Identification of eating, drinking and swallowing difficulty in early-stage dementia

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Abstract

Eating, drinking and swallowing (EDS) difficulty is common in dementia and earlier identification could reduce morbidity, mortality, healthcare costs and improve quality of care. A proactive and condition-specific strategy for identifying EDS difficulty at an early stage for people living with dementia has yet to be developed. Before this can be achieved, holistic person-centred early indicators of EDS difficulty in early-stage dementia are needed and more understanding of barriers to early identification is required. Hence, the aim of this thesis is to inform earlier identification of EDS difficulty for people living with dementia. By employing an integrated multi-method approach, involving published evidence, personal experience, and expert opinion, it was possible to provide insights to inform early identification and discover key indicators of EDS difficulty in early-stage dementia. Lack of awareness and service pressures may explain why people living with dementia present late for help with EDS difficulties. A population-based intervention, providing information and raising awareness of EDS difficulty and dementia is necessary in the opinion of experts. This research has therefore addressed specific knowledge gaps showing how EDS difficulties might be identified. Further practice development plans will require careful facilitation, taking full account of post-pandemic clinical context. Early awareness, identification and education for people living with dementia are the key tenets of this research.

Key words: Eating, drinking and swallowing; dementia

Abbreviations

CI	Confidence interval
EAT-10	Eating Assessment Tool
EDS	Eating, drinking and swallowing
FEES	Fibreoptic Endoscopic Evaluation of Swallow
NCEPOD	National Confidential Enquiry into Patient Outcome and Death
NICE	National Institute for Health and Care Excellence
NHLBI	National Heart Lung and Blood Institute
OR	Odds ratio
PAS	Penetration Aspiration Scale
QUADAS	Quality Assessment of Diagnostic Accuracy Studies
RCSLT	Royal College of Speech and Language Therapists
RQIA	Regulation and Quality Improvement Authority
SIGN	Scottish Intercollegiate Guidelines Network
SLT	Speech and Language Therapist
SQD	Swallowing Disturbance Questionnaire

Declaration

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List of papers and statement indicating the PhD Researcher's contributions

Paper 1: Identification of eating, drinking and swallowing difficulties for people living with early-stage dementia: a systematic review

Paper 2: Exploring the connection between dementia and eating, drinking and swallowing difficulty: findings from home-based semi-structured interviews

Paper 3: Identification and management of eating, drinking and swallowing difficulties for people living with early-stage dementia: a survey of specialist speech and language therapists

Paper 4: Experts agree greater emphasis on early identification of eating, drinking and swallowing difficulties: System wide reflections from an Expert panel review

PhD Researcher's contributions to all four manuscripts was as first and corresponding author and included planning, performing, drafting and refining the papers.

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1 Introduction

1.1 Eating and drinking

Eating delivers the energy and nutrients from food to the body: essential for healthy existence (Tapsell et al., 2016). Liquids are also essential for life: without water, humans can only survive for a matter of days before succumbing to dehydration (Popkin et al., 2010). Drinking is the process used to replenish fluid losses and maintain fluid balance (Saker et al., 2016). Furthermore, eating and drinking are not just physical necessities required to sustain life, they are also important social activities (Blum et al., 2020). Many aspects of society are centred on food, thus eating and drinking are an integral part of a normal social life (Smithard, 2018). Eating and drinking ability can therefore positively affect quality of life (Sasegbon and Hamdy, 2017). Although these are basic activities that are taken for granted, they are not without risk (Mistry and Hamdy, 2008).

Choking can occur when a person is eating or drinking and is a common cause of accidental death (Simpson, 2016). In 2016 in England and Wales 252 deaths from choking were reported with over 60% of these deaths taking place in hospitals and healthcare settings (Office for National Statistics, 2017). Reducing the risk of death by choking has become an active public health issue in Northern Ireland (The Public Health Agency and the Health and Social Care Board, 2021) and was the subject of a high-profile independent review by the Regulation and Quality Improvement Authority (RQIA). The key recommendations for choking prevention included staff training, better communication between staff and shorter waiting times for swallowing assessment (RQIA, 2022).

1.2 Swallowing

The ability to swallow is a complex physiological and anatomical process that is central to the process of safely eating and drinking (Sasegbon and Hamdy, 2017). The act of swallowing is the fundamental ability to safely pass oral intake from the mouth through the oropharynx and into the oesophagus while simultaneously avoiding any inadvertent transfer of swallowed substances into the respiratory tract via the larynx (Kumar, 2010). In this respect three separate anatomical stages of swallowing (oral, pharyngeal and oesophageal) can initially be considered although from a physiological perspective all three stages are interrelated (Bakheit, 2001). The oral stage of swallowing can be further subdivided into the voluntary oral preparation phase and the oral transport phase (Schindler and Kelly, 2002). This results in a total of four physiological stages (oral preparatory, oral transport, pharyngeal and oesophageal) that make up the sequential model of swallowing (Matsuo and Palmer, 2008). However, even before the oral phase has begun, a fifth “pre-oral” stage consisting of sensorimotor information may influence anticipatory eating-related mouth movements and thus subsequent stages of swallowing (Shune et al., 2016). Also, from a neuroanatomical and physiological perspective the process is much more complex and consists of a broad range of sensory input (touch, pressure, temperature, proprioception and taste), feedback from higher cortical centres of the brain, and brainstem coordination of intricate motor systems involving almost 50 pairs of oropharyngeal muscles (Kumar, 2010).

1.3 Eating, drinking and swallowing difficulty

Difficulty in eating, drinking or swallowing (EDS) is used interchangeably with the clinical term dysphagia (Robertson et al., 2018) and is defined below.

Definition of EDS difficulty

A term used interchangeably with the clinical term dysphagia (Robertson et al., 2018), which is defined as "swallowing impairment" that "can result in penetration or aspiration of food, drink or medication into the airway" (Lancaster, 2015)

EDS difficulty is prevalent in several neurological diseases especially dementia, multiple sclerosis, amytrophic lateral sclerosis, Parkinson's disease and stroke (González-Fernández and Daniels, 2008) (Calcagno et al., 2002). Subjective reports of EDS difficulty occur in 22%-53% of people living with Alzheimer's disease (Kai et al., 2015), 33% of people living with Parkinson's disease (Kalf et al., 2011) and 36% of people living with multiple sclerosis (Guan et al., 2015). There is objective evidence of EDS difficulty in 26%-42% of people living with Alzheimer's disease (Özsürekci et al., 2020), 80% of people living with Parkinson's disease (Kalf et al., 2011), 34% of people living amyotrophic lateral sclerosis (Plowman et al., 2016) and 81% of people living with multiple sclerosis (Guan et al., 2015). However, if progressive neurological and neurodegenerative conditions are diagnosed early, early multidisciplinary intervention for EDS could therefore positively impact quality of life as well as reducing the risk of malnutrition, weight loss and potentially fatal respiratory complications (Tabor et al., 2016).

In progressive neurological and neurodegenerative conditions, it is imperative to diagnose EDS difficulty at the earliest opportunity so that negative consequences such as malnutrition, aspiration, pneumonia, and associated deaths can be avoided (Wieseke et al., 2008). In patients with neurological disorders there is a relationship between patient reported EDS symptom severity and swallowing related quality of life (Arslan et al., 2019). It has been reported, from interviews with individuals with EDS difficulty, that there is a high prevalence of avoidance of eating with other people (37%), anxiety (41%), reduced enjoyment from eating (45%), and a negative impact on the enjoyment of life (55%) (Ekberg et al., 2002).

1.4 Eating, drinking and swallowing difficulty in dementia

Accidental *aspiration* involves the passage of material below the vocal folds and into the anatomical space of the trachea (Malhi, 2016). In a retrospective study of 2000 patients with various conditions undergoing videofluoroscopic swallowing studies, 106 had dementia. The rate of aspiration in this dementia group was 72/106 (68%) and silent aspiration occurred in 49/72 (68%) (Garon et al., 2009). More recently, the prevalence rate of EDS difficulty in dementia was reported as even higher with 219 of 255 people affected (86%). In this study the 88% of people living with dementia had moderate to severe cognitive impairment (Espinosa-Val et al., 2020). There is an increasing prevalence of EDS difficulty in dementia as the severity of dementia increases (Kai et al., 2015, Özsürekci et al., 2020).

In people living with dementia the presence of EDS difficulty is a significant independent risk factor for poorer outcomes during hospitalisation and increased use of resources. In a large retrospective cohort study of 234,006 patients with dementia in United States in 2012 it was demonstrated that patients with EDS difficulty had significantly higher probability of having percutaneous endoscopic gastrostomy placement during the admission (OR 13.68, 95% CI 12.53-14.95, p<0.001), aspiration pneumonia (OR 6.27, 95% CI 5.87-6.72, p<0.001), pneumonia (OR 2.84, 95% CI 2.67-3.02, p<0.001), malnutrition (OR 2.5, 95% CI 2.27-2.75, p<0.001), mechanical ventilation (OR 1.69, 95% CI 1.51-1.9, p<0.001), sepsis (OR 1.52, 95% CI 1.39-1.67, p<0.001), and anorexia (OR 1.29, 95% CI 1.01-1.65, p=0.04). In addition, length of hospital stay was over two days longer, mean cost per case was higher, and the odds of being discharged to a skilled nursing, rehabilitation, or long-term facility was 1.6 times higher in people with EDS difficulties (Paranji et al., 2017). Therefore, every effort must be made to maintain safe eating and drinking status where possible and avoid hospitalisation for people living with dementia.

1.5 Carers' experience of people living with dementia who have EDS difficulty

The Alzheimer's Society 'Food for thought' project found that one third of caregivers of people living with dementia worried about swallowing problems (Alzheimer's Society 2000). In previous studies, carers of people living with dementia have reported EDS problems of passivity, distraction, inappropriate feeding velocity and refusal to eat (Correia et al., 2010). For carers, early identification of EDS difficulty may help reduce stress (Papachristou et al., 2013) and isolation associated with these problems (Gillies, 2012).

Speech and Language Therapists (SLT) frequently cite the need for family and care staff training in mealtime support (Egan et al., 2020). There is preliminary evidence, based upon one small scale study (involving 12 nursing home residents with dementia and 8 direct caregivers), to suggest that the aspiration risk in people living with dementia may be increased at mealtimes by task-centred caregiver approaches (e.g., outpacing, interrupting, ignoring and verbally/physically controlling actions) in comparison to person-centred approaches (e.g., adjusting to pace, showing approval, orientation, direct eye-gaze, asking for help/cooperation and providing choices) (Gilmore-Bykovskyi et al., 2018). This highlights the need for training for caregivers, and in a previous survey of 125 SLTs all respondents agreed that caregivers needed knowledge of dementia related EDS difficulty (Egan et al., 2020).

1.6 Identifying EDS difficulty

There are different methods for detecting EDS difficulties including clinical swallow evaluation, and objective assessment (the most accurate being fibreoptic endoscopic evaluation of swallow and videofluoroscopy) (Lancaster 2015, Egan et al., 2020). However, less onerous and less invasive means of identifying EDS difficulty are highly desirable, and by reducing the need for videofluoroscopy could avoid exposure to ionising radiation. As a result, swallowing questionnaires and various other screening tests have been developed, as potential means of supporting early identification of EDS difficulty.

The validated questionnaires currently in widespread use globally for EDS difficulty include the Eating Assessment Tool (EAT-10) (Belafsky et al., 2008), swallowing disturbance questionnaire (Manor et al., 2007, Cohen and Manor, 2011), Sydney Swallow Questionnaire (Wallace et al., 2000, Holland et al., 2011), Seirei dysphagia screening questionnaire (Kawashima et al., 2004), and SWAL-QOL (McHorney et al., 2000, McHorney et al., 2000, McHorney et al., 2002). The questionnaires that have been most extensively validated against objective assessment are the EAT-10 and swallowing disturbance questionnaires. The c-statistic for concordance of EAT-10 with actual EDS difficulty is between 0.76-0.88 indicating fair to good discrimination (Carter et al., 2016, Giraldo-Cadavid et al., 2016, Plowman et al., 2016, Arslan et al., 2017, Table 1.1). The Edinburgh Feeding Evaluation in Dementia

Questionnaire (EdFED-Q) is an instrument used to assess EDS difficulty in people living with late-stage dementia (Stockdell & Amella, 2008).

Questionnaire	Population	Number	Cut-off score	Reference tool	Reference standard	Sensitivity	Specificity	C-statistic	Reference
EAT-10	Mixed	360	>15	Videofluoroscopy	PAS>5	71%	53%	-	Cheney et al. (2015)
EAT-10	Mixed and healthy	134	>2	Videofluoroscopy	PAS>5	83%	25%		Rofes et al. (2014)
EAT-10	Mixed	133	≥4	FEES and sensory	-	94%	50%	0.81	Giraldo-Cadavid et al. (2016)
EAT-10	Amytrophic lateral sclerosis	70	>8	Videofluoroscopy	PAS>5	86%	72%	0.88	Plowman et al. (2016)
EAT-10	Mixed neurological	259	>15	Videofluoroscopy	PAS>5	81%	58%	0.76	Arslan et al. (2017)
SDQ	Parkinson's disease	57	≥11	FEES and clinical	-	81%	81%	-	Manor et al. (2007)
SDQ	Mixed	100	≥12.5	FEES	-	80%	73%	-	Cohen and Manor (2011)

Table 1-1 Summary of questionnaire tools to identify EDS difficulty

Showing the comparison of questionnaire sensitivity and specificity for diagnosing EDS difficulty in comparison to videofluoroscopy and fibreoptic endoscopic evaluation of swallow

FEES-fibreoptic endoscopic evaluation of swallow, SDQ-swallowing disturbance questionnaire, PAS-penetration aspiration scale

One of the most established and simplest bedside swallowing screens to perform is the water swallow test, during which patients are given three ounces (approximately 90 ml) of water in a cup and asked to drink it without interruption. If the patient coughs during, or for one minute after completion, or develops a wet-hoarse voice, then the test is considered abnormal and the screen is positive for dysphagia (DePippo et al., 1992).

The authors of a water swallow screen meta-analysis reported that pooled estimates for single sip volumes (1-5 mL) were 71% sensitive (95% CI 63% - 78%) and 90% specific (95% CI 86% - 93%) for aspiration. Consecutive sips of 90 to 100 mL trials were 91% sensitive (95% CI 89% - 93%) and 53% specific (95% CI 51% - 55%) for aspiration. Trials of progressively increasing volumes of water were 86% sensitive (95% CI 76% - 93%) and 65% specific (95% CI 57% - 73%) for aspiration. The analysis was said to compliment previous research suggestive that multiple clinical signs of aspiration offer improved screening accuracy. The authors went on to conclude that the water swallow test is useful to exclude overt signs of aspiration and that combining clinical signs improves diagnostic accuracy. It was also suggested that a stepwise approach to water swallow test could be beneficial by using consecutive sips from large volumes (most sensitive approach) and single sips of any volume (most specific approach) but that this needs further explored (Brodsky et al. 2016).

Bours et al. (2009) conducted a systematic review to determine the usefulness of bedside screening tools for detecting EDS difficulty in patients with neurological disorders. Kertscher et al. (2014) performed an updated the systematic review using the methodology previously described by Bours et al. (2009) in order to identify new bedside screening tests for the detection of EDS difficulty in patients with neurological disorders. It is interesting to note that despite a high prevalence of EDS difficulty in the studies presented in the two systematic reviews (Bours et al., 2009, Kertscher et al., 2014), and the meta-analysis of the water swallow test (Brodsky et al., 2016), that none of the screening tools evaluated thus far have demonstrated sufficient reliability in terms of sensitivity and specificity for EDS difficulty to warrant widespread adoption by clinicians.

In the more recent review by Kertscher et al. (2014), the Toronto Bedside Swallowing Screening Test had the highest reported sensitivity (91%) and specificity (67%) in stroke patients (Martino et al., 2009). An additional consideration is that Toronto Bedside Swallowing Screening Test requires purchase before administering the protocol (Schepp et al., 2012). The Yale swallow protocol is freely available, has higher sensitivity (100%) and similar specificity (64%) to Toronto Bedside Swallowing Screening Test, and has been validated across patients with a wider range of neurological diseases. However, the population was small in the validation study (n=25 patients) of the Yale swallow protocol and all included patients were referred for EDS assessment. So, the included patients were likely symptomatic at the time of referral (Suiter et al., 2014). In summary, no single swallowing screening tool has demonstrated sufficient reliability to be universally adopted by clinicians, including SLTs.

1.7 Role of Speech and Language Therapy

Swallow screening should be contrasted with a clinical swallow evaluation by a specialist clinician, usually a SLT. Clinical swallow evaluation is a more comprehensive assessment that considers swallowing history and may include the use of a questionnaires, and a detailed past medical history. It is typically followed by an oral motor and sensory exam before progressing to the evaluation of swallowing of foods and liquids of different textures and consistencies (Alagiakrishnan et al., 2013). Predicting the likelihood of a patient aspirating is only one purpose of the clinical swallow evaluation and other multifaceted components of the assessment include the establishment of an individual's capabilities, limits, and requirement for safe and satisfying oral intake (McCullough et al., 2001). Different swallowing screens may overlap to a varying degree with SLT performed clinical swallow evaluation (Lancaster, 2015). More extensive and complex swallowing screens could potentially impact on the health care professionals within the multi-disciplinary team that have the necessary skills to perform the screen. Following a stroke, the majority of patients are screened for EDS difficulty (typically by a trained nurse) and those suspected of having EDS difficulty go on to receive a comprehensive swallow evaluation by a SLT (Bray et al., 2016).

