic/rehabilitation (*n*=64), long-term care/nursing home/day care (*n*=43), private practice/in-home care (*n*=22), academic/university patient clinic (*n*=8) and other (*n*=6). The level of experience working with adults with OD varied. Nearly half of the nurses (22/50; 44%) had 6-15 years, while OTs (110/224; 49%) and SLPs (61/122; 50%) had ≤5 years of experience working with adults with OD.

Level of education and self-reported expertise in OD management for Nordic nurses, OTs and SLPs

The majority of respondents completed their professional education from 2000-2019 (302/396). Most nurses and OTs had a bachelor (3-4 years), while most SLPs had a master level education (4-6 years). Most survey respondents reported receiving 1-5 lecture hours (177/396; 45%) and none (105/396; 26%) or less than ½-1 day (146/396; 37%) of supervised training in OD during their professional education. Considering possible changes in education curriculum over time, a post hoc analysis was performed for number of lecture hours and supervised training, comparing those that were educated from 2009-2019 and those educated prior to 2009. An increase in SLP supervised training in OD was the only significant difference found in the past decade. The type of post-graduate training that most professionals participated in was varied. Most nurses participated in internships or training by colleagues, while OTs and SLPs attended local dysphagia networks and workshop/conferences/research symposiums, respectively. The most reported reasons for not partaking in post-graduate training were lack of available training offered in the profession (nurses), financial reasons (OTs and SLPs) and lack of available time to attend (SLPs).

Most nurses, OTs and SLPs reported above average/high level of expertise for screening (203/388; 52.3%) and non-instrumental CSA (197/386; 51.0%). A larger percent of nurses (39/48; 81.3%) and OTs (155/217; 70.8%) reported no expertise (233/386; 57.8%) with instrumental assessments (FEES, VFSS), while SLPs reported very high/above average (37/121; 30.6%) or average (34/121; 28.1%) expertise. Most OTs ranked their level of expertise for treatment very high/above average (100/218; 45.9%), while nurses (16/48; 33.3%) and SLPs (57/121; 47.1%) reported having an average level of expertise.

Professional(s) that usually perform the OD screening and non-instrumental clinical assessments and the measurement tools used to identify and diagnose OD

Professional roles in screening and non-instrumental CSA are displayed in Figure 9. Although each profession reported that their profession usually performed screenings at their workplace, there were overlaps of other professions being involved. Conversely, a large percent of OTs and SLPs reported their own professions as usually performing non-instrumental CSA, while nurses reported mostly SLPs. When able to choose from a list of valid and reliable measurement tools recognised from the OD literature, half of respondents (199/396; 50%) reported using “other” type of screening and non-instrumental CSA. Examples of “other”

from the free-text were non-specified water tests or locally developed tests. The GUSS and FOIS were the two most used measurement tools on the list. The largest percentage of all three professions reported not using any PROM (225/396; 60.8%), while a small percentage (71/396; 19.2%) used the EAT-10.

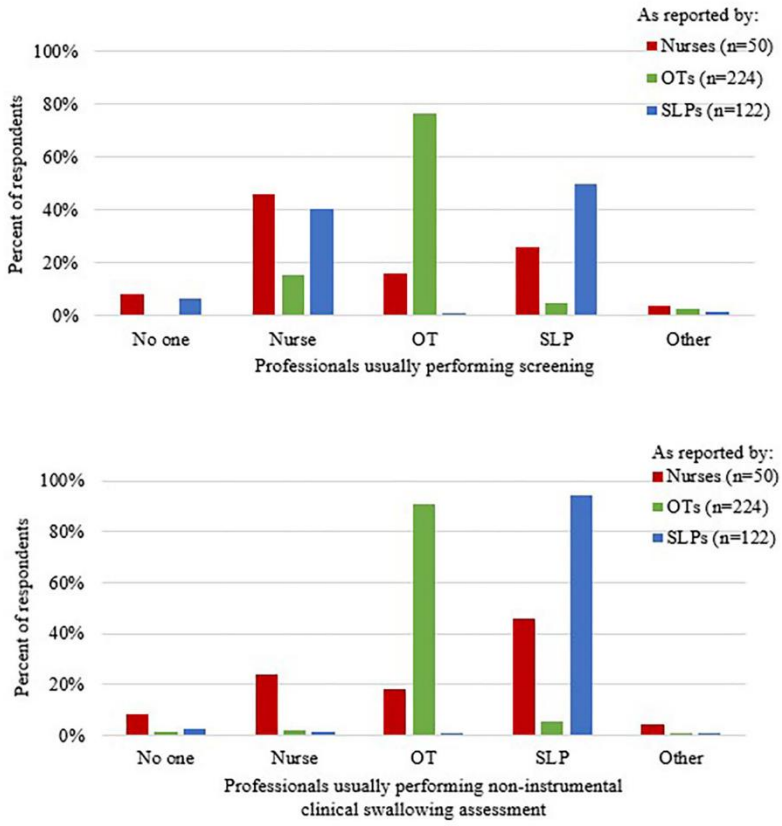

***Figure 9**. Profession that usually performs screening and non-instrumental clinical swallowing assessment (CSA) for adults with OD as reported by nurses, OTs and SLPs (n=396) in Study III.*

Availability and use of instrumental assessments and outcome measures mostly used for OD diagnosis

The availability of FEES (168/396; 42.4%) was greater than VFSS (110/396; 27.8%) for the respondents of this survey regardless of work setting. Access to instrumental assessments was greatest in the acute care setting (FEES: *n*=80/110, 72.7%; VFSS: 48/110, 43.6%), followed by inpatient rehabilitation (FEES: 58/145, 40%; VFSS: 42/145, 29%) and outpatient rehabilitation setting (FEES: 20/64, 31.3%; VFSS: 14/64, 2.9%). The other settings had less than 10 respondents reporting use of FEES and VFSS. For those respondents with access to FEES or VFSS, knowledge of and use of visuoperceptual assessment tools was more common for SLPs than OTs and nurses. The PAS was the most recognised tool by the respondents for both FEES and VFSS.

Treatment interventions used by nurses, OTs and SLPs, and their participation in multidisciplinary meetings

Respondents' answers when asked which professions usually provided treatment (compensatory and rehabilitative) are found in Figure 10. Each profession reported that their profession provided compensatory treatment, such as head and body positioning and bolus modification, very often/always. OTs reported that they very often/always used Facial Oral Tract Therapy (F.O.T.T.), a technique commonly used in Denmark as a rehabilitative treatment (145/224; 69.4%), in addition to oromotor exercises (131/224; 61.5%). SLPs did not report using any rehabilitative treatment very often/always. SLPs reported sometimes providing oromotor exercises (61/122; 50.8%) and effortful swallow (46/122; 40.7%). All three professions reported rarely/never using other rehabilitative techniques such as MDTP or EMST.

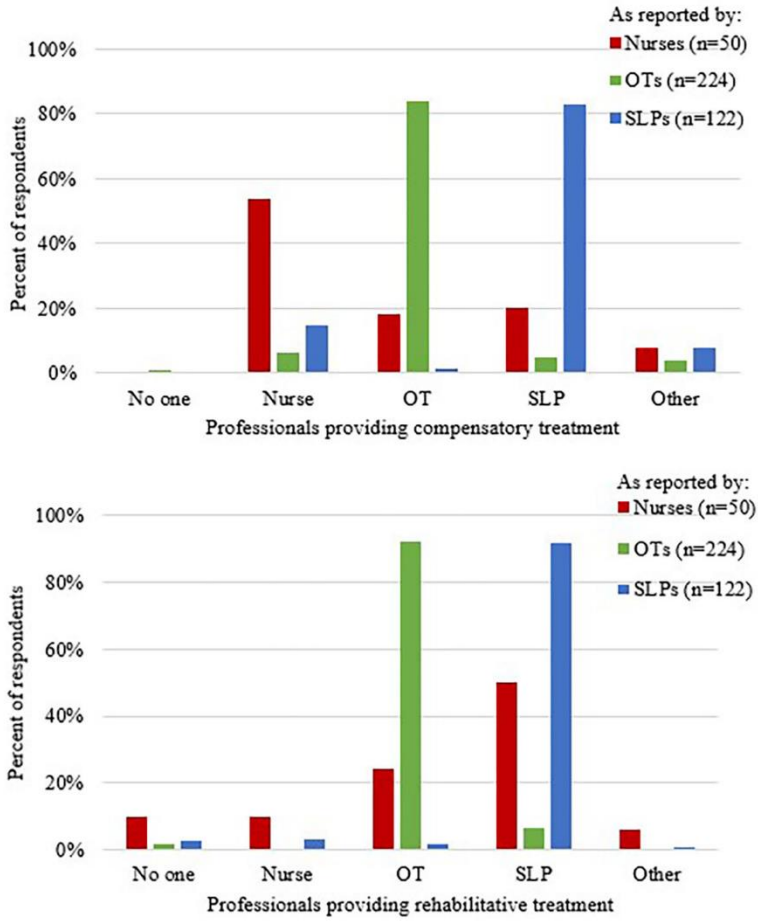

Figure 10. *Profession that usually provides compensatory and rehabilitative treatment as reported by nurses, OTs and SLPs (n=396) in Study III.*

The results from participants regarding multidisciplinary meetings were limited to those working in acute care or inpatient rehabilitation due to the low response from respondents from other settings. OTs (56/131; 42.8%) and SLPs (41/83; 50.0%) reported often/always participating, while nurses participated sometimes (18/40; 45.0%).

How do the roles for nurses, OTs and SLPs in OD management differ between countries?

Table 5 shows the role similarities and differences for nurses, OTs and SLPs between countries. In Denmark, the OTs were the primary therapist for OD for screening, non-instrumental CSA and treatment. In the other Nordic countries, the nurse and SLP had a central role in screening and compensatory treatment, while the SLP was the primary therapist for non-instrumental CSA and rehabilitative treatments.

Table 5. *Professionals usually performing screenings, non-instrumental clinical swallowing assessments, compensatory and rehabilitative treatment for OD per country of employment (n=396).*