1.8 Benefits of identifying EDS difficulty early

Identifying EDS difficulty could reduce morbidity, mortality, healthcare costs and improve quality of care (Brodsky et al., 2016). By identifying people with EDS difficulty early, referral for management of swallowing could lower future risk and prevent complications (Bours et al., 2009). Following a stroke, the majority of patients are screened for EDS difficulty (typically by a trained nurse) and those suspected of having EDS difficulty go on to receive a comprehensive swallow evaluation by a SLT (Bray et al., 2016). In a non-randomised study, evidence of a reduction in stroke associated pneumonia has been demonstrated by timely access to swallow screening and SLT assessment. Using clinical registry data from the Sentinel Stroke National Audit Programme (April 2013-March 2014) a prospective cohort study of 63,650 patients admitted with acute stroke to 199 hospitals in England and Wales was performed. The overall incidence of stroke associated pneumonia in the study was 8.7% but delays in screening for and assessing EDS difficulty after stroke were associated with higher risk of stroke associated pneumonia. Patients with the longest delays in screening had a significantly higher risk of stroke associated pneumonia (4th quartile adjusted OR 1.14, 95% CI 1.03 - 1.24). Patients that had the longest delays for assessment by SLT had an even greater risk of stroke-associated pneumonia (4th quartile adjusted OR 2.01, 95% CI 1.76 to 2.30) (Bray et al., 2016). Therefore, identifying and treating EDS difficulty can potentially reduce the impact of serious associated complications, such as aspiration pneumonia, in this patient group.

Across other conditions, multidisciplinary teams of health care workers, capable of identifying and treating EDS difficulty, can potentially reduce the impact of complications like aspiration pneumonia with an associated reduction in hospital admissions, prolonged lengths of stay and cost (Wieseke et al., 2008). In a large retrospective observational study from Japan of 98,374 patients hospitalised with aspiration pneumonia, EDS rehabilitation (n=22,819 patients) compared to no EDS rehabilitation (n=75,555 patients) resulted in significantly higher rates of total oral intake (determined by a maximum score on the functional oral intake scale) on discharge from hospital (78.0% vs. 75.2%, adjusted OR 1.32, $p<0.001$) (Momosaki et al., 2015). In another smaller study of 370 elderly patients with severe pneumonia, a multidisciplinary comprehensive EDS care package consisting of regular swallow assessments, management of aspiration, oral hygiene, nutritious texture-modified foods and early mobilisation was an independent determinant of hospital stay and functional oral intake scale score ≥ 4 at discharge (hazard ratio 1.42, 95% CI 1.09 - 1.85) (Koyama et al., 2016). Identifying EDS difficulty early is key for receiving timely support.

The majority of the literature from systematic reviews performed to date (Bours et al., 2009, Kertscher et al., 2014, Brodsky et al., 2018) has focussed on screening people considered high risk of EDS difficulties at the time point of screening. This can be considered the "traditional patient pathway" and has been described as "reactive" since it involves waiting for either signs, symptoms or consequences of EDS difficulties to develop before referring for assessment (Kristensen et al., 2020).

An alternative approach is an "idealised pathway" for EDS difficulties that proactively seeks to support identification of swallow deterioration, avoid aspiration and prevent hospitalisation (Figure 1.1). The barrier to implementing an idealised pathway and the research gap this work helps to address is how best to target individuals who are at the highest risk and most likely to benefit, since universal adoption of such a pathway would likely be prohibitively resource intensive. Despite the potential clinical benefit of an idealised pathway, the acceptability of a proactive approach to service users is unknown and requires exploration.

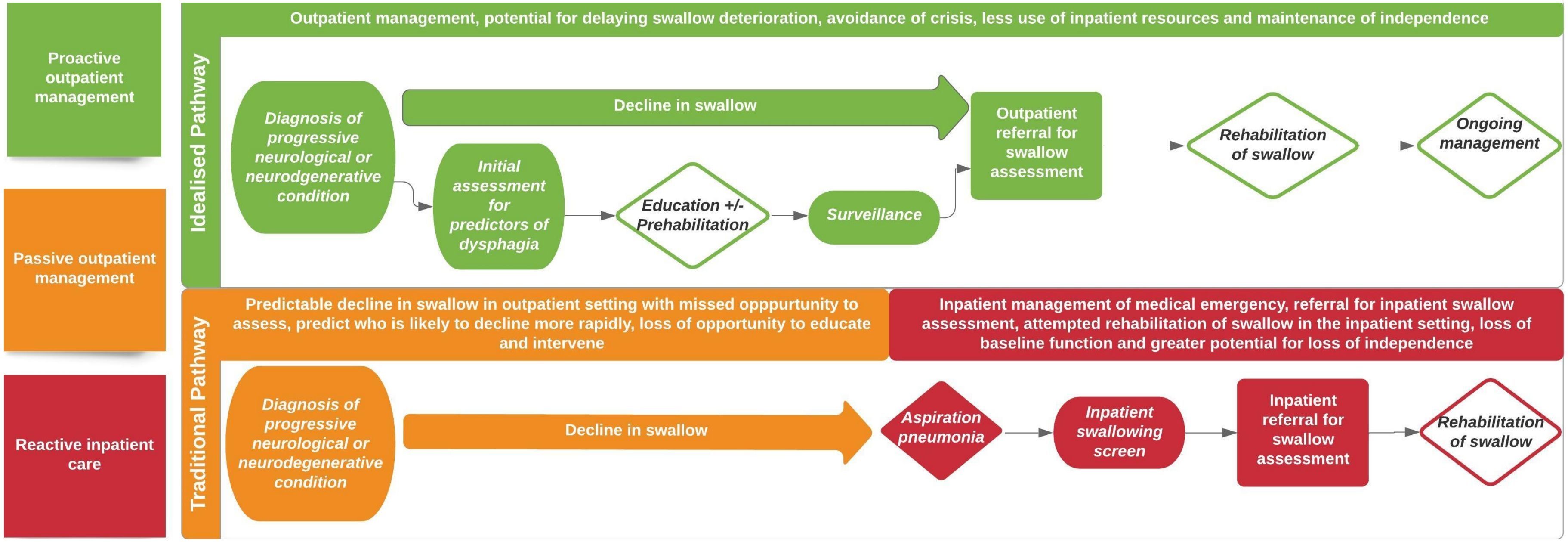

Figure 1-1 Clinical pathways for EDS difficulty

Idealised pathway (upper) contrasted with traditional pathway (lower) for EDS difficulty in individuals diagnosed with progressive neurological or neurodegenerative conditions. Colour legend: green – proactive outpatient management | amber - passive outpatient management | red - reactive inpatient care.

Audit and research reports from within Northern Ireland suggest that care for people living with dementia needs to be improved by enhancing education and training for healthcare staff and reducing inequality of access (Patient and Client Council, 2017). These issues map over to management of EDS difficulty in dementia where improvement in care is also needed.

1.9 The importance of context

In contrast to people who have had a stroke, people who have progressive neurological and neurodegenerative conditions, such as dementia, may not initially have any EDS difficulty and if aspiration of oral intake is present it may be silent (Malhi, 2016). EDS difficulty in progressive neurological and neurodegenerative diseases (e.g., dementia) also usually worsens with time, while following a stroke EDS difficulty is typically most severe immediately after the acute neurological event, before going on to improve (Kumar, 2010).

Early identification of EDS difficulty in progressive neurological and neurodegenerative diseases is a topical issue. The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) recently reviewed the quality of EDS care provided to patients with Parkinson’s disease and gave five key messages in the report entitled “Hard to Swallow”. The key messages included documentation of the swallow status of all patients with Parkinson’s disease at the point of referral to hospital; screening patients with Parkinson’s disease for swallowing difficulties at admission; referring patients with Parkinson’s disease who have swallowing difficulties (or who have problems with communication) to SLT; notifying the specialist Parkinson’s disease service (hospital and/ or community) when a patient with Parkinson’s disease is admitted, if there is any indication from the notes, or following discussion with the patient or their relatives/carers, that there has been a deterioration or progression of their clinical state; and providing written information at discharge on how to manage EDS difficulties (Koomson et al., 2021).

At the most severe end of EDS difficulty spectrum, choking (caused by eating, drinking and swallowing difficulties) is a prevalent public health concern in Northern Ireland. Since 2016, there have been 23 choking related Serious Adverse Incidents reported across Health and Social Care and the private and independent sector. Of these 23 Serious Adverse Incidents related to choking, 21 have tragically resulted in death. Five of these Serious Adverse Incidents have occurred since February 2021. In addition, there have been approximately 1383 choking related Adverse incidents reported across Northern Ireland between 2016 and February 2021 (The Public Health Agency and the Health and Social Care Board, 2021). Since February 2021, a further 10 potentially preventable deaths due to choking have occurred in Northern Ireland. A recent high-profile independent review of the implementation of recommendations to prevent choking incidents across Northern Ireland has been conducted by RQIA. The key recommendations included enhanced training for staff, shorter waiting times for assessment by SLT, and better communication between staff (RQIA, 2022).

1.10 Gaps in knowledge

Suitable bedside screening tests for EDS difficulty should be sensitive, specific, time efficient, cost effective and easily administered without extensive training (Kertscher et al., 2014). However, to date it has proved challenging to develop a swallowing screening tool that is amenable to learn and can be delivered readily in a non-invasive and non-distressing fashion but still produces reliable results (Bours et al., 2009). Currently there is no universally adopted screening tool for EDS difficulty for people living with dementia. It may be that the complexity of established swallow decline is too multifactorial to ever be addressed adequately by a single screening tool for all types of dementia. A more proactive and condition specific approach, aimed at identifying EDS difficulty at an earlier stage may be more feasible and beneficial to people living with dementia. However, before early identification of EDS difficulty can be achieved, more data on the early indicators of EDS difficulty in early-stage dementia is needed. A better understanding of barriers to early identification is required.

1.11 Aim and Objectives

Given the background concerns, this thesis aim was to inform earlier identification of EDS difficulties for people living with early-stage dementia. Accordingly, this research set out to:

1. Identify reliable and clinically measurable indicators from published literature;
2. Understand the experiences of people living with dementia and their family carers;
3. Understand SLT perspectives based upon their professional experience; and

4. Elicit the opinion of an expert panel on findings, to inform next steps.

These objectives were intended to address the study aim, helping to address the above knowledge gaps.

1.12 Rationale for and overview of empirical work

A systematic review was undertaken with to identify reliable and clinically measurable indicators of EDS difficulty in early-stage dementia. Semi-structured interviews were then undertaken to understand the lived experience of EDS by people living with dementia and their carers. A survey of Specialist Dysphagia SLTs was carried out to capture and analyse practice-based evidence from SLTs on the early identification of EDS difficulty in people living with early-stage dementia. Finally, a group of experts were invited to an online meeting to establish if there was consensus on the research findings, system-wide barriers to early identification of EDS difficulty and discuss translation of the research findings into practice.

1.13 Outline

In line with local practice, the work is presented “with papers”. Following this introduction and methodology, four substantive manuscripts are presented with the intention that they may be submitted for wider dissemination in appropriate academic or professional journals. The format of the papers in Chapter 3, 4 and 5 is for submission to the International Journal of Language and Communication Disorders. This journal requires a section after the abstract to signal ‘what this paper adds’. Otherwise a standard scientific paper format is used.

Chapter	Title
1	Introduction
2	Methods
3	Paper 1: Identification of eating, drinking and swallowing difficulties for people living with early-stage dementia: a systematic review
4	Paper 2: Exploring the connection between dementia and eating, drinking and swallowing difficulty: findings from home-based semi-structured interviews
5	Paper 3: Identification and management of eating, drinking and swallowing difficulties for people living with early-stage dementia: a survey of specialist speech and language therapists
6	Paper 4: Experts agree greater emphasis on early identification of eating, drinking and swallowing difficulties: System wide reflections from an Expert panel
7	Discussion
8	References
9	Appendices

Table 1-2 Thesis outline

Papers are presented in manuscript form in individual chapters.

2 Methods

Chapter 1 has provided an overview of EDS difficulty and the thesis outline. At the time of writing, a proactive and condition-specific guideline or strategy for identifying Eating, Drinking and Swallowing (EDS) difficulty at an early stage for people living with dementia had not been developed. Before this could be achieved, holistic person-centred data on the early indicators of EDS difficulty in early-stage dementia was needed, and a greater understanding of barriers to early identification was required. Hence, the overall aim was to inform earlier identification of EDS difficulty for people living with dementia. This chapter examines the design of the thesis, rationale for methodology and the frameworks that were used to guide the underpinning research.

The approach to address the overall purpose of the research study was a multi-faceted and blended design consisting of four study phases informed by the underlying principles of two common frameworks (Wagner, 1998, Department of Health, Social Services & Public Safety, 2011). In phase 1 (Chapter 3), a systematic review is presented, which considered the reliability, clinical measurability and applicability of indicators of EDS difficulty to early-stage dementia. In phase 2 (Chapter 4), online semi-structured interviews are used to understand the experience of EDS by people living with dementia and carers. Phase 3 (Chapter 5), presents an online survey that was administered to understand specialist SLT perspectives on identification of EDS difficulty in people living with early-stage dementia. Findings are consolidated in phase 4 (Chapter 6), in which an expert panel participated in an online meeting to establish consensus on the research findings, explore barriers to identification of EDS difficulty and discuss translation of the research findings into practice.

To enable a user-centred approach to the investigation, a partnership was developed with a local charity (Dementia NI) who provided a channel for people who are living with dementia to be recruited as "experts by experience" to inform, influence and co-produce the work. Specific details on the rationale for the methods used in each phase are provided within this chapter and the methods used are summarised in the papers that were written about each study phase (Chapter 3, 4, 5 and 6). The elements from each study phase are drawn together into a conceptual space within the discussion chapter of the thesis (Chapter 7).

2.1 The role of Frameworks to inform methodology

Application of theoretical frameworks to research studies allows for expansion of previous bodies of research and assures a thorough examination of new data (Fox et al., 2014). Frameworks also provide a systematic structure and organisation to support the rationale for research studies and justification for the approach used (Ringsted et al., 2011). In this thesis, the underlying principles of two frameworks were used to underpin and guide the subsequent research, as opposed to being used as a scaffold for the different phases of the study. The frameworks used are (i) the chronic care model (Wagner, 1998) and (ii) the model for supporting people with dementia and their families (Department of Health, Social Services & Public Safety, 2011).

2.1.1 Chronic care model

The chronic care model was first developed as a strategy to manage chronic disease and to improve care (Davy et al., 2015). The aim of the chronic care model is transformation of acute and reactive care of people to a planned, proactive and population-based approach (Garland-Baird and Fraser, 2018). The model consists of six elements which combine to enhance outcomes: community resources, the health care system surrounding the provider organisation, patient self-management, decision support, delivery system redesign, and clinical information systems (Bodenheimer, 2003) (Figure 2.1). A systematic review of evidence on the effectiveness of elements that have been included in the chronic care model and have been used for improving healthcare practices and health outcomes within primary healthcare settings, found that the most used elements were *self-management support* and *delivery system design* (Davy et al., 2015).

Early identification of EDS difficulty aligns with the *delivery system redesign element* of the chronic care model in that involves transformation of existing pathways that are essentially reactive (i.e., responding only when a person presents with EDS difficulty) to ones that are proactive and focused on keeping the individuals healthy as possible (Wagner, 1998).

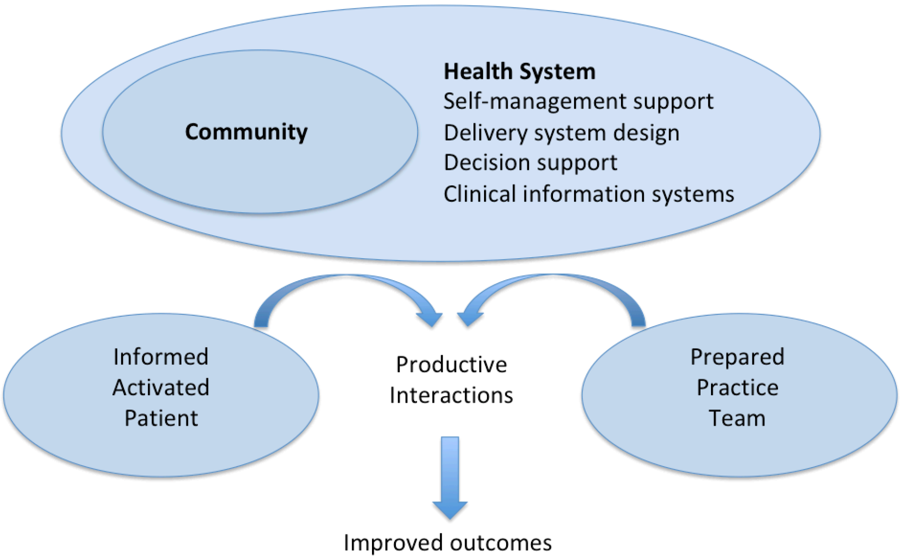

Figure 2-1 Chronic care model summary diagram

Showing how the influences of three main actors combine to create a therapeutic alliance to address health needs

Adapted from
https://www.ihi.org/resources/Pages/Changes/ChangestoImproveChronicCare.aspx

2.1.2 Model for supporting people with dementia and their families

The chronic care model is applicable to any chronic condition. So, with a specific focus on dementia, the principles of a further methodological framework were applied. A holistic model for supporting people with dementia and their families is one in which individuals with dementia are valued members of society. The model for supporting people with dementia and their families was identified from the Dementia Strategy (2011). It was developed to provide person-centred support and care are provided by developing community, family, carers and services around the person living with dementia (Department of Health, Social Services & Public Safety, 2011). Early identification of EDS difficulty aligns with services element for the Model for supporting people with dementia and their families, which requires services for individuals with dementia to be seamless, accessible and proactive. Identifying the risk of EDS problems at an early stage would also help drive interventions that promote maintenance of swallow thus preserving individual's independence and usual patterns of daily living.

2.2 The use of frameworks

Following a review of potential underpinning frameworks and theories, two related core conceptual models were selected for consideration.

Firstly, the principles of the chronic care model were used to promote the concept of proactivity in the identification of symptoms with a focus on addressing these, hence keeping the individuals as healthy as possible, encouraging self-management and avoiding hospitalisation (Wagner, 1998). The chronic care model also emphasises the different roles of an engaged community: hence the voices of a variety of stakeholders are considered to be essential. Secondly, the model for supporting people with dementia and their families was used to consider the approaches that could be used to facilitate early identification of EDS difficulty with a view to preserving their independence and usual patterns of daily living (Department of Health, Social Services & Public Safety, 2011). While proactivity and early identification were concepts that emerged from frameworks, further scoping work was needed to uncover the needs of key stakeholders such as clinicians and consider the purpose and direction of the study, always considering previous work in this area as the foundation.