Profession	**Country** *n* (%)				
	Denmark	Finland	Iceland	Norway	Sweden
Screening					
No one	1 (0.5)	2 (5.9)	0 (0.0)	5 (7.1)	5 (8.2)
Nurse	36 (16.6)	13 (38.2)	6 (42.9)	20 (28.6)	**32 (52.5)**
OT	**174 (80.1)**	0 (0.0)	0 (0.0)	6 (8.6)	0 (0.0)
SLP	0 (0.0)	**19 (55.9)**	**8 (57.1)**	**37 (52.9)**	21 (34.4)
Other	6 (2.8)	0 (0.0)	0 (0.0)	2 (2.9)	3 (4.9)
Total	*217 (100.0)*	*34 (100.0)*	*14 (100.0)*	*70 (100.0)*	*71 (100.0)*
Non-instrumental clinical swallowing assessment					
No one	1 (0.5)	1 (2.9)	0 (0.0)	6 (8.6)	2 (3.3)
Nurse	5 (2.3)	2 (5.9)	3 (21.4)	5 (7.1)	3 (4.9)
OT	**208 (95.9)**	0 (0.0)	0 (0.0)	5 (7.1)	0 (0.0)
SLP	0 (0.0)	**30 (88.2)**	**10 (71.4)**	**54 (77.1)**	**56 (91.8)**
Other	3 (1.4)	1 (2.9)	1 (7.1)	0 (0.0)	0 (0.0)
Total	*217 (100.0)*	*34 (100.0)*	*14 (100.0)*	*70 (100.0)*	*71 (100.0)*
Compensatory treatment					
No one	2 (0.9)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Nurse	15 (6.9)	12 (35.3)	5 (35.7)	20 (28.6)	7 (11.5)
OT	**190 (87.6)**	1 (2.9)	0 (0.0)	7 (10.0)	1 (1.6)
SLP	1 (0.5)	**20 (58.8)**	**8 (57.1)**	**41 (58.6)**	**52 (85.2)**
Other	9 (4.2)	1 (2.9)	1 (7.1)	2 (2.9)	1 (1.6)
Total	*217 (100.0)*	*34 (100.0)*	*14 (100.0)*	*70 (100.0)*	*71 (100.0)*
Rehabilitative treatment					
No one	4 (1.8)	3 (8.8)	1 (7.1)	3 (4.3)	1 (1.6)
Nurse	0 (0.0)	1 (2.9)	2 (14.3)	2 (2.9)	4 (6.6)
OT	**211 (97.2)**	1 (2.9)	0 (0.0)	7 (10.0)	1 (1.6)
SLP	1 (0.5)	**29 (85.3)**	**11 (78.6)**	**56 (80.0)**	**54 (88.5)**
Other	1 (0.5)	0 (0.0)	0 (0.0)	2 (2.9)	1 (1.6)
Total	*217 (100.0)*	*34 (100.0)*	*14 (100.0)*	*70 (100.0)*	*71 (100.0)*

Note: OD: oropharyngeal dysphagia; OT: Occupational Therapist; SLP: Speech-Language Pathologist. The values written in bold highlight the answers chosen by the majority of respondents per profession and per country.

Study IV

Effects of expiratory muscle strength training on swallowing function in people with Parkinson's disease or multiple sclerosis as assessed by flexible endoscopic evaluation of swallowing.

The primary research question for *Study IV* was:

> Is there a change in swallowing safety and/or efficiency, and self-perceived swallowing difficulties following EMST in people with PD or MS?

Secondary-questions to be answered in this study were:

1. Is there a change in maximum expiratory pressure (MEP)?
2. Is there a change in airway safety?
3. Is there a change in swallow efficiency?
4. Is there a change in the participants' self-perceived swallowing difficulties?

The final analysis included nine participants with PD between the ages of 61-82 (M 71.6 years; SD 6.4) and six participants with MS between the ages of 53-63 (M57.3 years; SD 3.6). Time since diagnosis for participants with PD ranged from 0.5-13 years and between 7-20 years for participants with MS. Additional participant demographic information is found in Table 6.

***Table** 6. Study IV participant demographic information.*

ID	SEX	AGE	TSSD[a]	TSD[b]	H&Y/EDSS	GROUP
PD1	M	61	1	0.5	H&Y 3	B
PD2	F	71	8	7	H&Y 2.5	B
PD3	M	82	2	1	H&Y 2.5	A
PD4	M	67	5	4	H&Y 2	B
PD5	M	67	10	5	H&Y 2	A
PD6	F	79	12	10	H&Y 2	A
PD7	M	73	3	3	H&Y 1.5	B
PD8	F	74	6	5	H&Y 2	A
PD9	M	70	18	13	H&Y 3	A
MS1	F	63	30	20	EDSS 8	A
MS2	M	57	9	7	EDSS 6	A
MS4	F	53	11	9	EDSS 6	B
MS5	F	58	15	9	EDSS 7.5	A
MS6	F	59	35	15	EDSS 6	B
MS7	F	54	19	17	EDSS 6.5	B

Note: ID=participant identification; [a] TSSD=Time since symptom debut in years; [b]TSD=Time since diagnosis in years; H&Y=Hoehn and Yahr scale; EDSS=Expanded Disability Status Scale; GROUP=Intervention group (A-EMST only; B-sham); PD=Parkinson's disease; MS=multiple sclerosis; F=Female; M=Male

Prior to answering the secondary questions, it was important to determine intra-rater reliability for the scoring of PAS, YPRSRS-vallecula and YPRSRS-pyriform sinus scales. Interrater reliability was not computed as the FEES assessments were evaluated by one SLP independent from data collection. The intra-rater reliability was excellent (100%) for the PAS and good for the YPRSRS-vallecula (85%; 62-95%) and YPRSRS-pyriform sinus (88%; 81-95%). In addition, findings from the training diaries determined that the average compliance for EMST for participants with PD or MS were 99.6% and 98.9% respectively. Compliance for maintenance training for participants with PD averaged 85.2% and 97.7% for participants with MS. None of the participants reported adverse effects from EMST training.

To answer the first question, the findings revealed that EMST had a positive statistically significant effect on maximum expiratory pressure for participants with PD or MS from baseline to following EMST (Z=2.668, p=0.008; Z=2.207, p=0.027, respectively) and baseline to three months after EMST (Z=2.524, p=0.012; Z=2.201, p=0.028, respectively). Significant improvements were also found in MEP total values for Group A directly after EMST compared to baseline (Z= -2.524, p=0.012), but not for Group B participants directly after sham

EMST compared to baseline. Similar to Group A, Group B showed significant improvements in total MEP values after five weeks with EMST as compared to baseline values (Z=2.366, *p*=0.018). Both Group A and B had significant improvements in MEP values from three months after EMST compared to baseline (Z= -2.366, *p*=0.018; Z=2.371, *p*=0.018, respectively), but not following maintenance training; three months after-EMST to directly following EMST.

There were no significant changes following the 12 week maintenance training period; three months after EMST compared to directly after EMST, for the participants either grouped by diagnosis (PD or MS) or treatment group (Group A or B).