2.3 Initial scoping work

Before the research methodology is outlined, detail will be provided on the initial scoping work that was undertaken. Scoping work was needed in the design phase of the research project to identify clinical problems that front-line clinicians had in the area of EDS, that might be amenable to research. With their input, the problems could then be refined to ensure the scale and scope was manageable. Initial ideas about practical aspects of research methodology could then be discussed with an emphasis on data collection, survey design and service user involvement, if appropriate. Initial scoping was undertaken informally with colleagues of one Health provider: currently the employer of the researcher.

Scoping was commenced within an integrated health and social care provider organisation that incorporates acute hospital services and community health and social services. The trust serves a population of approximately 345,000 people across specific districts in Northern Ireland and has a large SLT department. An initial meeting took place between the SLT managers and SLTs and members of the PhD research team. Specialist SLT clinicians identified receiving referrals for people with dementia at a later stage of their disease as a challenge to providing population health approaches to care; early awareness, education and employing compensatory strategies to reduce the risk of choking.

The 10,000 more voices project is Public Health Agency initiative that offers patients and clients the opportunity to describe their experience of receiving health and social care and in particular highlight what is important to them and what matters to them. A meeting took place between the Public Health Agency and the PhD research team to discuss previous work on EDS difficulty and survey design. The representative from the Public Health Agency was involved in the 10,000 more voices project on experiences of swallowing difficulties. The purpose of the 10,000 more voices project on ‘Your Experience of Living with Swallowing Difficulty’ was to explore the experience of living with a swallowing difficulty, identify key features of positive experiences and learn where further developments are required. A key finding from the project was that people with EDS difficulty reported living with their condition for up to 18 months before seeking professional help and patients presenting to hospital with issues related to EDS difficulty had often not been seen by SLT services prior to admission. Also, the survey found that people were admitted via Emergency Departments in an unscheduled fashion as a result of choking (PHA, 2021). The importance of designing surveys on what people want to tell you was emphasised and it was advised that this can be facilitated by open-ended questions. The management of data in terms of confidentiality and anonymisation was also addressed.

Following these initial discussions an agreed purpose and direction was decided and entailed a focus on supporting early identification of EDS difficulty in dementia. The potential being for an exploration of integrated person-centred indicators of EDS to guide clinical practice and personal identification of EDS to improve care and outcomes.

2.4 Overview of sequential study phases

Following refection upon the current knowledge, consideration of relevant theories and informal discussions with professional colleagues a mixed methods design was adopted to optimise data collection from multiple sources that included published literature, service users, specialist SLTs and strategic leaders. The work was supported throughout by a panel of co-researchers (see section 2.5).

Four study phases were used to provide a blended and integrated approach of multiple sources that, in their totality, addressed the aim of informing earlier identification of EDS difficulty in dementia. Each phase of the study informed and influenced the next phase. In phase 1, a systematic literature review was conducted. In phase 2, published evidence pertaining to EDS difficulties in dementia from Phase 1 was considered and used to inform question generation for an online semi-structured interview. In phase 3, an online survey for specialist SLTs, was co-produced with Dementia NI “co-researchers” using data from Phase 2 and 3. Findings from all previous phases were consolidated in phase 4 (Chapter 6), in which an expert panel participated in an online meeting to establish consensus on the research findings from previous Phases, explore barriers to identification of EDS difficulty and discuss translation of the research findings into practice (Figure 2.2).

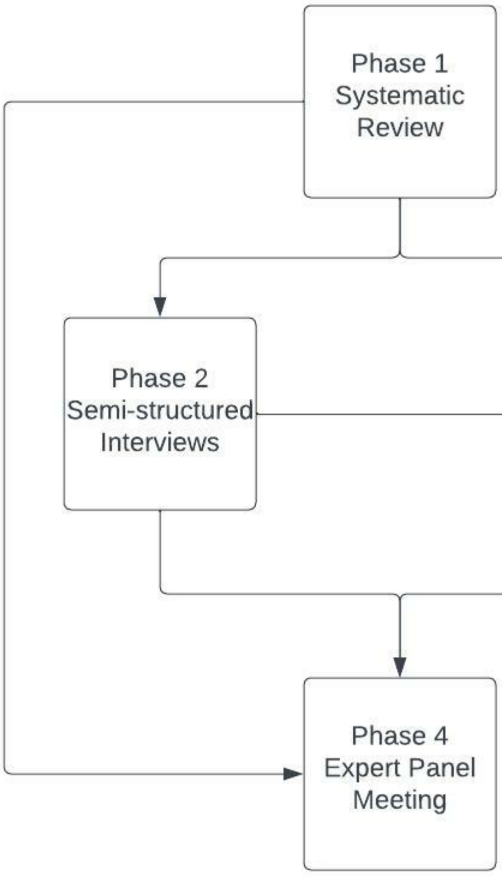

Figure 2-2 Summary of sequential study phases

Showing the influence of each phase on the next (see arrows)

Further detail on the methods used in each phase are provided within this Chapter and in the papers that were written about each study phase (Chapter 3, 4, 5 and 6). This chapter explains in more detail the rationale for the methods used and the overall study design.

2.4.1 Phase 1, existing foundation knowledge

In order to identify reliable and clinically measurable indicators of EDS difficulty in early-stage dementia a systematic literature search was conducted. Articles reporting indicators of EDS difficulty in early-stage dementia or mild cognitive impairment were included. The reliability of included studies were critically appraised using risk of bias tools. Study outcomes were integrated using a narrative data synthesis that considered the reliability, clinical measurability and applicability of EDS indicators to early-stage dementia. The rationale for conducting the systematic literature review first was to identify and appraise what was already known about early identification of EDS difficulty in early-stage dementia. Further details appear below (section 2.6 and Chapter 3).

2.4.2 Phase 2, voices of those with direct experience

In order to understand the experience of EDS by people living with dementia in their own home, published evidence pertaining to EDS difficulties in dementia from phase 1 was considered and used to inform question generation for an online semi-structured interview. Given the published literature reported EDS changes in early-stage dementia, the survey specifically explored this stage of the person's journey. Dementia NI "co-researchers" and an empowerment officer from Dementia NI assisted with design of the interviews. Further members of the charity living with dementia and carers were invited to participate. Twelve responses were analysed using framework analysis guided by narrative elements. This phase provided information from a service user perspective and overall wellbeing of those affected. Further details appear below (sections 2.7, and Chapter 4).

2.4.3 Phase 3, therapists' views

In order to understand specialist SLT perspectives on identification of EDS difficulty in people living with early-stage dementia, the combined data from systematic literature review and semi-structured interviews, gained from previous phases, were used to generate questions for SLTs. An online survey for SLTs was co-produced with Dementia NI "co-researchers" and piloted with final year SLT students. Qualified SLTs actively working in EDS and with experience of working with individuals living with dementia were then approached to participate. SLTs were then recruited via several networks and social media. Data was analysed using a mixed methodology approach including descriptive statistics, summative and conventional content analysis. Further details appear below (section 2.9 and Chapter 5).

2.4.4 Phase 4, expert consolidation

Findings were consolidated by an expert panel of strategic leaders who participated in an online meeting to reflect and, where possible, establish consensus on the research findings. They also discussed translation of the research findings into practice.

Finally, all elements from different approaches were drawn together into a conceptual space, informed by theory, and further developed within the discussion chapter (Chapter 7).

2.5 Patient and public involvement

This research project was conducted with special emphasis to the principles of user involvement. Four people living with dementia were recruited as "experts by experience" to inform, influence and co-produce the work. In line with professional ethics, their contribution was kept confidential and to ensure beneficence, it was necessary to ensure that such involvement had a meaningful impact. "Experts by experience" were considered co-researchers.

A partnership was developed with a local charity (Dementia NI) who provide a voice for people who are living with a diagnosis of dementia. The aim of Dementia NI is to empower and support people with dementia in Northern Ireland to live well and drive positive change. This partnership allowed the research team to hear and include members' views and understand their experience of eating, drinking and swallowing. The staff of Dementia NI (two advocacy and empowerment officers) and four members ensured that the research project was relevant to people living with Dementia. Dementia NI circulated information regarding the project to its members and those individuals with an interest in co-production self-selected as co-researchers. Dementia NI issued a separate advertisement for individuals interested in participating in the qualitative semi-structured interview elements of the study.

The four members of Dementia NI were in regular contact with the research team for the duration of the project. The four Dementia NI members agreed to be involved in co-production with initial one-hour meetings every 6-8 weeks during the project. The vast majority of the input from Dementia NI members involved in co-production was at the initial stages of the project. As the project progressed, the meetings centred around providing updates and acquiring focused input. These meetings were much shorter in duration (15-20 minutes). The meetings were held online (using Zoom). An empowerment officer from Dementia NI was present to facilitate the meetings. The research team worked flexibly around the time commitments of the Dementia NI volunteers. For example, when one participant was unable to participate due to sickness or extenuating circumstances. If others withdrew, the plan was that Dementia NI could have re-advertised for interested parties.

As “Experts by experience” the Dementia NI members helped inform and develop plans, contribute to planning and co-produced the research. People with experience of living with dementia were therefore consulted throughout the project: reviewing the approach, appraising questionnaires in terms of appropriate, understandable language, checking findings and interpretations. They had an established role and voice in the research, and their contribution was fully integrated. Thus, the questions that were asked were relevant and confirmed as being meaningful to those affected by dementia.

2.6 Phase 1: Systematic Review

This phase aimed to identify reliable and clinically measurable indicators of EDS difficulty in early-stage dementia from published literature. A systematic search was conducted using the MEDLINE, EMBASE and PsychInfo databases. An expert librarian assisted with the search strategy used for the systematic review. Further methods employed in the review are detailed in Chapter 3. Specific considerations regarding databases searched and critical appraisal of included studies are discussed below.

2.6.1 Searching for evidence

In a systematic search, the search strategy is generally more exhaustive and comprehensive than other types of reviews (e.g., scoping reviews) (Grant and Booth, 2009). It is advised to use multiple databases when performing a systematic search. Although a balance exists between searching too many databases, which will be time consuming, and potentially missing important studies if too few databases are searched.

In a review of 58 previous systematic reviews, EMBASE and MEDLINE were the databases that retrieved the most unique included references (Bramer et al., 2017). When combined together EMBASE and MEDLINE have more coverage than Google Scholar (Bramer et al., 2016).

The Ovid platform provides access to both the EMBASE and MEDLINE. Ovid also provides access to PsychInfo, which is typically more useful for identifying additional studies in the field of behavioural sciences and mental health (Bramer et al., 2017). The addition of PsychInfo to an existing Ovid search does not add significantly to the time required to perform a search.

The CINAHL database is considered essential for reviews of qualitative studies covering topics in the nursing field (Wright et al., 2015). However, given that the topic of this review was in the area of EDS difficulty, it was unclear whether the additional resource and effort required to search CINAHL would be justified in terms of identifying unique studies not found in the other databases. In previous studies CINAHL has only retrieved additional included references when the topic of the review has been directly related to nursing content (Bramer et al., 2017).

2.6.2 Critical appraisal

The studies from the systematic review were classified by evidence level (Scottish Intercollegiate Guidelines Network (SIGN), 2015) into four levels of evidence depending on quality assessment and risk of bias. These levels are summarised in appendix 8.1.

The reliability of the studies was formally assessed using the following risk of bias tools; Newcastle-Ottowa scale (Wells et al., 2013), the National Heart, Lung, and Blood Institute Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (NHLBI, 2014), and The Quality Assessment of Diagnostic Accuracy Studies (QUADAS-2) (Whiting et al., 2011). These tools are summarised in appendix 8.2.The evidence drawn up in phase 1 was used to inform the later empirical and synthesis phases.

2.7 Phase 2: Semi-structured interviews with people living with dementia and their carers

Published evidence pertaining to EDS difficulties in dementia was considered and used to inform question generation for an online semi-structured interview. Dementia

NI “co-researchers” and an empowerment officer from Dementia NI assisted with design of the interviews. Further members of the charity living with dementia and carers were invited to participate. In line with the recommendation that researchers can conduct highly meaningful projects with interviews of 8–12 participants (DeJonckheere et al., 2019), a sample of up to 12 participants with dementia and their carers was estimated to be sufficient. Twelve responses were analysed using framework analysis guided by narrative elements. Further methods employed in the semi-structured interviews are detailed in Chapter 4. Specific considerations regarding the use and conduct of framework analysis are discussed below.

Framework analysis was selected for data analysis in phase 2 because it can be influenced by existing ideas, permits the analyst to play a greater role in deriving themes, provides a structured approach to transcript analysis, and leaves a transparent audit trail (Ward et al., 2013). In addition, it allows for researchers and co-researchers to work together (Furber et al., 2009). Framework analysis was initially conducted by data familiarisation, immersion, and group discussion to form a draft theoretical framework. Data indexing, summarisation of indexed data and thematic charting was used to formulate the final theoretical framework (Furber et al., 2010).

In summary, familiarisation with the data was achieved by reading field notes taken during interviews, watching recordings of online interviews, listening to audio files, transcription, and repeated reading. Core ideas were documented in handwritten notes in a reflexive journal during the familiarisation stage. A sample of transcripts was shared with co-authors and core ideas were openly discussed. Following data immersion and group discussion (with supervisors), recurring ideas from the familiarisation process were grouped into draft themes, which were refined to reach a consensus at supervision meetings.

The analysis was guided by Propp's narrative theory (1968) in which he distinguished several basic character types. To enable narrative analysis of individuals or processes reported to be helpful or unhelpful in the person living with dementia or their carer's experience of EDS, responses were dramatically framed into symbolic roles under the draft themes of heroes and villains (Wagner-Egger et al., 2011).

Data from the transcripts were then imported into a qualitative data management system (NVivo 12) before further reading. Data fragments from the transcripts were then indexed under the headings of a draft theoretical framework consisting of draft themes. Draft themes appear in italics in the results section of the manuscript prepared for Phase 2 (Chapter 4).

Indexed data was shared with co-authors for discussion and agreement of coding by consensus. Examples of indexed data appear in quotation marks in the results section of the manuscript. The participant number is documented in parentheses as part of the audit trail back to the original transcripts (e.g., participant one is documented as [P1]).

Indexed raw data was then summarised into brief synopses. Brief synopses appear in italics within punctuation marks in the results section of the manuscript. The draft framework was then adapted to key themes and subthemes of a final theoretical framework. This final stage involved synthesis of the data by reviewing thematic charts and agreeing with co-authors on a final theoretical framework (Furber, 2010). Final themes and subthemes appear in italics in the results section of the manuscript.

2.8 Phase 3: Survey of professionals

An online survey for SLTs was co-produced with Dementia NI “co-researchers”. The survey was initially piloted with final year SLT students. Qualified SLTs actively working in EDS and with experience of working with individuals living with dementia were then approached to participate. SLTs were then recruited via several networks and social media. Data was analysed using a mixed methodology approach including descriptive statistics, summative and conventional content analysis. Further methods employed in the survey are detailed in Chapter 5. Specific considerations regarding the use and conduct of content analysis are discussed below.

2.9 Use of content analysis for phase 3

The qualitative methods used for content analysis are described according to the Standards for Reporting Qualitative Research (O'Brien et al., 2014). As there is no guiding theoretical framework of the role of SLT in early-stage dementia specifically an overall pragmatic research paradigm was adopted (Glogowska, 2011).

Conventional content analysis was used to analyse responses to open-ended questions. In conventional content analysis the codes are discovered directly from the data (Hsieh and Shannon, 2005), this is an inductive approach that is adopted when no previous studies dealing with a phenomenon have been described (Vaismoradi et al., 2013). Responses of survey participants were read numerous times by the lead researcher (M.O); codes were then derived from key concepts that emerged and sections of text were then assigned to codes.

For questions relating directly to the presenting features of EDS, summative content analysis was used to establish the most frequent responses. Summative content analysis is a more quantitative approach to qualitative analysis involving counting and comparing words and content, prior to performing an interpretive analysis (Bristowe et al., 2015).

The data for analysis was collected using Qualtrics software (Qualtrics, Provo, UT). Quantitative comparisons and text analyses for summative content analysis were respectively performed on R v3.4.0 (R Foundation for Statistical Computing)

2.10 Phase 4: Expert panel meeting

A number of options were considered for gaining consensus on the findings of the three papers detailed in this thesis (Chapter 3, 4 and 5) and planning future directions. These options included The Nominal Group Technique (Olsen, 2019), Delphi Technique (McMillan et al, 2016) and an expert panel meeting.

The Nominal Group Technique involves meeting to explore stakeholder views, while the Delphi technique involves multiple rounds of questionnaires. More time is required for the Delphi technique, and it can be complex for lay people to complete multiple questionnaires (McMillan et al, 2016). As such, it was not considered suitable as it would not facilitate the input of co-researchers from Dementia NI.

The Nominal Group Technique could potentially have facilitated the input of the co-researchers from Dementia NI. However, rather than evaluating existing information, the Nominal Group Technique typically focuses on determining new issues that require more in-depth inquiry and highlighting issues that may not have been identified (Olsen, 2019).

Ultimately, an expert panel meeting was decided upon as a means of gaining feedback on the research findings from expert stakeholders and discussing translation of the research findings into practice. Further detail on the methods employed in the expert panel meeting are provided in Chapter 6.

2.11 Overall Ethics

Overall, the project benefits were predicted to exceed any risk of harm, inconvenience or any other ethical challenge to participants. Benefits included new knowledge of indicators EDS difficulty in dementia, learning outcomes associated with advanced research and potential to enhance care through early detection of difficulties. Risk of harm, inconvenience and ethical challenges to participants are addressed below. Relevant data protection and research governance guidelines were followed. Ethical approval application was submitted and ethical approval was granted by the research ethics committee for semi-structured interviews and a professional engagement survey (REC/20/0071).

2.11.1 Ethical considerations for semi-structured interviews

In broad terms, early detection of clinical issues is a low-risk endeavour: the primary risk is of successful disclosure of previously unidentified or sub-clinical signs: thus a disclosure protocol was devised. There was a slight risk of distress to participants and informal carer: a short distress protocol was therefore devised.

Participant autonomy was guarded through usual processes of informed consent, with ongoing consent being assured at every contact point. A withdrawal process was laid out, so that participants could withdraw at any time (up to the point of anonymisation). Participant information including personal details were kept secure: all approaches to participants were made through a previously known contact (who acted as a gatekeeper). This minimised any coercion to participate.

At all times participant safety remained paramount, taking precedence over research objectives. In the semi-structured interviews, there could be psychological risk involved in discussing the symptoms of EDS difficulties or dementia and the impact these might have on a person’s life. Members of the team that conducted the interviews had extensive previous experience working with people with EDS difficulties and dementia and the associated difficulties they have. The research team were therefore experienced in discussing difficult topics as well as managing emotional situations. If it was felt that a participant was becoming uncomfortable or emotional during a discussion a break was given. Discreet comfort could then be given to the individual who would be able to leave the discussion at any time.

Carers were welcome to come along to the interview with participants. If they added anything to the discussions, they were noted as a carer in the transcript. All participants were given a unique identification code, which was used to label audio data and transcriptions. Participants' personal details were known only to the researchers. In any papers prepared for publication, participants were given a pseudonym. All digital data was stored on a secure server accessible only by password-protected computers. Recordings were immediately deleted from the voice recorders as soon as they were transferred to the computer. Paper based data (consent forms) were stored in a locked filing cabinet office within a locked room.

2.11.2 Ethical considerations for survey

Responses to surveys were anonymous and no identifying information was collected. Participants completing and submitting the survey were deemed to have given consent for participation storage and analysis of responses. They were informed this was the case.

2.12 Summary

The overall aim of this research is to inform earlier identification of EDS difficulty for people living with dementia. The methodology to address this aim was informed by the principles of two common frameworks that seek to implement a proactive approach to service provision for people with chronic disease and dementia respectively. Initial scoping work in the design phase of the research project identified that the clinical problems that front-line clinicians face align with these aims and principles. In order to address ‘user involvement’ a partnership was developed with Dementia NI who provided a channel for people who are living with dementia to be recruited as "experts by experience" to inform, influence and co-produce the work.

The study design was applied through a sequence of four phases. In phase 1 (Chapter 3), a systematic review was conducted, which considered the reliability, clinical measurability and applicability of EDS indicators to early-stage dementia. In phase 2 (Chapter 4), published evidence pertaining to EDS difficulties in dementia was considered and used to inform question generation for an online semi-structured interview with people living with dementia and carers. In phase 3 (Chapter 5), an online survey was administered to understand specialist SLT perspectives on identification of EDS difficulty in people living with early-stage dementia. Findings were consolidated in phase 4 (Chapter 6), in which an expert panel participated in an online meeting to establish consensus on the research findings, explore barriers to identification of EDS difficulty and discuss translation of the research findings into practice. Finally, all elements from different approaches were drawn together into a conceptual space, informed by theory, and further developed within the discussion chapter (Chapter 7). An ethical approval application was submitted, and ethical approval was granted by the research ethics committee.

3 Chapter 3: Identification of eating, drinking and swallowing difficulties for people living with early-stage dementia: a systematic review

The thesis aim was to inform earlier identification of EDS difficulties for people living with early-stage dementia. However, before early identification of EDS difficulty can be achieved, more information on indicators of EDS difficulty in early-stage dementia is needed. In this chapter, a systematic review is presented, which considers the reliability, clinical measurability and applicability of indicators of EDS difficulty to early-stage dementia. This phase aimed to identify reliable and clinically measurable indicators of EDS difficulty in early-stage dementia from published literature. The systematic search for literature was conducted using the MEDLINE, EMBASE and PsychInfo databases.

Identification of eating, drinking and swallowing difficulties for people living with early-stage dementia: a systematic review

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Running head

Eating, drinking and swallowing in dementia: a review of indicators

Keywords

Eating, drinking, swallowing, dementia, systematic review

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Declaration of interest

None

Abstract

Background

The prevalence of dementia is increasing, bringing a range of challenges, such as eating, drinking and swallowing (EDS) difficulties that are associated with aspiration, which can be fatal. Early identification of EDS difficulty in early-stage dementia may prevent complications but reliable indicators are needed to help develop pathways to support diagnosis. Previous reviews of this area require updating.

Aims

We set out to identify reliable and clinically measurable indicators of EDS difficulty used in early-stage dementia.

Methods & Procedures

A systematic search was conducted using common databases (MEDLINE, EMBASE and PsychInfo). Articles reporting indicators of EDS difficulty in early-stage dementia or mild cognitive impairment were included. The reliability of included studies were critically appraised using risk of bias tools. Study outcomes were narratively reviewed by considering the reliability, clinical measurability and applicability of EDS indicators to early-stage dementia.

Outcomes & Results

Initial searches returned 2,443 articles. After removing duplicates, limiting to English language and human studies 1,589 articles remained. After reviewing titles, 60 abstracts were reviewed, yielding 18 full text articles. Twelve articles were excluded

that that did not report at least one indicator of EDS difficulty in early-stage dementia, or where the reported association was not strong. Six included studies reported eight indicators of EDS difficulty in early-stage dementia (mainly Alzheimer's disease). On the balance of measurability, reliability and applicability the most promising indicators of EDS difficulty were: delayed oral transit, rinsing ability, sarcopenia and polypharmacy. Additional, less reliable and applicable indicators included: always opened lips and non-amnestic mild cognitive impairment, especially in men. Delayed pharyngeal response is subjectively measured when instrumental assessment is not available and the "candy sucking test" cannot be recommended because there is an inherent choking risk.

Conclusions & Implications of this review

EDS difficulty in early-stage dementia may be highlighted by four indicators that could be combined to create enhanced pathways to support the early identification of EDS difficulties for people living with early-stage dementia. Exploring the experiences of people living with dementia and their families' perspective on potential indicators of EDS difficulty may add to the existing evidence base.

What this paper adds

What is already known on the subject

Early identification of EDS difficulty in early-stage dementia may prevent complications but more reliable and clinically measurable indicators of EDS difficulty are needed to help develop pathways to support diagnosis.

What this paper adds to existing knowledge

A comprehensive range of studies related to EDS identification in early-stage dementia have been selected and reviewed. Across six included studies, the most promising indicators of EDS difficulty in early-stage dementia included delayed oral transit, poor rinsing ability, presence of sarcopenia and polypharmacy.

What are the potential or actual clinical implications of this work?

This work could help to develop pathways to support the early identification of EDS difficulties for people living with early-stage dementia with a view to preventing complications.

Introduction

The Global Burden of Diseases, Injuries, and Risk Factors Study reported that the prevalence of dementia has more than doubled from 20.2 million in 1990 to 43.8 million in 2016 (Nichols et al., 2019). In 2019, the prevalence of dementia locally in Northern Ireland was estimated to be 6.9%, expected to reach 8.5% by 2040 (Wittenberg et al., 2019).

Over half of people living with dementia may have eating, drinking and swallowing (EDS) difficulties (Alagiakrishnan et al. 2013). Deterioration in cognitive and executive function in early-stage in dementia may predispose to EDS difficulty (Rogus-Pulia et al., 2015), with around 20% of people living with early-stage dementia being affected (Kai et al. 2015).

EDS difficulty in dementia is a significant independent risk factor for poorer outcomes including aspiration pneumonia and malnutrition (Paranji et al., 2017). Although there are few proven interventions to treat established EDS difficulty in people living with dementia, early identification of EDS difficulty may allow for modification of risk (Abdelhamid et al., 2016). Speech and Language Therapists (SLTs) primarily use compensatory strategies in this client group and frequently cite the need for family and care staff training in mealtime support (Egan et al., 2020).

Expert opinion suggests that impairment in self feeding (Rogus-Pulia et al., 2015) and altered sensations are early signs of EDS difficulty (Winchester and Winchester, 2016). However, opinions are sometimes challenged. Hence, more reliable and clinically measurable indicators of EDS difficulty are needed to help develop pathways to support diagnosis. Previous reviews of this area have not focussed on identification of EDS difficulty in early-stage dementia. The literature searches also require updating for newer evidence (Affoo et al., 2013, Alagiakrishnan et al., 2013). This area of practice involves a range of factors, early indicators, signs and symptoms that can be presented together. Here, we use the term indicator to cover all potentially relevant factors that have been associated with the pathophysiology of EDS difficulty.

Clinical application

The model for supporting people with dementia and their families requires support services to be seamless, accessible and proactive (Department of Health, Social Services & Public Safety, 2011). If people living with dementia and EDS difficulty are identified, Speech and Language Therapists can implement compensatory strategies, and initiate family and care staff training (Egan et al., 2020). There is preliminary evidence to suggest that caregiver approach to people living with dementia may influence aspiration risk (Gilmore-Bykovskyi et al., 2018) and for carers, early identification of EDS difficulty may help reduce stress (Papachristou et al., 2013) and isolation associated with this problem (Gillies, 2012). To integrate existing information and enable rational decision making, an updated review could establish whether findings are consistent and can be generalised across populations, settings, and stages of disease (Mulrow, 1994).

Aim and Objectives

The overall aim of this systematic review was to identify reliable and clinically measurable indicators of EDS difficulty in early-stage dementia. This was addressed via three objectives, each with respect to populations of early-stage dementia...

1. To find studies reporting on early identification of EDS difficulty.
2. To discover reliable indicators of EDS difficulty.
3. To review the clinical measurability of specific indicators of EDS difficulty.

Methods

A systematic review was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Page et al., 2021). Difficulty in EDS was previously termed dysphagia (Robertson et al., 2018). For the purposes of the review the term EDS difficulty is used to describe what is termed ‘dysphagia’ in the included studies. Early-stage dementia is considered to be consistent with a clinical dementia rating of 1 or with the descriptor ‘mild dementia’ (Morris, 1993).

Search strategy

A search for relevant literature was conducted on the Ovid platform using the MEDLINE, EMBASE and PsychInfo databases using the search terms in Appendix 1. Duplicate articles were removed, and limitations set were English language and human studies. A review of article titles was performed to identify potentially relevant studies before assessing article abstracts and then performing full text reviews to identify included studies.

Inclusion and exclusion criteria

Articles reporting indicators of EDS difficulty in studies including people with early-stage dementia or mild cognitive impairment were included. The rationale for including mild cognitive impairment is that it can precede dementia (Winchester and Winchester, 2016) and EDS difficulty is recognised at this stage of cognitive decline (Takahashi et al., 2019). Studies were excluded that did not report at least one indicator of EDS difficulty in early-stage dementia, or where the reported association between indicators and EDS difficulty was not considered strong (Akoglu, 2018). Conference proceedings and abstracts without full text were excluded due to a lack of information to assess risk of bias. The date of publication was not used as an inclusion or exclusion criteria.

Critical appraisal

The reliability of the studies was formally assessed depending on the study type using the following risk of bias tools; Newcastle-Ottowa scale (Wells et al., 2013), the National Heart, Lung, and Blood Institute Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (NHLBI, 2014), and The Quality Assessment of Diagnostic Accuracy Studies (QUADAS-2) (Whiting et al., 2011). Included studies were classified in terms of evidence level by the Scottish Intercollegiate Guidelines Network grading system (SIGN, 2015). Studies were not excluded on the basis of risk of bias or quality.

Narrative review

There was clinical heterogeneity in the included studies therefore the studies and findings on critical appraisal were narratively reviewed by considering the reliability and bedside (i.e., non-instrumental/non-invasive) clinical measurability of reported indicators of EDS difficulty. Narrative review also considered the applicability of studies reporting indicators to the early-stage dementia population.

Results

Search results

The search returned 2,443 articles. After removing duplicates and limiting to English language and human studies, the titles of 1,589 articles were reviewed for relevance leaving 60 abstracts that were reviewed. Eighteen full text articles were further reviewed, see flow chart (Figure 1).

Two studies were excluded that only compared different forms of dementia with each other in terms of swallowing and EDS characteristics as opposed to identifying specific indicators of EDS difficulty (Ikeda et al., 2002, Suh et al., 2009). Three other studies were excluded as they included no participants with early-stage dementia (Horner et al., 1994, de Correia et al., 2010) or where no breakdown of dementia severity in participants was provided (Wada et al., 2001).

Three studies that did not report an indicator of EDS difficulty were excluded (Suto et al., 2014, Goes et al., 2014, Miarons et al., 2019). Two studies in which a reverse relationship was assessed were excluded (Takagi et al., 2017, Edahiro et al., 2012). For example, one of these two studies assessed for associations with decreased skeletal muscle in people living with dementia and identified EDS difficulty as having an independent association (Takagi et al., 2017). The other study assessed for associations with the ability to self-feed in people living with dementia and identified EDS difficulty as having an independent association (Edahiro et al., 2012).

In a further study, the Mann Assessment of Swallowing Ability had a statistically significant negative correlation with aspiration on videofluoroscopic swallowing studies, but the strength of the association (Spearman's Rho –0.349) was not strong enough to consider the assessment an indicator (Ji et al., 2019). The strength of this association would be considered moderate (Akoglu, 2018).

Finally, one study was excluded that reported an indicator of EDS difficulty in early-stage dementia (reduced hyolaryngeal elevation), but assessment of swallow was performed in a supine position. Swallowing assessments were made in the supine rather than upright position because the study also involved the use of functional magnetic resonance imaging scans performed during swallowing. People don't EDS lying flat therefore a judgement was made that this study was not considered applicable enough for inclusion (Humbert et al., 2010).

A total of six studies were included, and the references of these studies were investigated for additional potentially relevant publications, but none were identified (Figure 1). Eight indicators of EDS difficulty were reported across the six included studies (Priefer and Robbins, 1994, Sato et al., 2014, Yang et al., 2014, Mori et al., 2017, Naruishi et al., 2018, Özsürekci et al., 2020) (Table 1).

Narrative review of findings

The six studies generate several indicators associated with EDS difficulty.

(a) Delayed oral transit and delayed pharyngeal response

In a good quality case control study by Priefer and Robbins (1997) (SIGN evidence level 2+) it was identified that compared to healthy control subjects, delayed oral transit and delayed pharyngeal response were features of swallowing impairment in mild Alzheimer's disease, considered equivalent to early-stage dementia (McGee et al., 2017). However, measurements of oral transit and pharyngeal response were taken on videofluoroscopic swallowing studies, which limits applicability to clinical measurement of these features at the bedside. Despite this they are key findings that resonate with other indicators of EDS difficulty that may reflect impairment in oral transit, such as lack of rinsing ability (Sato et al., 2014). The relationship of these swallowing impairments (i.e., delayed oral transit and delayed pharyngeal response) with more advanced deterioration in swallow (i.e., penetration or aspiration) was not demonstrated. This suggests that delayed oral transit and delayed pharyngeal response predate significant swallowing impairment and are as such potentially very useful to identify.

(b) Lack of rinsing ability

In a good quality cross-sectional study from Sato et al. (2014) (SIGN evidence level 2+), the easy to measure lack of rinsing ability was demonstrated to have an independent relationship on logistic regression analysis with EDS difficulty. People who could rinse rhythmically sequentially without leaking water were defined as having “better” function, whereas those who could not were defined as “worse”. Therefore, rinsing ability would be easy to measure at the bedside. However, EDS difficulty was defined only by water swallow test, which is less sensitive and specific than either of the gold standard reference tools of videofluoroscopic swallowing study or fibreoptic endoscopic evaluation of swallow. The study also included patients with all degrees of severity of Alzheimer’s disease and the combined prevalence of poor rinsing ability in 18% was reported in the mild and moderate Alzheimer’s disease populations. It is therefore unclear how common rinsing ability would be if just assessed in early-stage of dementia. Despite this the multivariate analysis performed by Sato et al. (2014) controlled for clinical dementia rating scale (i.e., dementia severity), which suggests that rinsing ability is likely an indicator of EDS difficulty across all severities of Alzheimer’s disease, including those with early-stage disease.

(c) Sarcopenia and polypharmacy

In another good quality cross-sectional study by Özsürekci et al. (2020) (SIGN evidence level 2+), the easily measurable factors of sarcopenia and polypharmacy demonstrated significant and independent relationships with EDS difficulty on videofluoroscopic swallowing studies. This study covered the full range of Alzheimer’s disease severity but excluded patients more likely to have severe dementia e.g., those unable to comply with instructions. The applicability of this study to the target population of early-stage dementia therefore appears relatively good. The prevalence of polypharmacy and sarcopenia (probable sarcopenia, sarcopenia and severe sarcopenia) in the mild Alzheimer’s disease group was high at 65% and 61% respectively. In addition, the logistic regression analysis for independent predictors of EDS difficulty that Özsürekci et al. (2020) performed controlled for clinical dementia rating scale. So, the factors identified are likely applicable to the mild Alzheimer’s disease group in the study.

(d) Non-amnestic cognitive impairment

In the cognitively impaired populations, the absence of memory impairment (i.e., non amnestic cognitive impairment) was reported to have a significant and independent relationship with EDS difficulty in patients with mild cognitive impairment but only in men. Memory impairment would be relatively easy to assess and measure. However, an important criticism of the study by Yang et al. (2014) is the use of an unvalidated swallowing assessment for defining EDS difficulty. Although the study otherwise scored fairly using the risk of bias tool for cross-sectional studies (NHLBI, 2014) the risk of bias was considered high (SIGN evidence level 2-). The number of individuals with mild cognitive impairment in the study was also low (cognitive impairment n=81 vs. No cognitive impairment n=334) thus reducing its applicability to the target population of interest. While a potentially interesting observation was identified in the study, one must be mindful that this study describes an association between the type of cognitive impairment and EDS difficulty (Yang et al., 2014). It seems biologically implausible that the type of cognitive impairment would be a causative factor in EDS difficulty, particularly as it is only a feature in male patients.

(e) Open lips at all times

A fair quality cross-sectional study by Naruishi et al. (2018) (SIGN evidence level 2-), identified the features of oral condition (stability of posterior occlusion as defined by normal posterior teeth or dentures) to be independently related to aspiration pneumonia. Oral condition was assessed by dentists, which may make this study difficult to replicate. Aspiration pneumonia is a multifactorial outcome measure and may not just be related to EDS difficulty (Langmore et al., 1998). The study also included patients with and without cognitive impairment, did not report results for the severity of cognitive impairment and only assessed swallowing function by videofluoroscopic swallowing study in 17% of the study population. In this small subset of the study population, a significant relationship was observed between identification of a swallowing disorder on videofluoroscopic swallowing studies and always opened lips. It would be easy to measure opened lips at all times, but this would be a relatively advanced sign of EDS difficulty.