The second and third questions in this study concerned potential changes in swallowing safety and / or swallowing efficiency following EMST. The baseline results with PAS revealed normal swallowing safety for the majority of participants across consistencies. YPRSRS-vallecula and YPRSRS-pyriform sinus baseline scores were trace and none-trace, respectively and across consistencies. Thus, indicating minimal to no OD at baseline. Despite the positive results for improvement of MEP following EMST, results revealed no clinically relevant improvements or declines across consistencies for any participants from baseline to directly after EMST or sham. The same lack of change was seen from baseline to three months after EMST. In other words, EMST had no treatment effect on swallowing safety and/or efficiency in this sample of participants with PD or MS. Results for PAS, YPRSRS-valleculae and YPRSRS-pyriform sinus are displayed in Tables 7, 8 and 9.

The final question is this study pertained to possible changes in participants' self-perceived swallowing difficulties following EMST. The changes in the mean total SSQ score for participants with PD or MS were non-significant for both three months after EMST and directly after EMST compared to baseline. A statistically significant change was seen in Group A participants' mean total SSQ score from three months after EMST compared directly following EMST (Z=2.201, *p*=.028); after the maintenance period. Group A did not show significant change in mean total SSQ scores from baseline to directly after EMST or baseline to three months after EMST. Non-significant changes were seen in Group B mean total SSQ scores for all assessment time-periods.

Table 7. *Results for Penetration-Aspiration Scale (PAS) scores for Group A and Group B in Study IV.*

Penetration - Aspiration Scale (PAS)																			
Group A demographics				THICK 10ml				WATER 10ml				PUREE 10ml				1/2 CRACKER			
ID	SEX	AGE	STAGE	BL	p-EMST	N/A	3mo	BL	p-EMST	N/A	3mo	BL	p-EMST	N/A	3mo	BL	p-EMST	N/A	3mo
PD3	M	82	H&Y 2.5	1	1		1	1	6		1		1		1		1		1
PD5	F	67	H&Y 2	3	3		3	3	5		3	1	1		1	1	1		1
PD6	M	79	H&Y 2	1	1		1	1	1		1	1	1		1	1	1		1
PD8	M	74	H&Y 2	1	1		1	1	1		1	1	1		1	1	1		1
PD9	M	70	H&Y 3	1			1	1			1	1			1	1			1
MS1	F	63	EDSS 8	1	1		1	1	1		1	1	1		1	1	3		1
MS2	M	57	EDSS 6	1	1		1	1	1		1	1	1		1	1	1		1
MS5	F	58	EDSS 7.5	1	1		1	5	1		1	1	1		1	1	1		1
Group B demographics				THICK 10ml				WATER 10ml				PUREE 10ml				1/2 CRACKER			
ID	SEX	AGE	STAGE	BL	p-sham	p-EMST	3mo	BL	p-sham	p-EMST	3mo	BL	p-sham	p-EMST	3mo	BL	p-sham	p-EMST	3mo
PD1	M	61	H&Y 3	1		1	1	1	6	1	1	1	1	1	1	1	1	1	1
PD2	F	71	H&Y 2,5	1		1	1	1		1	1	1	1	1	1	1	1	1	8
PD4	M	67	H&Y 2	1	1	1		1	5	1		1	5	1		1	1	1	
PD7	F	73	H&Y 1,5	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
MS4	F	53	EDSS 6	1	1	1		1	1	1		1	1	1		1	1	1	
MS6	F	59	EDSS 5	1	1	1		1	1	1		1	1	1		1	1	1	
MS7	F	54	EDSS 6,5	1	1	1		1	1	1		1	1	1		1	1	1	
PAS color coding				1-2 Normal				3-5 Penetration				6-8 Aspiration				No data			

Note: ID=participant identification; STAGE=disease stage; H&Y=Hoehn & Yahr scale; EDSS=Expanded Disability Status Scale; BL=Baseline; p-sham=post-sham training; p-EMST=post-Expiratory Muscle Strength Training; N/A=No 15-week Assessment; 3mo=3-months after EMST.

Table 8*. YPRSRS-VAL scores for Group A and Group B (sham) in Study IV.*

Yale Pharyngeal Residue Severity Rating Scale - vallecula (YPRSRS-VAL)																			
Group A demographics				THICK 10ml				WATER 10ml				PUREE 10ml				1/2 CRACKER			
ID	SEX	AGE	STAGE	BL	p-EMST	N/A	3mo	BL	p-EMST	N/A	3mo	BL	p-EMST	N/A	3mo	BL	p-EMST	N/A	3mo
PD3	M	82	H&Y 2.5	3	4		3	3	3		3	4	4		4	4	4		4
PD5	F	67	H&Y 2	2	3		2	2	2		1	2	2		3	2	2		1
PD6	M	79	H&Y 2	2	4		2		4		2	3	4		4	2	4		4
PD8	M	74	H&Y 2	2	2		2	2	2		3	2	2		2	1	1		2
PD9	M	70	H&Y 3	2			2	2			2	2			3	4			2
MS1	F	63	EDSS 8	2	1		2	2	2		1	2	2		1	2	2		1
MS2	M	57	EDSS 6	2	1		2	3	2		2	3	2		2	2	2		2
MS5	F	58	EDSS 7.5	3	2		2	3	2		2	2	3		2	2	1		1
Group B demographics				THICK 10ml				WATER 10ml				PUREE 10ml				1/2 CRACKER			
ID	SEX	AGE	STAGE	BL	p-sham	p-EMST	3mo	BL	p-sham	p-EMST	3mo	BL	p-sham	p-EMST	3mo	BL	p-sham	p-EMST	3mo
PD1	M	61	H&Y 3	2	2	2	2	3	3	2	2	2	2	2	1	1	2	1	1
PD2	F	71	H&Y 2,5	2		2	2	2		2	1	2	2	2	2	2	2	3	2
PD4	M	67	H&Y 2	1	1	2		2	3	2		1	2	1		1	2	2	
PD7	F	73	H&Y 1,5	4	2	2	2	3	2	3	2	4	3	4	4	4	4	4	4
MS4	F	53	EDSS 6	1	1	1		1	2	2		1	2	2		1	1	1	
MS6	F	59	EDSS 5	1	2	1		2	1	1		1	2	1		1	2	1	
MS7	F	54	EDSS 6,5	1	2	1		2	3	2		2	3	2		2	3	2	
YPRSRS color coding				None				Trace				Mild				Moderate			
Severe				No data															

Note: ID=participant identification; STAGE=disease stage; H&Y=Hoehn & Yahr scale; EDSS=Expanded Disability Status Scale; BL=Baseline; p-sham=post-sham training; p-EMST=post-EMST; N/A=No 5-week Assessment; 3mo=3-months after EMST.

Table 9. *Yale Pharyngeal Residue Severity Rating Scale –pyriform sinus scores for Groups A and B in Study IV.*

Yale Pharyngeal Residue Severity Rating Scale - pyriform sinus (YPRSRS-PS)																			
Group A demographics				THICK 10ml				WATER 10ml				PUREE 10ml				1/2 CRACKER			
ID	SEX	AGE	STAGE	BL	p-EMST	N/A	3mo	BL	p-EMST	N/A	3mo	BL	p-EMST	N/A	3mo	BL	p-EMST	N/A	3mo
PD3	M	82	H&Y 2.5	3	3		3	3	3		2	2	2		3	2	1		2
PD5	F	67	H&Y 2	2	2		2	2	2		2	2	2		2	1	1		1
PD6	M	79	H&Y 2	2	2		2	3	3		2	3	3		3	1	2		3
PD8	M	74	H&Y 2	2	3		2	2	2		2	1	2		2	1	2		1
PD9	M	70	H&Y 3	1			1	2			2	1			2	1			1
MS1	F	63	EDSS 8	1	1		1	2	2		2	1	2		1	1	2		1
MS2	M	57	EDSS 6	1	1		2	3	2		2	2	2		2	1	2		2
MS5	F	58	EDSS 7.5	2	1		2	3	2		2	2	3		3	2	1		1
Group B demographics				THICK 10ml				WATER 10ml				PUREE 10ml				1/2 CRACKER			
ID	SEX	AGE	STAGE	BL	p-shamp-EMST		3mo	BL	p-shamp-EMST		3mo	BL	p-shamp-EMST		3mo	BL	p-shamp-EMST		3mo
PD1	M	61	H&Y 3	1		1	2	3	3	2	2	1	2	2	1	1	2	2	1
PD2	F	71	H&Y 2,5	1		2	2	2		2	1	2	1	2	1	1	1	2	1
PD4	M	67	H&Y 2	1	1	1		2	3	2		1	2	1		1	1	1	
PD7	F	73	H&Y 1,5	2	2	2	2	2	2	3	2	3	2	2	2	2	2	2	1
MS4	F	53	EDSS 6	1	1	2		1	2	2		1	1	2		1	1	1	
MS6	F	59	EDSS 5	1	1	1		2	1	1		1	2	1		1	1	1	
MS7	F	54	EDSS 6,5	1	1	1		2	2	2		1	1	1		1	1	1	
YPRSRS color coding				None		Trace		Mild		Moderate		Severe		No data					

Note: ID=participant identification; STAGE=disease stage; H&Y=Hoehn & Yahr scale; EDSS=Expanded Disability Status Scale; BL=Baseline; p-sham=post-sham training; p-EMST=post-EMST; N/A=No 5-week Assessment; 3mo=3-months after EMST.

Discussion

The overall aims of the present thesis were to contribute to a stronger evidence base for the improvement of the identification and treatment of adults with oropharyngeal dysphagia. The findings in this thesis underscore the complexity of OD and challenges in providing an evidence-based approach in the management of OD.

Complexity of oropharyngeal dysphagia

Heterogeneity or variability across included studies in a systematic review is common, as no two studies will be the same. However, the synthesis of included literature in this systematic review in *Study II* found considerable heterogeneity in the definitions or lack thereof of oropharyngeal dysphagia in the included studies. The general term "dysphagia" was used interchangeably with OD and several studies provided a generic definition of OD or description that could also encompass esophageal dysphagia (e.g. generally unsafe swallow, difficulty or discomfort in the progression of the bolus from mouth to stomach). These findings support a white paper by the European Society of Swallowing Disorders, indicating insufficient clarification as to what constitutes oropharyngeal dysphagia in the epidemiologic literature. Consequently, continued use of imprecise definitions of oropharyngeal dysphagia in prevalence research complicate the acquisition of accurate prevalence estimates (Speyer et al., 2021).

In addition to the use of registries, surveys and medical chart reviews, there was also heterogeneity in the type of screening and assessments used to determine OD prevalence in *Study II*. Some screenings included only a water swallow test while others included administration of different food/liquid consistencies. This not only indicates discrepancies in definitions of a screening, but also the purpose of a screening as compared to a non-instrumental clinical swallowing assessment (Speyer et al., 2021).

An overall OD prevalence of 36.5% was estimated in the hospital setting. Considerable heterogeneity was found in the hospital setting, which was evident in wide variation of estimates. Two studies had relatively high prevalence (≥ 60%) while a third had OD prevalence of 7%. The methodological differences in these studies, such as definition, inclusion/exclusion criteria, and sample population, help explain heterogeneity included in the studies.

OD prevalence from the rehabilitation setting was estimated at 42.5% from two studies. A higher OD prevalence in the rehabilitation than hospital setting likely reflects the severity of the disease or injury and co-morbidities. Both studies included post stroke participants, used non-instrumental clinical assessments and were from rehabilitation units, which likely contributed to low heterogeneity.