(f) Candy sucking test

Finally, in a pilot diagnostic study the novel “candy sucking test” showed a significant relationship with oral transit time on videofluoroscopic swallowing studies (Mori et al., 2017). The study population in the study by Mori et al. (2017) was not as representative of the target population of early-stage dementia (median mini-mental state score of 10) and was at particular risk of both selection and reporting bias. The mini-mental state examination score can be used as a surrogate measure for the clinical dementia rating. Scores of 11-20 have substantial agreement with moderate dementia, and 0-10 for severe dementia (Perneczky et al., 2006). In addition, the possibility of accidental swallowing or choking precludes use of the “candy sucking test” from a risk-benefit perspective.

Discussion

More reliable and clinically measurable indicators of EDS difficulty are needed to help develop pathways to support diagnosis, and previous reviews of this area require updating with a specific focus on indicators of EDS difficulty (Affoo et al., 2013, Alagiakrishnan et al., 2013). In the scoping review by Affoo et al. (2013) evidence was identified that EDS difficulty, as well as autonomic nervous system dysfunction may occur in Alzheimer's disease. In the systematic review by Alagiakrishnan et al. (2013) it was identified that EDS difficulty developed during the late stages of frontotemporal dementia, but it was seen during the early stage of Alzheimer’s disease.

In this study a comprehensive range of studies related to EDS evaluation in early-stage dementia (mainly Alzheimer’s disease) have been identified and reviewed. On the balance of measurability, reliability and applicability the most promising indicators of EDS difficulty include delayed oral transit (Priefer and Robbins, 1997), rinsing ability (Sato et al., 2014), sarcopenia (Özsürekci et al., 2020) and polypharmacy

(Özsürekci et al., 2020). Additional less reliable and applicable indicators to be considered include opened lips at all times (Naruishi et al., 2018) and non-amnestic mild cognitive impairment in men (Yang et al., 2014). Delayed pharyngeal response (Priefer and Robbins, 1997) is subjectively measured when instrumental assessment is not available and the “candy sucking test” (Mori et al., 2017) cannot be recommended because there is an inherent choking risk. This information could help to develop pathways to support the early identification of EDS difficulties for people living with early-stage dementia with a view to preventing complications of EDS difficulty (Gilmore-Bykovskyi et al., 2018), supporting family members/carers (Egan et al., 2020) and reducing overall healthcare consumption (Paranji et al., 2017).

The indicators of EDS difficulty in early-stage dementia identified by this review are diverse, and on different levels of evidence. It is unclear if the EDS indicators highlighted are associated with EDS difficulty or if they are causative factors. Certain indicators of EDS difficulty reported in the literature are also medical in nature (e.g., sarcopenia and polypharmacy), and less likely to be reported by a service user. There was a lack of studies identified on indicators of EDS difficulty from the perspective of people living with dementia or their carers.

Priefer and Robbins (1997) reported delayed oral transit and delayed pharyngeal response as potential indicators of EDS difficulty in early-stage dementia but measurements were taken during videofluoroscopic swallowing studies. In a study by Branco et al. (2019) in the Parkinson’s disease population, a more useful and clinically applicable definition of delayed oral transit is provided (over four seconds). This clinical definition could be incorporated into identification of EDS difficulty in early-stage dementia. Unfortunately, a clinical definition for reduced larynx elevation, which was another part of the assessment used by Branco et al. (2019) was not provided in the study. This would have been of interest given that reduced hyolaryngeal elevation on videofluoroscopic swallowing studies has been observed in patients with early Alzheimer's disease. Although these observations were made in the supine rather than upright position in a functional magnetic resonance imaging study of swallowing. So, the applicability of this observation is limited and was a reason for excluding (at the full text assessment stage) the study that reported this observation (Humbert et al., 2010).

In cognitive impairment two different approaches were identified for the detection of EDS difficulty and included assessment of oral condition and evaluation of executive function (Yang et al., 2014, Naruishi et al., 2018). One of the main findings was that the co-existence of cognitive impairment with oral frailty was found to significantly increase the risk of aspiration pneumonia (Naruishi et al., 2018). The risk of aspiration pneumonia was even higher when cerebrovascular disease was also present (Naruishi et al., 2018). A further finding was that men with non-amnestic cognitive impairment, which is associated with a poorer level of executive function, as opposed to amnesic mild cognitive impairment, are more likely to have EDS difficulty on a Standardized Swallowing Assessment. Neither type of mild cognitive impairment was related to EDS difficulty in women (Yang et al., 2014).

Patients with dementia frequently suffer reduced salivary secretions, poor oral health and bacterial overgrowth (Rogus-Pulia et al., 2015). In a study of oral condition, mild cognitive impairment patients exhibited significantly more tooth staining and poorer performance on repetitive saliva swallow test (Takahashi et al., 2019). In dentulous nursing home residents, there was a significant association between preserved cognitive function and a reduced risk of EDS difficulty on water swallow test. Although a similar relationship was not identified in the edentulous participants, edentulous individuals with cerebrovascular disease had an increased risk of EDS difficulty. This highlights cerebrovascular disease as a potential important confounding factor in this study and again emphasises cerebrovascular disease as an important risk factor for EDS difficulty in the cognitively impaired client group (Yatabe et al., 2018). Two studies assessing the relationship of oral function with EDS difficulty in patients with cognitive impairment have also emphasised the importance of co-existing cerebrovascular disease (Yatabe et al., 2018, Naruishi et al., 2018). In keeping with this observation, a further study in individuals with Alzheimer's disease identified the presence of silent brainstem infarction as a significant independent predictor of aspiration pneumonia (Wada et al., 2001). This observation is similar to the independent relationship between brainstem impairment and EDS difficulty in multiple sclerosis, further underpinning the importance of brainstem control of safe and effective swallowing (Calcagno et al., 2002).

Other clinical factors associated with EDS difficulty in the Alzheimer's group included sarcopenia and polypharmacy (Özsürekci et al., 2020). In a reverse of this analysis, another study identified in the search reported that an independent relationship existed between poor swallowing function on modified water swallow test and decreased skeletal muscle index (Takagi et al., 2017). This study assessed for indicators of decreased skeletal muscle as opposed to indicators of EDS difficulty (so was excluded at the full text review stage), but it does show that the reverse relationship exists (Takagi et al., 2017). However, no relationship was identified between nutritional status and EDS difficulty in another study patients that was also excluded at the full text assessment stage (Goes et al., 2014). The authors of this study discussed that this small study of 30 patients was contrary to other evidence, and in their study the process of malnutrition was slower to evolve than the EDS difficulty. This collective evidence suggests that it is worth exploring further the relationship between sarcopenia and nutrition with EDS difficulty, but the timing of EDS assessment is critical when considering whether there is definite association.

Consistent with importance of polypharmacy there was a significant association identified between aspiration pneumonia and neuroleptic use in the Alzheimer's disease population (Wada et al., 2001). The use of antiepileptic drugs that have sedative properties are also independently associated pneumonia risk in community-based individuals with Alzheimer's disease (Taipale et al., 2019). When specifically assessing the impact of antipsychotic medications, a study identified in the systematic search reported that on videofluoroscopic swallowing studies there were no differences in the penetration aspiration scale or laryngeal vestibule closure time in patients with dementia that were taking and not taking antipsychotic medications (Miarons et al., 2019).

Importance, strengths and limitations

A strength of this review is the systematic approach taken, which was required given the heterogeneous nature of the study populations. Mild cognitive impairment can be considered a prodromal phase between healthy aging and Alzheimer's dementia (Winchester and Winchester, 2016). However, a diagnosis of mild cognitive impairment is distinct from dementia and may precurse other diseases such as cerebrovascular disease (Knopman and Petersen, 2014). The severity of dementia can be classified according to a clinical dementia rating scale and mild cognitive impairment is consistent with a clinical dementia rating scale of 0.5 (Takahashi et al., 2019). In some previous studies that have aimed to recruit individuals with “early-stage” dementia, inclusion criteria are variable and have included a clinical dementia rating 0.5-1 (Boots et al., 2018), a clinical dementia rating 0.5-1 or a formal diagnosis of early-stage dementia (by General Practitioner or Specialist) (Stockwell-Smith et al., 2019), a clinical dementia rating no greater than 1 (McGee et al., 2017), or mild to moderate cognitive impairment (as determined by a Mini Mental State Examination score of ≥ 18 points) (Clare et al., 2019). The lack of consensus with regards to defining early-stage dementia contributes to the heterogeneity of the published literature. In the area of early-stage dementia research there is a need for uniformity of clinical definitions and more robust studies on indicators of EDS difficulty. It is interesting to note the absence of previous episodes of EDS difficulty as Scharitzer et al. (2017) have highlighted the importance of taking a full patient history in order to identify swallowing difficulties. History taking is often implicit in the process of implementation of clinical indicators, but it may also highlight important new factors to consider in any listing of predictors.

The search used in this systematic review has identified all studies included in previous reviews (Affoo et al., 2013, Alagiakrishnan et al., 2013). So, the search strategy was validated. In a previous scoping review of swallowing in Alzheimer’s disease by Affoo et al. (2013) a summary of clinical studies using instrumental assessment of swallowing in Alzheimer’s disease identified similar studies to this systematic review. The evidence level of studies identified by Affoo et al. (2013) was classified using the Oxford Centre for Evidence-Based Medicine Levels of Evidence (Table 2). However, when using the Oxford Centre for Evidence-Based Medicine levels of Evidence many of the studies were not assigned a particular evidence level by Affoo et al. (2013). In a systematic review of swallowing in dementia by Alagiakrishnan et al. (2013), similar studies were identified to Affoo et al. (2013), and the levels of evidence were graded according to the Agency for Healthcare Research and Quality Interpretation (Table 3). This current review has updated the previous reviews with more recently published studies (Sato et al., 2014, Yang et al., 2014, Mori et al., 2017, Naruishi et al., 2018, Özsürekci et al., 2020) and has had a much greater focus on discovering indicators of EDS difficulty.

Conclusions

There remains a lack of consistency in the approach to identifying EDS difficulty in early-stage dementia. There is a relative paucity of studies reporting indicators of EDS difficulty for people with early-stage dementia in the published literature. The indicators of EDS difficulty in early-stage dementia reported in the literature are diverse. EDS difficulty in early-stage dementia is associated with delayed oral transit, poor rinsing ability, as well as presence of sarcopenia and polypharmacy. These indicators of EDS difficulty could help to initiate pathways to support the early identification of EDS difficulties for people living with early-stage dementia. However, the evidence would be incomplete without eliciting the experiences of people living with dementia, their families' perspectives and professional opinion on potential indicators of EDS difficulty. There is a need for further studies to explore indicators of EDS difficulty from the perspective of people living with dementia and carers.

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Figures and tables

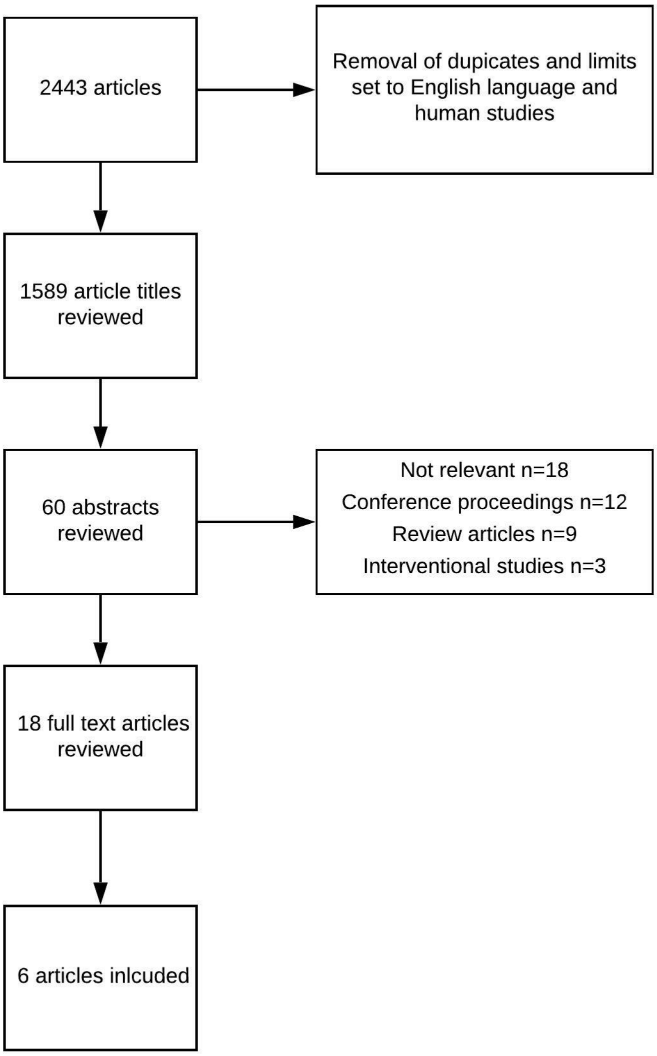

Figure 1| Study selection flow diagram

Reference Country	Identifier of EDS difficulty (effect size in multivariate analysis)	Study population	Prevalence of identifier	Evidence level	Study assessment tool	Study assessment score	Clinical Measurability
Mori et al. (2017) Japan	Candy sucking test	Alzheimer's disease (n=23) Median MMSE 10	Not applicable	2-	QUADAS-2	-	Poor
Naruishi et al. (2018) Japan	Opened lips at all times (OR 1.99, 95% CI 1.1-3.7)	Cognitive impairment (n=698) No cognitive impairment (n=476)	Not applicable	2-	NHLBI	7/11	Good
Özsürekci et al. (2020) Turkey	Sarcopenia (OR 4.9, 95% CI 1.2-19.6)	Alzheimer's disease Mild (n=26), Moderate (n=31), Severe (n=19)	Probable sarcopenia 31% Sarcopenia 15% Severe sarcopenia 15%	2+	NHLBI	8/11	Good
Özsürekci et al. (2020) Turkey	Polypharmacy (OR 6.1, 95% CI 1.6-23.9)	Alzheimer's disease Mild (n=26), Moderate (n=31), Severe (n=19)	65%	2+	NHLBI	8/11	Good
Priefer and Robbins (1997) USA	Delayed oral transit	Mild Alzheimer's disease (n=10) Controls (n=15)	Not reported	2+	Newcastle-Ottawa	8/9	Good
Priefer and Robbins (1997) USA	Delayed pharyngeal response	Mild Alzheimer's disease (n=10) Controls (n=15)	Not reported	2+	Newcastle-Ottawa	8/9	Poor
Sato et al. (2014) Japan	Rinsing ability (OR 4.8, 95% CI 1.9–12.1)	Alzheimer's disease Mild (n=26), Moderate (n=68), Severe (n=61)	18% (mild and moderate)	2-	NHLBI	6/11	Good
Yang et al. (2014) Korea	Non amnestic mild cognitive impairment in men (OR 3.77, 95% CI 1.1–12.7)	Cognitive impairment (n=81) No cognitive impairment (n=334)	Not applicable	2-	NHLBI	7/11	Good

Table 1| Summary of evidence and critical appraisal

Abbreviations National Heart, Lung, and Blood Institute Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (NHLBI)

Mini-mental state examination (MMSE), odds ratio (OR)

Study	Study description	Oxford Centre for Evidence-Based Medicine Level of evidence	Conclusion
Humbert et al. (2010)	Described or characterised dysphagia in Alzheimer’s disease through comparison of two or more groups	Not assigned	Dysphagia occurs early in Alzheimer’s disease Dysphagia in early Alzheimer’s disease may be associated with functional change of the cortical swallowing network
Humbert et al. (2011)	Described or characterised dysphagia in Alzheimer’s disease through comparison of two or more groups	Not assigned	Dysphagia occurs early in Alzheimer’s disease Dysphagia in early Alzheimer’s disease may be associated with functional change of the cortical swallowing network
Priefer and Robbins (1994)	Described or characterised dysphagia in Alzheimer’s disease through comparison of two or more groups	Not assigned	Dysphagia occurs early in Alzheimer’s disease Dysphagia occurs in the oral and pharyngeal stages of swallowing
Horner et al. (1994)	Prospective case series	4	Dysphagia occurs in the oral and pharyngeal stages of swallowing Disease severity may be associated with dysphagia severity
Suh et al. (2009)	Described or characterised dysphagia in Alzheimer’s disease through comparison of two or more groups	Not assigned	Dysphagia occurs in the oral and pharyngeal stages of swallowing
Wada et al. (2001)	Described or characterised dysphagia in Alzheimer’s disease through comparison of two or more groups	Not assigned	Dysphagia in the oral and pharyngeal stages of swallowing Disease severity may be associated with dysphagia severity

Table 2| Summary of studies included in previous review from Affoo et al. (2013).