The nursing home setting revealed the highest estimated overall prevalence of 50.2%. This was hypothesised a priori, considering previous literature on higher prevalence with increased age, chronic illness and co-morbidities, which is characteristic of the nursing home population. These results support previous literature defining OD as a geriatric syndrome (Baijens et al., 2016) A significant difference was found in estimated OD prevalence for between-group analyses in the nursing home setting between the studies using screening test and PROM; one study using a PROM showing a lower prevalence than the two studies that used screenings. These findings support previous research showing higher OD prevalence in relation to the use of objective versus subjective assessment (Doan et al., 2022; Martino et al., 2005).

The scarcity of prevalence studies from the rehabilitative and palliative care settings give rise to questions concerning the management of OD in these populations. One challenge in determining the prevalence in palliative population is that palliative populations may be located in different healthcare settings such as hospitals and nursing homes. One study included in this systematic review had excluded participants that received palliative care during prevalence testing (Huppertz et al., 2018). This highlights the potential legal and ethical challenges that may arise in providing clinical services and performing research with this population (Bogaardt et al., 2014; Kelly et al., 2018). Nonetheless, there is a shortage of information on prevalence palliative care and rehabilitation settings. Without this information, it is difficult to quantify the extent of the problem, which in turn induce procedures and services needed to prevent serious medical consequences (e.g. poor nutrition, hydration, pulmonary complications) and negative effects on quality of life.

In *Study III*, the number of respondents reporting from long-term care/nursing home settings represented a small fraction of the total respondents. These findings suggest that many residents in long-term care/nursing homes are at risk for OD and not identified. In a Norwegian national survey, respondents estimated

the prevalence of eating and swallowing difficulties of nursing home residents with stroke and dementia to be as little as 0-10%. Routine screening or assessments for swallowing difficulties were not common practice in nearly 75% of nursing homes. Further, nurses were reported to be the primary staff responsible for eating and swallowing difficulties and the majority were not required to have undergone education or training in eating and swallowing difficulties (Engh & Speyer, 2021).

Another interesting finding in *Study III* was the obvious difference in professional roles between Denmark and the other Nordic countries. The large response of Danish OTs indicates a united professional association that promote their role in the management of people with OD; a role that is supported by the Danish national clinical guidelines for OD (Sundhetsstyrelsen, 2018). Additionally, the Danish OTs approach to screening and assessment of adults with OD were characterised by the reported use of facial oral tract therapy (F.O.T.T.) which was reported as rarely/never used by nurses or SLPs in this survey, and has limited evidence (Hansen & Jakobsen, 2010; Jakobsen et al., 2019).

Evidence-based practice in oropharyngeal dysphagia

Study III revealed that the amount of education and training of Nordic nurses, OTs and SLPs in the identification and management of OD is minimal. The results from this study resemble those from were similar to a survey of SLPs in the United States 20 years ago. The majority of survey respondents in Study II had 1-5 hours of classroom training and less than ½-1 day of supervised training. One explanation for this may be that OD is a relatively new field of study in some Nordic countries. Currently, speech-language pathology in Norway is not an authorised profession as there are no professional guidelines in the university curriculums offering graduate programs. Even though this survey found a small increase in supervised training in OD for SLPs educated in the past decade, the meagre amount of education and training dedicated to OD in the Nordics is disconcerting. These findings call attention to the probability that a large number of SLP graduates that enter the workplace are unqualified to provide evidence-based assessment and treatment services to meet the needs of their patients with OD. *Study III* findings are also supported by a study mentioned earlier by Engh

and Speyer, in that training in OD for the majority of nurses in Norwegian nursing homes was not mandatory (Engh & Speyer, 2021). Although caution should be used when generalising the results of *Study III*, results exemplify the need for implementation of curricular standards in training and competency requirements in line with international professional organisations (Royal College of Speech and Language Therapists (RCSLT), 2014, 2019). Furthermore, these findings highlight the importance of access to post-graduate training, mentoring and clinical supervision for professionals prior to becoming responsible for the assessment and treatment of adults with OD. There is a growing amount of research supporting interdisciplinary and post-graduate training of health care professionals (Boaden, 2020; Gilbert et al., 2010; Guthrie et al., 2017; Miles et al., 2016)

Another interesting finding in this survey was that despite having a minimum of education and practical training in OD, the majority of respondents reported having above average or higher expertise in nearly all areas of OD management with the exception of instrumental assessments. Although we were unable to verify respondents' subjective reports through objective competency measures, the phenomenon of overestimation of knowledge and competencies is not uncommon (Snibsøer et al., 2018). The high level of expertise reported by respondents in this study may be a reflection of contextual factors that influence self-reported expertise. Thus, respondents may be one of few professionals in their workplace with some knowledge in the management of adults with OD.

Both *Study II* and *Study III* in this thesis revealed insufficient use of validated and reliable screenings and non-instrumental clinical assessments in the identification and diagnosis of OD. The use of locally developed, modified and non-validated measures was evident in both studies. Sixty percent of *Study III* respondents reported not including a PROM in their non-instrumental clinical assessment. There were no questions in the survey to explore possible reasons for this, such as personal preference, time limitations or the availability of valid and reliable outcome tools. There has been, however, an increase in the publication of validation studies from Nordic countries in the recent literature, particularly for PROs (Hajdú et al., 2017; Hedström et al., 2020; Järvenpää et al., 2022).

Access to valid and reliable outcome measure was the motivation for the translation, cultural adaptation and validation of the SWAL-QOL *(Study I)*. Although there are variations in guideline recommendations found in the literature for translation and cultural adaptation, the majority of studies include five primary

stages that are believed to ensure optimal equivalence between the translated and original outcome measure. The inclusion of laypersons and multiple disciplines (neuropsychologist, sociologist, nurse, speech-language pathologists and occupational therapist) was intended to strengthen the translation. Several were bilingual, experts in the field of OD and experienced in translation research. Pretesting and interview involved only seven participants with OD; however, responses revealed that there were few grammatical, semantic and conceptual discrepancies to be addressed. Adjustments were made for questions concerning education and differentiation of ethnical group was removed as it was determined inappropriate for the Norwegian population.

The differences in results of the principle component analysis in the Norwegian SWAL-QOL compared to the original may be attributed to the differences in sample populations such as severity of OD and length of time living with OD. However, this information was not available from the original study. The SWAL-QOL, like many other non-instrumental assessments for OD, was developed in the early part of the 21st century. Thus, the methodological quality of validation and reliability studies for OD screening and non-instrumental clinical assessments using the classical test theory (CTT), have been scrutinised in the recent literature. Recommendations include the development of new assessments using modern psychometric research methods, specifically the item response theory/Rasch analyses (Cordier et al., 2023). Furthermore, development has begun for new instruments that represent the two different concepts of FHS and HRQoL that are frequently combined in disease-related quality of life measures (Speyer et al., 2022).

The use of instrumental assessment of the swallowing is often recommended to guide evidence-based treatment strategies or methods (Baijens et al., 2016; European Society for Swallowing Disorders (ESSD), 2012). Results from *Study III* showed that FEES was the most common type of instrumental assessment available in the Nordics. However, the availability of FEES in rehabilitation and long term care/nursing home settings was low (≤ 40%) compared to acute care facilities (73%). This low availability is somewhat surprising considering that the majority of respondents (88%) worked in urban/metropolitan areas. These results would suggest that a majority of nurses, OTs and SLPs in the Nordics treat patients solely on the results of screening and/or non-instrumental assessments. Previous research has shown that even though non-instrumental assessments may provide valuable information to form an impression of overall severity of OD and hyolaryngeal movement, no significant information on pharyngeal physiological swallow function, such as swallow safety or efficiency can be determined (Rangarathnam & McCullough, 2016).

FEES was used in *Study IV* to assess of the effects of EMST on swallowing function in people with PD or MS. Findings from this exploratory randomised study support previous research showing significant improvements in MEP values for EMST, but not sham in participants with PD or MS (Pitts et al., 2009; Silverman et al., 2017). The lack of significant increase nor decline in MEP in maintenance training values from directly after EMST to 3-months post-EMST may suggest that maintenance training with EMST may help preservation function. On the other hand, previous studies have also shown sustained effect of EMST after 3 months without maintenance training for people with PD (Claus et al., 2021; Troche et al., 2014).

Despite the improvements in MEP values following EMST, there were no improvements in swallowing function (safety or efficiency) following EMST as compared to sham. A few methodological issues may have contributed to these findings. First, the main inclusion criteria for this study was based on the participants' subjective report of their swallowing and breathing functions and whether these had changed in the course of their disease. Therefore, the severity of OD was not confirmed with FEES prior to inclusion. Baseline FEES assessments for the majority of participants in this study revealed trace pharyngeal residue and no penetration or aspiration, independent of consistency, thus reducing the ability to show clinically relevant improvements in swallowing function. The inclusion of participants with mild OD was a common finding in a systematic review of studies investigating EMST effects on swallowing function (Mancopes et al., 2020). In addition to the inclusion of participants with more severely impaired OD, Mancopes and colleagues suggest that inclusion criteria for future studies focus on studying specific parameters of swallowing function: integrity of laryngeal vestibule closure, pharyngeal constriction and shortening. Another limiting issue may have been the use of ordinal outcome measures. The reliability of visuo-perceptual quantification of the amount of residue in relation to the pharyngeal structure size, bolus size and location have been questioned, in addition, to statistical limitations when using ordinal outcome measures such as the YPRSRS and PAS (Pisegna et al., 2018; Steele & Grace-Martin, 2017). Studies have shown positive results in the use of outcome measures that provide continuous interval-based rating scales to rate residue, such as visual analog scales (Curtis et al., 2022; Pisegna et al., 2020).

The evidence to support the use of EMST to improve swallowing safety and efficiency in the PD or MS population is not strong. Claus and colleagues, the only other study to use FEES for the assessment of treatment outcomes following EMST in the PD population, used a five-point FEES dysphagia score, developed from an earlier study measuring three parameters of swallowing (premature spillage, penetration-aspiration, and pharyngeal residue) (Claus et al., 2021). This study showed significantly improved total FEES score and residue score (combined vallecula and pyriform sinus), but no significant effect for premature spillage and penetration-aspiration with EMST compared to sham. The effects of EMST swallowing safety in people with MS has been explored in one previous study. This study revealed that the most of the participants in both the EMST and sham groups had unchanged PAS scores (Silverman et al., 2017).

A decrease (improvement) in the Sydney Swallowing Questionnaire total scores from baseline to 3-months post-EMST for both groups (PD or MS; Group A or Group B) suggest that the patients' felt that EMST was helping their swallowing, even though no change in swallow safety or efficiency was evident from FEES assessments. Nonetheless, improvements in expiratory strength, as seen by the increased MEP values, may help participants breathe easier and improve cough production, which are two important aspects of swallowing function. The poor correlation between self-reported symptoms with physiological and clinician-reported outcomes may emphasize the limitations of the more objective assessments ability to reflect the patients' experiences in relation to interventions and living with disease (Johnston et al., 2022).

Limitations

The studies included in this thesis are not without limitations and some of them are reviewed below.

The SWAL-QOL, which includes 44 items has been suggested as being too long. The original time to fill in the questionnaire was estimated at 14 minutes, however most participants in this study used between 15-30 minutes. One explanation for this increase in time use is that many participants required assistance to fill out the questionnaire, e.g. read the questions and /or write the answers. An important concern that was raised in the original SWAL-QOL was the appropriateness of the use of this questionnaire with people that are tube-fed. However, there were not more missing items from tube-fed than non-tube fed participants.