Study	Design	Prevalence	Subjects and assessment method	Type of assessment	Conclusions/outcomes	Evidence level
Priefer and Robbins (1994)	Prospective case-controlled study	32%	N = 10 Alzheimer's disease (mild as defined by clinical dementia rating scale) N= 13 (controls) Mean age = 68 Observed patients and controls have a meal	Clinical swallow evaluation Videofluoroscopic swallowing studies	Alzheimer's disease patients had prolonged oral transit duration for solids, pharyngeal response for liquids and total swallow duration for liquids, received more cueing or assistance by caregiver.	B
Humbert et al. (2010)	Case–control study	Not provided	N=24 (13 mild Alzheimer's disease, mean mini-mental state examination score = 23) Functional Magnetic Resonance Imaging BOLD	Videofluoroscopic swallowing studies	Alzheimer's disease patients had reduced mean extent of hyoid movement and mean extent of laryngeal elevation	B
Horner et al. (1994)	Prospective cohort study	Moderate 28.6% Severe 44%	N=25, 56% female Mean age = 74 Mini-mental state examination score 10–20 in moderate and 1-10 in severe (mean 13.24) Caregiver questionnaire	Clinical swallow evaluation Videofluoroscopic swallowing studies	Severe Alzheimer's patients had worse oral praxis score and global video fluoroscopic score	B

Suh et al. (2009)	Retrospective cohort study	Alzheimer’s disease 13% Vascular dementia 47%	N=49 38% female Mean age = 73 years	Videofluoroscopic swallowing studies	Vascular dementia patients had significant difficulty in bolus formation and mastication and had significantly increased risk of silent aspiration Alzheimer’s disease patients had a significant oral transit delay of well over 5 seconds	B
Ikeda et al. (2002)	Survey	Fronto-temporal dementia 26% Alzheimer’s disease 7%	N=91 37% female Mean age = 65 years Mini-mental state examination score mean 20.2 Questionnaire evaluating five domains: swallowing problems, appetite change, food preference, eating habits, other oral behaviour	Clinical swallow evaluation	Difference between Alzheimer’s disease and fronto-temporal dementia in the overall frequency of abnormal eating behaviours in different domains and it was higher in fronto-temporal dementia, except for swallowing problems which is higher in Alzheimer’s disease	B

Table 3| Summary of studies included in previous review by Alagiakrishnan et al. (2013)

Appendix 1

Search terms

1. Deglutition Disorders/
2. (dysphagia or swallow* or deglut*)
3. 1 or 2
4. indicat*
5. detect* or identif* or sign* or behavio?r or predict*)
6. 4 or 5
7. Cognitive Dysfunction/
8. dementia/ or alzheimer disease/
9. (MCI or mild cognitive impairment or alzheimer* or dementia)
10. 7 or 8 or 9
11. 3 and 6 and 10
12. Deglutition Disorders/
13. (dysphagia or swallow* or deglut*)
14. 12 or 13
15. indicat*
16. (detect* or identif* or sign* or behavio?r or predict*)
17. 15 or 16
18. Cognitive Dysfunction/
19. dementia/ or alzheimer disease/
20. (MCI or mild cognitive impairment or alzheimer* or dementia)
21. 18 or 19 or 20
22. 14 and 17 and 21

4 Chapter 4: Exploring the connection between dementia and eating, drinking and swallowing difficulty: findings from home-based semi-structured interviews

The previous chapter identified a lack of research studies exploring indicators of EDS difficulty from the perspective of people living with dementia and carers. In this chapter, published evidence pertaining to EDS difficulties in dementia was considered from the previous phase, and used to inform question generation for an online semi-structured interview. Dementia NI “co-researchers” and an empowerment officer from Dementia NI assisted with design of the interviews. Further members of the charity living with dementia and carers were invited to participate. The aim was to understand the experience of EDS by people living with dementia with the view to gaining a better understanding of expectations, priorities, difficulties and support needs in relation to EDS.

Exploring the connection between dementia and eating, drinking and swallowing difficulty: findings from home-based semi-structured interviews

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Running head

Eating, drinking, and swallowing in dementia

Keywords

Eating, drinking, swallowing, dementia, semi-structured interviews

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Abstract

Background

Eating, drinking, and swallowing (EDS) difficulties are important to identify early. Awareness of EDS changes starts with those living with dementia, or their family carers. However, little is known about early identification from the perspective of people with dementia.

Aims

The aim of this study was to understand the experience of EDS by people living with dementia in their own home with the view to gaining a better understanding of expectations, priorities, difficulties and support needs in relation to EDS.

Methods

Published evidence pertaining to EDS difficulties in dementia was used to inform an online semi-structured interview guide. Four people living with dementia and a third-sector Empowerment Lead were invited to become co-researchers. People living with dementia and their carers were invited to be interviewed. We enquired about their past and present experiences, and future expected changes in EDS, information needs, opinions on early problem identification, and lifestyle modifications following onset of EDS difficulty. Narrative concepts of heroes and villains in their “stories” were identified. Responses were subjected to framework analysis informed by narrative enquiry.

Results

Seven people living with dementia and five family carers were interviewed. The overarching theme was a ‘missed connection’ between EDS difficulty and dementia. Where EDS difficulties were identified, ‘compensatory changes’ and a need for ‘access to information’ were noted.

Conclusions

The connection between potential EDS difficulties and a dementia diagnosis may not be made, even though EDS changes were recognised by people living with dementia and their family carers. This may be explained by behaviours that mask problems or allow individuals to cope or compensate. Reduced awareness may also be due to inadequate access to information and lack of specialist services. If the connection between dementia and EDS difficulty is missed it could further delay access to support services.

What this paper adds

What is already known on the subject

The prevalence of dementia is increasing and is expected to affect 9% of the population by 2040. EDS difficulties are common in people living with dementia and predispose to poorer outcomes. Better awareness of EDS changes early in the disease process of dementia or at preclinical stages can identify individuals at risk and allow for intervention prior to advanced EDS difficulties developing.

What this paper adds to existing knowledge

This paper reports the perspective of people living with dementia and family carers and provides insights into experiences of EDS, challenges faced and identifies commonalities. The connection between potential EDS difficulties and dementia is missed despite various changes reported by both people living with dementia and their family carers, who tend to make compensatory lifestyle changes without support.

What are the potential or actual clinical implications of this work?

Lack of awareness of the connection between potential EDS difficulties and dementia may arise due to inadequate access to information to support people living with dementia and their family carers. Access to such information is needed and the quality assurance of information from reputable sources is important to people living dementia. There is a need for greater service user awareness of signs of EDS difficulty and how to access specialist services.

Introduction

In 2019, the prevalence of dementia among older people in the UK was estimated to be 7.1% (Wittenberg et al., 2019). The average age of the population is accelerating in the UK. Accordingly, the proportion of people living with dementia is expected to reach 8.8% by 2040 (Livingston et al., 2017).

Eating, drinking and swallowing (EDS) difficulties, also known as dysphagia, have been reported to occur in up to 57% of individuals living with dementia (Alagiakrishnan et al. 2013). EDS difficulty can lead to aspiration pneumonia: the commonest cause of death in dementia (Parlak et al., 2021). Other sequalae include malnutrition, dehydration, weight loss (Sato et al., 2014), reduced quality of life (Boccardi et al., 2016), caregiver stress (Papachristou et al., 2013) and social isolation (Gillies., 2012). EDS difficulty is a significant independent risk factor for poorer outcomes during hospitalisation and increased use of resources (Paranji et al., 2017).

Better awareness of EDS changes early in the disease process of dementia or at preclinical stages may identify individuals at risk and allow for intervention prior to advanced EDS difficulties developing (Rogus-Pulia et al., 2015). Speech and Language Therapists (SLTs) use compensatory strategies in this client group and frequently cite the need for family and care staff training in mealtime support (Egan et al., 2020).

It has been shown that many people can contribute and meet their own care needs (Thorstensen-Woll et al., 2021). They may even monitor and drive the quality of care provided by professionals (Robert et al., 2015). To achieve optimal outcomes, it is important to identify the support needed for EDS by people living with dementia and also their family carer's need. A better understanding of the needs of people living with dementia and the impact of EDS on daily life will assist identification of EDS difficulty. Tailored interventions to improve the delivery of support services could then be formulated. This may be achieved through collaborative approaches such as 'co-design' (Swarbrick et al., 2019).

Research ‘co-design’ has been defined as the meaningful involvement of research users during the study planning phase of a research project (Slattery et al., 2020). User involvement is considered essential for the high quality and relevant research but often people living with dementia are not included in design work due to perceived and actual challenges with their health, memory, concentration and communication (McArthur et al., 2021). In the design of this study people living with dementia were recruited as "experts by lived experience" to inform, influence and co-produce the work.

Clinical Application

Improving EDS services for people living with dementia and their family carers requires understanding of the evolution of EDS difficulties in dementia and an insight into the experience of those affected. Early identification of physiological signs of EDS in literature base often sits separately from lived experience and the impact on the person affected. This literature should be merged with the psychological impact and lived experience of EDS difficulty in dementia to provide more holistic understanding.

To shape priorities for clinical healthcare professionals and inform population approaches to EDS care, it is important to understand the expectations, needs and priorities of people living with dementia, so that all their requirements, (whether clinical, psychological, and social) may be fully addressed.

Aim

The aim of this study was to understand the experience of EDS by people living at home with dementia, with the view to gaining understanding of expectations, priorities, difficulties and support needs in relation to EDS.

Methods

Design

A qualitative approach using online interviews was adopted. Semi-structured interviews were selected for flexibility and versatility. Online videoconferencing (Zoom ®) was used for data collection as previously used for semi-structured interviews (Archibald et al., 2019). We concentrated on those with experience of living with or caring for people living with dementia. The focus was on EDS changes over time from the point of dementia diagnosis.

Published evidence was used to inform question generation (Affoo et al., 2013, Alagiakrishnan et al., 2013) and an interview guide was formulated (Kallio et al., 2016) (Table 1). Separate interview guides were formulated for people living with dementia and family carers (Webster et al., 2015). A summary of the questions posed to each group is provided in Appendix 1 and 2. No ethical concerns were identified through the University governance process: approval was granted on 2nd August 2020 (REC.20.0071). The transition from co-researcher to participant was considered and discussed. Care was taken to ensure personal details were given with consent. The ethical issues at the core of this process had approval from the chair of ethics committee.

Patient and public involvement

A partnership was developed with a local member-led, third sector advocacy group providing a voice for people living with dementia called Dementia NI. People living with dementia were recruited by a Dementia NI advertisement as "experts by lived experience" to inform, influence and co-produce the work. Their contribution at online planning meetings (e.g., discussing recruitment, consent, and interview format) and document design (e.g., lay protocol, participant information sheet, consent forms, and interview guides) fulfilled the definition of co-design in achieving “meaningful end-user engagement” (Slattery et al., 2020, page 2).

Recruitment and data collection

Five pilot interviews were conducted on the chosen online platform (Archibald et al., 2019) with the empowerment lead of the group and four co-researchers. The focus was to discuss pre-interview logistics, the research protocol, participant information sheet, consent process, introduction by researcher to interview questions and the content of interview questions. Feedback suggested the need for reminders on the day of the interview, sharing participant information sheets in large font on-screen while reading aloud and the opportunity to have carers present for interviews.

Due to the rich data obtained and because interview questions were unchanged, pilot data were included in subsequent analysis. A purposive sample of additional people living with Dementia and their family carers were then approached via the charity and invited to participate. We recruited through the charity volunteers who were affected by a confirmed diagnosis of dementia and had ability to participate in an interview. No exclusion criteria were applied. All interviews were conducted over the same online platform as pilot interviews. The interviews were audio visually recorded and managed according to GDPR 2018 (Ulster University, 2018)

Data analysis

Framework analysis was used to guide the work, provide a transparent audit trail (Ward et al., 2013), and allow researchers and co-researchers to work together (Furber et al., 2009). Published evidence was used to devise an initial draft framework (Affoo et al., 2013, Alagiakrishnan et al., 2013). Data from the transcripts were imported into a qualitative data management system (NVivo 12). Analysis began with data familiarisation, immersion, and group discussion to further refine an initial theoretical framework. Core ideas were documented in handwritten notes in a reflexive journal. A sample of transcripts was shared with co-authors and core ideas were openly discussed. Following data immersion and group discussion, recurring ideas from the familiarisation process were grouped into draft themes, which were refined to reach a consensus at further meetings. The initial theoretical framework was also guided by narrative themes. To enable narrative analysis of individuals or processes regarded as helpful (or unhelpful) in the person living with dementia or their carer's experience of EDS, responses were dramatically framed into symbolic roles under the draft themes of heroes and villains (Wagner-Egger et al., 2011). Data indexing, summarisation of indexed data into codes, and thematic charting was used to formulate the final theoretical framework (Furber et al., 2010). To enhance trustworthiness, an audit trail of raw data extracts (in quotation marks) from the original transcripts is provided with participant number documented in parentheses.

Results

Including the four pilot interviews with co-researchers, 12 people took part in semi-structured interviews (23rd February -24 June 2021). Of these, seven were people living with dementia (four male and three female) and five family carers (two male and three female). Two people living with dementia requested for their interviews to be conducted jointly with their carer's. The average interview time was 31 minutes. The interviews were transcribed verbatim (total 18.5k words). All data from all participants was included in analysis.

Initial understanding of EDS difficulties

The data explored the use of themes past and present experiences, and future expected changes in EDS, information needs, early problem identification, and lifestyle modifications following onset of EDS difficulty. The concepts of heroes and villains (Wagner-Egger et al., 2011) in the EDS journey were integrated into the framework analysis (Table 2).

Initial themes

The initial themes were past and present experiences, and future expected changes in EDS, information needs, early problem identification, lifestyle modifications following onset of EDS difficulty, heroes and villains. The final overarching theme was a 'missed connection' between EDS difficulty and dementia. Where EDS difficulties were identified, 'compensatory changes' and a need for 'access to information' were noted.

Past - Initial changes in eating, drinking, and swallowing when diagnosed with dementia.

When asked about their earliest recollection of EDS difficulties, three people living with dementia and two carers recalled changes to their eating habits. One person living with dementia said;

"*I noticed that I became slower in eating and swallowing. I was not aware that there was food there. I tend to drift off, but not sleeping, because it was taking so long to chew even pureed food* [P2]".

These reported changes were summarised by the codes '*eating slowly*' and '*forgetting food in the mouth*' (Table 4).

Other reported changes at the time of diagnosis were summarised by the codes '*dry mouth*', '*voice changes*', '*throat tightness*', and an '*aversion to eating*'. Examples of raw data extracts included;

"*I noticed that my mouth became very dry and I was sort of slabbering quite a lot so I know now that this was probably an indicator* [P2]".

"*My voice first, certainly my voice first changed [P12]*".

'*Forgetting to eat or drink*' was also reported as an EDS change at the time of dementia diagnosis and one person living with dementia said;

"*It is just the memory side of eating and drinking I would struggle with at times and it sounds hard to believe, you don't know when you are hungry or not* [P4]".

There was also a report from a carer of needing to provide '*prompting*' for their spouse to eat or drink.

"*The differences would be that he would have to be prompted to eat and when he drank he gulped a wee bit and not taking his time* [P5]".

These responses suggest that EDS changes were present at an early stage and had a corresponding impact on wellbeing.

Present - Currently what eating, drinking, and swallowing is like when living with dementia

When asked about EDS at the present time, people living with dementia (N=4) and their carers (N=3) reported ongoing changes at mealtimes. One said;

"*I am aware now that people finish their food round me and I am still there an hour and a half later, but that's just part of it (dementia)* [P2]".

This was coded '*finishing food after others*'. Another person living with dementia said;

"*This last couple of years I feel like sometimes that my throat has closed in. Sometimes I hate the idea of eating anymore. There is a lot of pressure trying to swallow. It's become a major issue* [P12]".

Other codes included eating slowly, gulping, coughing, spluttering, choking, loss of taste, loss of appetite, aversion to eating, sensation of throat closing, and need for prompting to eat or drink (Table 4). The responses generated suggest that the current EDS difficulties overlap to a degree with past symptoms of EDS difficulty and impacts on quality of life. This suggests that EDS difficulty might be noted at an earlier stage if awareness was improved and quality of life may benefit.

Future - What is needed to help with eating, drinking, and swallowing in the future when living with dementia

Factors to support EDS in future included '*availability of a background history of previous EDS issues*', '*need for results of tests with understandable explanations*', '*access to open and transparent medical records*', '*understanding and patience from the public*', and '*reminders of when to eat and drink*' (Table 4).

Examples of raw data extracts summarised by these codes included;

"*Everyone should have a background history of swallowing and eating* [P2]"

"*As long as they (members of public) are aware that I am not going to get any better, probably just a bit of understanding. Understanding of the condition and probably* *patience of which many people have not got. Patience with you and time, just a little bit more time with you* [P12]"

"*Something specific to remind you that you need to take a drink or you need to take mealtimes. Some sort of timer you could set all the time* [P4]"

Clearly, there are unmet needs for people living with dementia and EDS difficulties.

Information needs - The type and timing of information (if any) on eating, drinking, and swallowing that the respondent would prefer to receive

Overwhelmingly people identified that they would like more information about EDS at the beginning of their journey (N=6 people living with dementia and N=4 carers). One person living with dementia said;

"*So I think to get information that you can trust and you know that if you read it, it is factual and you know it is right, rather than from some random person of the internet [*P1]."

This was coded as '*trustworthy information*'. When asked if there is anything that would be useful to support EDS in the future, this person living with dementia said;

"*I think relevant and safe information* [P1]".

This was summarised by the code ‘*reliable information*’. Other summary codes about information included ‘*who to contact*’, ‘*what to look out for*’, ‘*anxiety with online information*’, ‘*something written to refer back to*’, ‘*what to do if choking*’, ‘*awareness from public*’, and inclusion of ‘*relevant education in courses for carers*’ (Table 4). One carer for a person living with dementia said;

“*From the Alzheimer’s Society point of view, it would be good for them to include that there may be an issue with your loved one having an eating, drinking or swallowing problems and if that was the case, maybe what to look out for. That wasn’t as far as I remember part of the course* [P8]”.

Collectively these responses suggest that for people living with dementia and EDS difficulties there is a need for reliable and timely information.

Early problem identification - Preferences regarding eating, drinking, and swallowing input

When asked whether they would have wanted their EDS screened at the beginning of their journey, four carers and three people living with dementia replied ‘yes’. Regarding EDS screening one carer said;

“*I would have probably questioned it in relation to why it was actually necessary* [P8]”.

This was coded ‘*would need awareness of rationale*’.

One of the reasons reported by a person living with dementia who would not want an EDS screen was as follows;

“*At the beginning you are overwhelmed by what has been told to you and for someone to throw that into the mix as well, I think I just would have found this hard to deal with* [P1]”.

This was summarised by the code ‘*too much at the time of diagnosis*’.

Another person living with dementia said;

“*At the very beginning I would have felt violated. I wouldn’t have wanted that. I would have been totally against it. Now, looking back, I would be accepting of it but at that particular time I would not have wanted it.* [P4]”.

This was summarised by the code ‘*viewed as intrusive*’. These responses suggest it is imperative to respect the difficulty of receiving a new dementia diagnosis when considering assessment of EDS difficulty.