The literature search in *Study II* was limited to the English language and used only two electronic databases for the search. Although PubMed and Embase were thought to provide optimal coverage relevant for the subject matter, inclusion of other databases may have produced more eligible articles for this review, thus reducing the possibility of publication bias. Additionally, heterogeneity or variability across included studies in a systematic review is common, as no two studies will be the same. Despite steps taken to reduce heterogeneity in meta-analyses, heterogeneity was seen in the definition of OD, definition of screening versus clinical swallowing assessment, methodological quality and quality of outcome measures in regards to known diagnostic performance and psychometric parameters. Systematic reviews and meta-analyses are considered the highest level of evidence; however, care should be taken in the interpretation of results in case of high heterogeneity.

Challenges with access to precise data, distribution, survey format and language skills were the basis of limitations for *Study III*. The actual numbers of all active professionals in each country was not obtainable, thus estimated prevalence of nurses, OTs and SLPs per capita, per country should be interpreted with caution. Survey distribution was restricted in some professional associations that may have resulted in low response rate from Iceland, Finland and the nursing profession. However, recruitment through professional association member contacts

was considered an option most likely to reach a large and non-biased sample. Lastly, the ease in filling out a questionnaire may have a direct impact on the number of responses. This survey did not have survey logic that allows respondent to skip questions that are not applicable and save time. Lastly, although English is a second language in the Nordic countries, it may have been an obstacle for some respondents. It might have been beneficial to ask about their English the proficiency.

The primary limitation for *Study IV* is the small sample size. Although not uncommon in exploratory research with PD or MS populations, small sample sizes restricts generalisability.

Conclusions and clinical implications

There was high heterogeneity in the definition of OD and the use of non-validated measures in studies included in the systematic review. Absence of the use of a clear operational definition when reporting OD prevalence promotes ambiguity and uncertainty in the field. In addition, the use of screening and non-instrumental clinical assessments inappropriate for the target population and with suboptimal validity and reliability may have a negative effect on research quality.

The estimated OD prevalence in hospital, rehabilitation and nursing home settings is high. These high prevalence estimates indicate that there are many adults at risk of unintentional weight loss, pulmonary infections and reduced quality of life. The paucity of prevalence research in rehabilitation and palliative settings reveal gaps in knowledge on the scope of OD in these two settings.

The professional education of nurses, OTs and SLPs in the Nordic countries provides a minimum of undergraduate education and practical training in OD. A likely consequence from this will result in allied health professionals entering the workforce without the knowledge and skills needed to provide adequate and evidence-based practice to people with OD. Hence, health care professionals will be dependent on post-graduate and on the job training to develop knowledge and skills, which can result in varying degrees of quality in the management of OD.

Use of evidence-based screening, non-instrumental clinical and instrumental assessments and rehabilitative treatments for OD by nurses, OTs and SLPs in the Nordic countries was limited. Continual use of suboptimal outcome measures diminishes the validity and reliability in the assessment and prognosis of a population vulnerable to serious medical and psychosocial consequences. Likewise, continued use of compensatory treatments alone can hinder potential physiological improvements in swallowing function, prolong the rehabilitative process and the negative affect OD has on a person's quality of life.

Health care professionals in Norway now have access to a culturally adapted, valid and reliable Norwegian version of the Swallowing Quality of Life questionnaire. Access to a dysphagia-specific patient-reported outcome measure supports the clinical implementation of a routine to include the measurement of the patients' perspectives in the non-instrumental assessment of OD. Consequently, improving the use of evidence-based practice by addressing the values and needs of the patient.

Availability of instrumental assessments was reportedly low considering that the majority of nurses, OTs and SLPs worked in metropolitan areas. Use of instrumental assessments is necessary to guide evidence-based rehabilitative treatments and assess treatment effectiveness is dependent on. There is a need for nurses, OTs and SLPs to advocate and collaborate in order to gain access to instrumental assessments in their workplace.

There was no change in swallowing safety and/or efficiency in people with PD or MS following EMST as assessed by FEES. Nonetheless, results showed positive effects of EMST with improved expiratory muscle strength and positive patient-reported experiences. Continued use of comprehensive assessments, including instrumental assessments prior to treatment is recommended to determine the applicability of compensatory and rehabilitative treatment approaches for individual patients.

Future perspectives

This thesis has illuminated a broad spectrum of areas relevant to the evidence-based management of adults with oropharyngeal dysphagia. Findings from the systematic review and meta-analyses on the prevalence of OD in healthcare settings revealed that there are gaps in knowledge regarding the prevalence of OD in rehabilitation settings, warranting further OD prevalence research, nationally and internationally. Furthermore, findings indicated a need to improve the quality of future prevalence research, aiming to minimize heterogeneity particularly in the terminology used to define oropharyngeal dysphagia and the appropriateness and quality of the outcome measures used to determine OD prevalence.

Challenges in the education and practical training of allied health professionals responsible for the care and management of adults with OD were also highlighted in this project. Possible contributions to these challenges may be the lack of evidence-based clinical practice guidelines regarding health care professionals' roles, responsibilities, knowledge and skill requirements in the field of OD. This affects the medical staff's ability to conduct a comprehensive assessment of OD, including the patients' perspectives. The cultural adaptation and validation of the Swallowing Quality of Life questionnaire will conceivably improve this in the Norwegian population.

There are institutions and clinicians specializing in the diagnosis and treatment of OD, however there is a great need to increase the transfer of knowledge into the education and healthcare systems in general. Use of simple measure such as accessible webinars, podcasts and quality assured websites could benefit people with OD their family and caretakers, as well as allied health students and professionals working with populations of adults at risk for OD. I am confident that by adding these aspects, use of evidence-based practice in the identification, diagnosis and treatment of OD can become more robust.

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