Lifestyle modifications following onset of EDS difficulty - Lifestyle modifications of participants to eating, drinking, and swallowing changes

When asked about how they responded to EDS changes, one person living with dementia responded to EDS changes as follows;

"*You get yourself into a system, it's maybe eating some then leaving it for a while, and then coming back later and eating some more* [P12]".

This was coded as '*coming back to finish food after a break*'. Other responses of people living with dementia to EDS changes were summarised by the codes '*avoid talking when eating*', '*need to concentrate when eating*', '*need for softened foods*', '*need for liquids at specific temperatures*', '*need for eating aids*', '*avoidance of food that is difficult to swallow*', '*chewing properly*', '*using straws to drink*', '*eating at home*', '*avoiding pressure of being watched*', '*using smaller glasses*', and '*cutting food into smaller pieces*' (Table 4).

One carer responded to EDS changes as follows;

"*We would normally sit down together and just sit at the table the two of us and have our meals together so that if anything happens, I am there. I encourage him to come to the table and start eating. He will always say he is not hungry but he will eat* [P5]".

This was summarised as '*having a carer present*' (Table 4).

Another carer responded to EDS changes as follows;

"*I am just aware of her eating. I am not staring at her, I am just looking and making sure that she is doing okay. I am doing it very subtly, I am not in her face, I am just making sure that things are okay* [P8]".

This was summarised by the code ‘*carer covertly observing*’. This response suggests that carers may not want to disempower people living with dementia who value their independence.

One person living with dementia said;

“*even simple solutions to mash the food down, to get a plate guard, to sit up straight, to use a small teaspoon instead of a knife and fork so that I wasn’t putting large amounts of food into my throat* [P2]”.

This was summarised by the code ‘*simple solutions*’. This response suggests that if EDS difficulty is recognised, interventions to support people living with dementia do not need to be complex in order to be effective.

Heroes - Individuals or processes reported to be helpful in the person living with dementia or their carer’s journey with eating, drinking, and swallowing

Healthcare Professionals reported to be helpful in the person living with dementia or their carer’s journey with EDS included a ‘*community psychiatric nurse*’, ‘*General Practitioner*’, and ‘*SLT*’. One person living with dementia said;

“*I appreciated the Speech and Language Therapist because obviously she knew what she was on about and you know she tried to improve my living with food and eating food* [P2]”.

'*Family*' were reported to be helpful in the person living with dementia or their carer's journey with EDS.

One carer for a person living with dementia also said;

"*I am on that group for TIDE NI and some of the girls, their husbands may be on a different part of the journey, a wee bit further down the line, and one of the girls has actually touched on the swallowing and drinking, it's amazing what you do pick up through our general wee coffee chat that we have every fortnight* [P5]".

This was summarised by the code '*support groups*'.

Villains - Individuals or processes reported to be unhelpful in the person living with dementia or their carer's journey with eating, drinking, and swallowing

Individuals or processes reported to be unhelpful in the person living with dementia or their carer's journey with EDS were summarised by the codes '*google*', '*missing hospital records*', '*lack of access to information about yourself*', '*lack of information at time of diagnosis*' and '*too much time between hospital check ups*'. Examples of raw data extracts are shown in Table 3.

The connection between dementia and eating, drinking and swallowing difficulty

Those with personal experiences of dementia were willing to explore EDS symptoms. However, reduced awareness of the potential for EDS difficulty in dementia may lead to a delay in seeking support.

"*I was surprised, to be honest, when I heard that people with dementia could suffer problems with swallowing and it came as quite a shock*" [P9].

As such, there is a stark need for *access to information* to support individuals, which was apparent as a theme and was supported by the following raw data extracts;

"*I think having at hand good clear, concise information that can sort of direct you and I think for family as well that support because they might know the signs that you might necessarily miss and they can sort of be keeping a check* [P1]".

"*Being informed about in the future what will happen with down the line. What will really happen. That is the scary side of it. Being informed is the key I think* [P11]".

As highlighted in the initial theme of information, the source of this information appears to be important with a reluctance to engage with online search engines for fear of finding untrustworthy information;

"*When (she) was diagnosed at first, I didn't go on the Mr Google and find out what was said because to me that was quite dangerous.* [P8]"

In the absence of the information to raise awareness of EDS difficulty, the ability of people living with dementia who “*value their independence* [P12]” and carers who “*don’t want to disempower* [P8]” leads to a range of *compensatory changes* or behaviours to adjust to EDS difficulty;

“*I like eating alone and doing it my way now and taking my time. I think the biggest thing now is feeling under pressure with other people around you watching you trying to struggle with that* [P12]”.

“*Say I wanted fish to eat. I would mash the fish up and make sure there is milk and mash it up to liquid form and that’s the process. You can’t do that in a restaurant. It's the fear of swallowing* [P12].”

There was an impact on social life by the *compensatory changes* made for EDS difficulty;

“*For me to go out to a restaurant with somebody, if they could see how slow I am trying to get something down and watching everything I eat. I just try and avoid all that. It has an impact on your life* [P12]”.

Also, despite the *compensatory changes* made, there were still serious choking incidents reported;

"*When she is choking, she can't say she is choking, she waves her arms, and it takes me a few seconds to realise there is something going on and I realise she is choking* [P11]".

The overarching theme was a c*onnection* between EDS difficulty with dementia that appears underappreciated either because of compensatory changes used or a lack of access to information. If the connection between dementia and EDS difficulty is missed it could delay access to support services;

"*I just thought that when she had that coughing incident, it was just a coughing incident, however there may have been a connection with her dementia* [P8]".

The *connection* is currently not being made despite the changes reported in EDS in the past and present by both people living with dementia and their carers. Even for those who have an awareness of the potential for EDS difficulty later in dementia, there is a lack of awareness that it can be an issue earlier on, as exemplified below;

"*I knew eating, drinking and swallowing could be a problem at a later stage but I never thought it would potentially be a problem at the early stages*" [P8].

"*I thought it was something that maybe happened later on in the dementia process*" [P10].

Overall, there are various EDS changes reported in the past and present by people living with dementia and their carers but little appreciation that of the link between

EDS difficulty and dementia. The final theoretical framework with final theme and subtheme definitions are provided in Table 5. A thematic map is provided in Figure 4.1.

Discussion

The aim of this study was to understand the experience of EDS by people living at home with dementia, with the view to gaining understanding of expectations, priorities, difficulties and support needs in relation to EDS. The overarching theme was a *missing connection* between EDS and dementia that was underappreciated by those effected. The *connection* between EDS and dementia was not made despite various changes reported in EDS in the past and present by both people living with dementia and their family carers. People living with dementia and family carers need education and support for EDS (Correia et al., 2010). There is also limited public knowledge of EDS difficulties with a need for greater general awareness of this largely invisible disorder (McHutchion et al, 2021).

The lack of awareness of the *connection* between EDS changes and dementia may be explained by *compensatory changes* that may mask problems or allow individuals to cope. Family carers can provide a unique insight into these behaviours. In the Alzheimer's Society 'Food for thought' project it was identified that one third of caregivers of individuals with dementia worried about swallowing problems (Alzheimer's Society 2000). In previous studies carers of people living with dementia have reported similar problems of passivity, distraction, inappropriate feeding velocity and refusal to eat (Correia et al., 2010).

Lack of awareness of the connection between EDS difficulties and dementia may also arise due to inadequate access to information to support people living with dementia and their family carers. The timing of this information, source and format is important to both groups, and is highlighted by an anxiety around online information and from unrecognised sources. A well-designed scoping review suggested that future interventions on information delivery to people with dementia and caregivers should focus on having required information on central platforms (e.g., Alzheimer's Association website) (Soong et al., 2020).

'Connection' is a term that was also used by participants themselves. When used by participants it may be an oversimplification of a complex multifactorial issue relating to a lack of knowledge or lack of awareness of EDS difficulty in dementia. As a final theme of this study 'connection' was defined as the underappreciated linkage between living with dementia and the potential for changes in EDS.

In this study, changes reported in EDS by people living with dementia and their carers included difficulty with eating and drinking independently, changes in eating patterns and evidence of altered sensation. In dementia difficulties are known to occur throughout the eating process, which encompasses all aspects of eating and drinking independently as well as swallowing function (Rogus Pulia et al. 2015). Impairment of independent eating and drinking has been observed in patients with mild Alzheimer's disease and, while not linked directly to changes in swallow on videofluoroscopic swallowing studies, it raises the potential for loss of independence with eating and drinking to be an important link or precursor to swallowing difficulties (Priefer and Robbins, 1997). Functional magnetic resonance imaging during swallowing has also identified decreased cortical function in areas of the brain involved in swallowing in individuals with mild Alzheimer’s disease compared to age-matched controls and is suggestive that changes in cortical control of swallowing may begin before swallowing difficulty becomes apparent (Humbert et al., 2010). Indeed, an association has been identified in the reverse direction with swallowing difficulty reported as an independent predictor of decreased independence in eating (Edahiro et al., 2012). Decreased independence with eating and EDS difficulty are clearly linked.

In people living with dementia, changes in taste and smell may adversely affect appetite (Rogus-Pulia et al., 2015) as well as food recognition (Suto et al., 2014). This can happen early, with individuals with mild cognitive impairment and early-to-moderate Alzheimer’s dementia experiencing changes in food preferences (Winchester and Winchester, 2016). Taste (Broggio et al., 2001) and smell (Behrman et al., 2014) also deteriorate in Alzheimer’s disease, and it has been suggested taste and smell receptor stimulation using sensory enhancement techniques may be effective in eliciting faster oral and pharyngeal initiation of the swallow (Rogus-Pulia et al., 2015) or reducing aspiration risk (Pelletier and Lawless, 2003).

Importance, strengths and limitations

The above findings are important because they describe the lived experience of EDS in dementia from the perspective of ‘experts through experience’

Advocates for people living with dementia call for active involvement of people living with dementia in research (Bryden, 2015), and co-design is a process that can facilitate meaningful involvement of people living with dementia in research studies (Swarbrick et al., 2019). A particular strength of the semi-structured interview process was that it was co-designed and piloted with people living with dementia as co-researchers.

The limitations of the semi-structured interviews includes that they were conducted over an online platform, therefore the body language of participants could not be fully observed. However, the fact interviews were conducted mostly from the comfort of the participant’s home environment allowed for time to build rapport, leading to an open discussion despite the potentially emotive nature of the content (Archibald et al., 2019).

Pilot semi-structured interviews should be carried out with participants that are similar to the participants that are recruited for further interviews (Turner, 2010). The feedback of people living with dementia in pilot interviews streamlined the further interviews for people living with dementia and their carers, thus allowing further respondents (at various stages in their dementia journey) to provide full responses regarding their experiences. Gathered data from pilot studies are considered “rich” when participants provide elaborated answers to interview questions (Malmqvist et al., 2019). The rich data from the pilot interviews warranted inclusion. However, because further participants in interviews were recruited from the same charity selection bias may have been introduced into the study.

In this study people with all stages of dementia and types of dementia were invited to participate. The focus was on EDS changes over time and the involvement of a wide range of participants gave an overview of the evolution of EDS difficulties. However, like disease severity, the underlying neuropathology of dementia may also influence the specific swallow disorders observed (Rogus-Pulia et al., 2015). A systematic review by Alagiakrishnan et al. (2013) identified that swallowing difficulties developed earlier in Alzheimer's disease and in the late stages of frontotemporal dementia. This study did not concentrate on a particular type of dementia. Alzheimer's disease is the most frequent variant of dementia. Although, it is frequently associated with other neuropathology and most commonly cerebrovascular disease. This makes mixed dementia the most common form of dementia overall (Arvanitakis et al., 2019).

Conclusions

The *connection* between EDS difficulty and dementia is currently not being made despite various changes in the past and present by both people living with dementia and their family carers. This may be explained by *compensatory actions* that may mask problems or allow individuals to cope. Lack of awareness of this connection may also arise due to inadequate *access to information* to support people living with dementia and their family carers. More high-quality research on indicators of EDS difficulty in dementia is needed in order to better inform people living with dementia. Future research could consider the experience of key staff such as SLTs involved in the management of EDS difficulties and consider how better awareness of EDS difficulty may translate into earlier presentation for assessment, better care and treatment.

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Tables

Steps	Process
a) Identifying the prerequisites for using semi-structured interviews b) Retrieving and using previous knowledge	Literature review provided a prerequisite for using semi-structured interviews in terms of having prior knowledge of the phenomenon under investigation
c) Formulating the preliminary semi-structured interview guide	Previous knowledge was used to formulate a provisional interview guide
d) Pilot testing the guide	A provisional interview guide that was "field tested" with Dementia NI members who agreed to participate in co-production of the study and pilot interviews
e) Presenting the complete semi-structured interview guide	Incorporation of feedback from the previous pilot was used to confirm the use of questions

Table 1 | Semi-structured interview design showing the five-steps used to prepare the interview guide (Kallio et al., 2016)

Draft Theme	Working Definition
Past	Initial changes in eating, drinking, and swallowing when diagnosed with dementia
Present	Currently what eating, drinking, and swallowing is like when living with dementia
Future	What is needed to help with eating, drinking, and swallowing in the future when living with dementia
Information	The type and timing of information (if any) on eating, drinking, and swallowing that the respondent would prefer to receive
Early problem identification	Preferences regarding eating, drinking, and swallowing input
Lifestyle modifications	Lifestyle modifications of participants to eating, drinking, and swallowing changes
Heroes	Individuals or processes reported to be helpful in the person living with dementia or their carer’s journey with eating, drinking, and swallowing
Villains	Individuals or processes reported to be unhelpful in the person living with dementia or their carer’s journey with eating, drinking, and swallowing

Table 2 | Initial theoretical framework refined by data familiarisation, immersion, and group discussion by the research team. Draft theme working definitions were agreed by consensus of the research team.

Draft Themes	Example extract from transcript
Past	“Occasionally when she was eating, the impression was that a piece of food went down the wrong way or something got stuck and she was coughing [P8]”
Present	“I haven’t got the same appetite. To be honest I think too a lot of food, it might be lovely food to other people but to me it’s tasteless [P9].”
Future	“Having the information and having the score from the Drs as well as the Speech and Language Therapist. A lot of the time there are so many people but they don’t talk to each other so you are only getting jigsaw pieces sent through and you know there is no way you are going to understand it [P2].”
Information	“If you had something written down as guidance as to what to look out for and what changes can happen as a result of dementia affecting, like how it (EDS) is going to change as they deteriorate so that I am aware of what actually to look out for because at this moment I don’t know [P5].”
Early problem identification	“I would have probably questioned it in relation as to why it (EDS assessment) was actually necessary but if you become well informed that if there is a link to say statistically people are more likely to have eating, drinking and swallowing issues with dementia more than other people, then I think it is important that we know that [P4].”
Lifestyle modifications	“I have noticed lately she would choke on water, sometimes taking a drink of water. She has to use a straw. When she was drinking from the glass, too much water was going down and she was choking [P11].”
Heroes	“I appreciated the Speech and Language Therapist because obviously she knew what she was on about and you know she tried to improve my living with food and eating food [P2].”
Villains	“You can google stuff, look things up online, but you don’t know if it’s factual or whether it is some eejit that has put this up [P1].”

Table 3 | Examples of raw indexed data under the themes of initial theoretical framework.

Initial Themes	Data summary codes
Past	Eating slowly, forgetting food in mouth, dry mouth, choking, voice changes, throat tightness, aversion to eating, forgetting to eat or drink, and need for prompting to eat or drink
Present	Eating slowly, gulping, coughing, spluttering, choking, loss of taste, loss of appetite, aversion to eating, sensation of throat closing, and need for prompting to eat or drink
Future	Availability of a background history of previous EDS issues, need for results of tests with understandable explanations, access to open and transparent medical records, understanding and patience from the public, reminders of when to eat and drink
Information	Who to contact, trustworthy information, reliable information, what to look out for, anxiety with online information, something written to refer back to, what to do if choking, awareness from public, and include relevant education in courses for carers
Early problem identification	Too much at time of diagnosis, viewed as intrusive, and would need awareness of rationale
Lifestyle modifications	Need to avoid talking when eating, need to concentrate, finishing food after others, need for softened foods, need for liquids at specific temperatures, need for eating aids, avoidance of food that is difficult to swallow, chewing properly, using straws to drink, eating at home, coming back to finish food after a break, avoiding pressure of being watched, using smaller glasses, having a carer present, carer covertly observing, cutting food into smaller pieces, simple solutions
Heroes	Community psychiatric nurse, General Practitioner, Speech and Language Therapist, Family, support groups
Villains	Google, missing hospital records, lack of access to information about yourself, lack of information at time of diagnosis, too much time between hospital check ups

Table 4 | Summary codes of raw data extracts showing meanings drawn by participants

Final Theme	Definition	Final Subthemes	Definition
Connection	The underappreciated connection between living with dementia and the potential for changes in eating, drinking, and swallowing	Compensatory changes	Changes in eating, drinking, and swallowing from a personal perspective and compensatory strategies used to overcome these deficits
		Access to information	The people and processes needed to support eating, drinking, and swallowing for person living with dementia and their carers. The need for trustworthy information from a reliable source, accessible and transparent records, education for carers and public, timely access to the individuals that can help

Table 5 | Final theme and subthemes in final theoretical framework showing that the overarching theme was a ‘connection’ between EDS difficulty and dementia. Where EDS difficulties were identified, ‘compensatory changes’ and a need for ‘access to information’ to support individuals, were noted as subthemes.

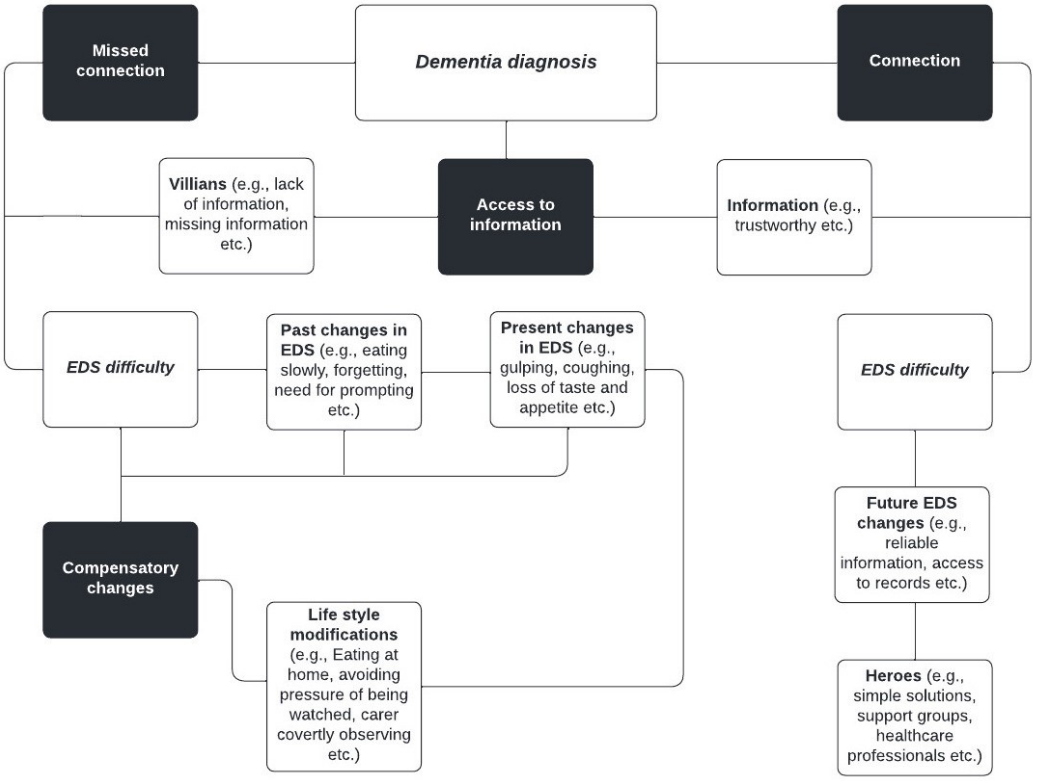

Figure 4-1 Thematic map

Showing initial themes that were clarified as part of the EDS journey for people living with dementia.

Appendix 1

Questions for people living with dementia

Can you tell me a little bit of what it was like in the early days of living with dementia at home?

About the Past

At the start of your journey living with dementia can you tell me a little bit about your eating, drinking and swallowing?

Is there anything that would have been helpful for you at the beginning?

At the beginning of this journey would you have liked some information about eating, drinking and swallowing?

How would you have felt about someone checking your eating, drinking and swallowing abilities at the beginning?

About the Present situation

As time has gone on have there been changes in how you eat, drink or swallow?

If there has been can you tell me some about what these earliest signs or changes were?

Is there anything that helps you when you are eating, drinking and swallowing?

Is there anything else that you think would be helpful now?

Questions looking to the Future

Thinking ahead is there anything that you think would be useful for you and your family for the future to support you with eating, drinking and swallowing?

Narrative enquiry

Has there been any individuals that have supported you with changes in eating, drinking and swallowing?

Is there anything else that would have been useful to support you earlier, now and in the future?

Conclusion

Thank you very much for answering these questions and sharing your experiences about eating, drinking and swallowing. Is there anything else you would like to share with me before we stop? Would you be willing to help us check that we have understood what you have told us today?

Would you like us to contact you again in a few months with a summary of the findings?

Appendix 2

Questions for carers of people living with dementia

Can you tell me a little bit of what it was like in the early days of living with a family member with dementia at home?

About the Past

At the start of your family member's journey living with dementia can you tell me a little bit about your family member's eating, drinking and swallowing?

Is there anything that would have been helpful for you or them at the beginning?

At the beginning of this journey would you have liked some information about eating, drinking and swallowing in dementia?

How would you have felt about someone checking your family member's eating, drinking and swallowing abilities at the beginning?

About the Present situation

As time has gone on have there been changes in how your family member eats, drinks or swallows?

If there has been can you tell me some about what these earliest signs or changes were?

Is there anything that helps you when they are eating, drinking and swallowing?

Is there anything else that you think would be helpful now?

Questions looking to the Future

Thinking ahead is there anything that you think would be useful for you and your family for the future to support your family member with eating, drinking and swallowing?

Narrative enquiry

Has there been any individuals that have supported your family member with changes in eating, drinking and swallowing?

Is there anything else that would have been useful to support you earlier, now and in the future?

Conclusion

Thank you very much for answering these questions and sharing your experiences about eating, drinking and swallowing in persons living with dementia. Is there anything else you would like to share with me before we stop? Would you be willing to help us check that we have understood what you have told us today?

Would you like us to contact you again in a few months with a summary of the findings?

5 Chapter 5: Identification and management of eating, drinking and swallowing difficulties for people living with early-stage dementia: a survey of specialist speech and language therapists

In the previous phase, it was found that the *connection* between EDS difficulty and dementia was not being made despite various changes in the past and present by both people living with dementia and their family carers. Research is needed to explore the experience of key professionals such as SLTs involved in the management of EDS difficulties and consider how better awareness of EDS difficulty may translate into earlier presentation for assessment, better care and treatment. In this phase, an online survey for SLTs was co-produced with Dementia NI “co-researchers”. The survey was initially piloted with final year SLT students. Qualified SLTs actively working in EDS and with experience of working with individuals living with dementia were then approached to participate. SLTs were then recruited via several networks and social media. Data was analysed using a multiple methodology approach including descriptive statistics, summative and conventional content analysis.

Identification and management of eating, drinking and swallowing difficulties for people living with early-stage dementia: a survey of specialist speech and language therapists

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Running head

Eating, drinking and swallowing in early dementia

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Abstract

Background

The prevalence of dementia is increasing. Eating, drinking and swallowing (EDS) difficulties are common in dementia and a risk factor for aspiration. Identification of EDS difficulty in early-stage dementia may permit action to prevent complications but supporting evidence is lacking. Speech and Language Therapists (SLTs) are involved as professional practitioners in this area and may provide a valuable source of practice-based expertise.

Aims

To understand specialist SLT perspectives on identification of EDS difficulty in people living with early-stage dementia.

Methods & Procedures

A cross-sectional, descriptive approach was taken. People living with dementia were recruited as "experts by experience" to co-produce an online survey for SLTs. This survey was piloted with final year SLT students. Qualified SLTs actively working in EDS and with experience of working with individuals living with dementia were approached to participate. SLTs were then recruited via several networks including clinical excellence networks and social media campaign involving the Royal College (RCSLT). A four-section survey covering SLT input, features of EDS difficulty in published literature, features of EDS difficulty reported by people living with early-stage dementia, and participant information

was used. Data were analysed using common descriptive statistics, summative and conventional content analysis.

Outcomes & Results

There were 49 fully completed surveys. Recruited SLTs had a median of nine years of experience in this area and people living with dementia formed a median of 50% of their caseloads. Coughing when eating or drinking, reduced appetite or lower oral intake and problems with textures were the most frequent EDS difficulties reported. Across motor, cognitive, psychological and sensory domains, the commonest EDS difficulties on examination were slowness, lack of awareness, lack of interest and taste changes when eating. Delayed oral transit, and reduced ability to eat and drink independently were also selected from a list of indicators presented from a systematic review of published literature. Common management included written information and discussion. Most SLTs (90%) reported that the Covid-19 pandemic had impacted upon their approaches, with specific themes including more remote assessment, personal protective equipment, and workforce pressures. Themes identified in discharging patients were stabilisation of EDS ability, minimising risks associated with EDS difficulty, providing support and pathways for re-referral. Many (85%) reported early identification of EDS difficulties as a priority with themes identified including prevention and preparation. Due to competing pressures on SLT time, less than half of respondents felt that current SLT practice either supports health promotion or supports early identification of EDS difficulties.

Conclusions & Implications

This study reports practice-based evidence from SLTs about the features, assessment approaches and management of EDS difficulty in early-stage dementia that could be used to help develop pathways to support the early identification of EDS difficulties.

What this paper adds

What is already known on the subject

The prevalence of dementia is increasing, as are associated EDS difficulties that can lead to aspiration. There is some evidence that identification of EDS difficulty in early-stage dementia might limit the incidence of complications.

What this paper adds to existing knowledge

This study adds practice-based evidence that comes from SLT practice to close research–practice gaps and support the identification of EDS difficulties for people living with early-stage dementia.

What are the potential or actual clinical implications of this work?

This information could be used to inform pathways to support the identification of EDS difficulties for people living with early-stage dementia with a view to preventing complications of EDS difficulty, reducing healthcare consumption, supporting family carers and improving quality of life.

Introduction

The number of people living with dementia in the UK is expected to rise as the population ages (Livingston et al., 2017): among the elderly population in the UK, the estimated prevalence rate of dementia was 7.1% in 2019 but it is expected to increase to 8.8% by 2040 (Wittenberg et al., 2019). Over half of people living with dementia may have eating, drinking and swallowing (EDS) difficulties (Alagiakrishnan et al. 2013), with a significant burden of EDS difficulty developing in early-stage dementia (Kai et al. 2015).

EDS difficulty in dementia is a risk factor for serious complications including aspiration pneumonia (Paranji et al., 2017), but proven interventions to treat EDS difficulties in people living with dementia are disparate and diverse (Abdelhamid et al., 2016). In patients with neurological disorders there is a relationship between reported severity of EDS difficulty and swallowing-related quality of life (Arslan et al., 2019).

There are features of EDS difficulties in early-stage dementia, such as delayed oral transit and reduced ability to self-feed, that are potentially detectable on clinical assessment and are known to predate aspiration (Priefer and Robbins, 1994). Identification of EDS difficulty in early-stage dementia may therefore form part of a strategy to prevent complications (e.g., aspiration pneumonia) of EDS difficulty, while having the added benefit of reducing healthcare consumption (Paranji et al., 2017), supporting family members/carers (Papachristou et al., 2013), and improving quality of life (Arslan et al., 2019). However, limited evidence exists to support identification of EDS difficulty in early-stage dementia. Speech and Language Therapists (SLTs) primarily use compensatory strategies in this client group and frequently cite the need for family and care staff training in mealtime support (Egan et al., 2020).

One approach to extending an evidence base is to include practice-based evidence along with user-based evidence and research-based evidence (Dobinson and Wren, 2019). Speech and Language Therapists (SLTs) play a key role in the identification and management of EDS difficulties and are well placed to provide practice-based evidence on the identification of EDS difficulties for people living with early-stage dementia.

Clinical application

This study was designed to capture and analyse practice-based evidence from SLTs on the identification of EDS difficulty in people living with early-stage dementia. This information is needed to develop pathways to support the identification of EDS difficulties for people living with early-stage dementia with a view to preventing complications of EDS difficulty, reducing healthcare consumption, supporting family members/carers and improving quality of life.

Aim

To explore SLT perspectives on identification and management of EDS difficulty in people living with early-stage dementia.

Objectives

1. To capture and analyse features of EDS difficulty in early-stage dementia from the perspective of specialist SLTs.
2. To understand the approaches to the assessment of EDS difficulty in early-stage dementia including in the context of the Covid-19 pandemic.
3. To identify management strategies for EDS difficulty in early-stage dementia.

Methods

Overall design

This study used a web-based survey (Qualtrics) to elicit the clinical opinion of SLTs with expertise in EDS difficulty and experience of working with individuals living with dementia. Planning and description of the online survey and results was influenced by published guidelines (Eysenbach, 2004). The survey was supported by Royal College of Speech and Language Therapists (RCSLT).

Co-production

A partnership was developed with a local charity (Dementia NI) that provide an advocacy service for people who are living with a diagnosis of dementia. People living with dementia were recruited as co-researchers and "experts by experience" to inform, influence and co-produce the survey.

Participants

Qualified SLTs involved in EDS and with experience of working with people living with dementia were invited to complete the questionnaire.

Survey design and pilot study

The clinical and academic research team along with co-researchers from Dementia NI devised a 15-item survey. The survey was piloted with six final year SLT students. The student pilot was intended to check for feasibility, logic and flow. The population for the main survey was anticipated to be limited in the context of the Covid-19 pandemic. The use of final year students meant that the students had sufficient learning to enable a trial of the method. In response to the pilot, minor changes were made to formatting and order of questions but not to content.

Following the student pilot, a qualified and highly experienced academic SLT working with individuals living with dementia was invited to complete the questionnaire. After changes were made to the survey a further three senior SLTs working in clinical practice were asked to complete the survey and provide feedback. Further changes were minimal, and the responses of the three senior SLTs working in clinical practice were included in the overall results.

The final survey (Appendix 9.3) contained four sections: (1) SLT input (EDS background, person report difficulties, carer information, assessment, management, changes to assessment during the Covid-19 pandemic, discharge and prioritisation) (2) features of EDS difficulty in published literature (3), features of EDS difficulty reported by people living with early-stage dementia, and (4) participant information.

For section two, a list of published features of EDS difficulty in dementia was derived by updating systematic literature reviews from previous publications (Affoo et al., 2013, Alagiakrishnan et al., 2013).

For section three, a list of features of EDS difficulty reported by people living with dementia was derived from semi-structured interviews of seven people living with dementia and five carers for people living with dementia.

Response formats included yes/no questions, multiple choice, Likert scales, open-ended questions and opportunities throughout to provide free text answers in order to describe responses more fully. Completion time was estimated at less than 20 min.

Recruitment and data collection

The host University granted ethical approval (REC.20.0071). Chairpersons of SLT clinical practice networks were approached for support. SLT participants were then approached via emails from the chairpersons of SLT clinical practice networks. E-mailed follow-up reminders were sent out as this has previously been shown to increase substantially the response rate in internet-based surveys of health professionals (Braithwaite et al., 2003).

With RCSLT agreement, participants not captured via the mailing list were alerted to the survey by the professional social media channels. As we were unable to ascertain the total number of potential participants in the UK, research participants were targeted strategically across several active clinical excellence networks (neurology and dysphagia) and via social media using Twitter including retweets from the RCSLT. Sharing of the survey among colleagues was encouraged by granting access to the survey link. In order to gather specialist expertise, only SLTs who have been involved or participated in the care of individuals with dementia and EDS were eligible to participate. This ensured that practice-based knowledge of SLTs was obtained. Responses were anonymous. Participants completing and submitting the survey were deemed to have given consent for participation and storage of responses. No incentives were offered. The survey was open for four weeks between December 2021 and January 2022.

Data analysis

Descriptive statistics were used to analyse closed questions. Non-parametric data is presented as the median with range.

Conventional content analysis was used to analyse responses to open-ended questions (Hsieh and Shannon, 2005) (Vaismoradi et al., 2013). Responses of survey participants were read numerous times by the lead researcher (M.O); codes were then derived from key concepts that emerged and sections of text were then assigned to codes (Table 1).

For questions relating directly to the presenting features of EDS, summative content analysis was used to establish the most frequent responses (Bristowe et al., 2015).

The data for analysis was collected using qualitative data management software (Qualtrics, Provo, UT). Quantitative comparisons and text analyses for summative content analysis were respectively performed (R v3.4.0, R Foundation for Statistical Computing)

Results

There were a total of 49 fully completed responses to the survey. The majority of SLT respondents were from Northern Ireland (n=30, 61%) and Scotland (n=14, 29%). Four respondents were from England (8%) and one was from Australia (2%). SLT respondents had been working with people living with dementia and EDS difficulties for a median of 9 years (range 0-33). People living with dementia and EDS difficulties were estimated to form a median of 50% (range 3-98) of the case loads of the respondents in the previous year. Only three respondents (6%) reported that they worked in a specialist dementia assessment centre.

On summative content analysis, SLT respondents reported that the three most frequent pieces of information on a referral for a SLT EDS specialist assessment for people living with early-stage dementia were coughing when eating or drinking, oral pocketing of food, and reduced appetite/oral intake. The respondents answered that the three most frequent EDS difficulties that people with early-stage dementia report themselves are coughing when eating or drinking, reduced appetite, reduced oral intake and difficulty swallowing. The respondents reported that the three most frequent pieces of information that a family member or carer could provide that indicates that an individual with early-stage dementia is presenting with current EDS difficulties are coughing when eating or drinking, reduced appetite/oral intake and previous chest infection (Figure 1).

When combining the commonest reported information on referrals for a SLT EDS specialist assessment, what EDS difficulties people living with early-stage dementia report themselves, and what family members/carers report, it was found that coughing when eating or drinking, reduced appetite/oral intake and problems with textures are the most frequent EDS features in early-stage dementia encountered overall (Figure 1).

On summative content analysis, the top five examination findings that indicate that an individual with early-stage dementia has EDS difficulties across cognitive (lack of awareness, distractibility, oral overfilling, forgetfulness, and sequencing difficulty), sensory (taste changes, sweet preference, smell changes, texture problems, and lack of awareness), psychological (lack of interest, low mood, distress, anxiety, and reduced appetite) and motor (slowness, reduced or repetitive chewing, lack of coordination, need for assistance and cutlery difficulty) domains were reported by SLT respondents (Figure 2).

Features reported in published literature as indicators or predictors of EDS difficulties in individuals with early-stage dementia and mild cognitive impairment were listed for SLT respondents; it was reported that reduced ability to eat and drink independently and delayed oral transit are the top features either frequently or always encountered in people living with early-stage dementia who have EDS difficulties (Table 2).

Features reported by people living with dementia as early indicators of EDS difficulties were listed for SLT respondents; respondents reported eating slowly, coughing when eating and loss of appetite are the top three features either frequently or always encountered in people living with early-stage dementia who have EDS difficulties (Table 3).

On a multiple choice question the management approaches that were most often reported by SLTs to be used either frequently or always to support individuals with early stage-dementia with EDS difficulties were provision of written information (98%), and discussion with family member/carer (95%) or the individual living with early-stage dementia (92%) (Table 4).

Only five of 49 SLTs reported that their approach assessing people living with early-stage dementia and EDS difficulty had not changed during the Covid-19 pandemic. On conventional content analysis of other responses, the themes identified regarding changes in approach as a result of the Covid-19 pandemic included use of remote assessment, impact of personal protective equipment, and workforce pressure (Table 5).

Using conventional content analysis, the themes identified about discharge or closing an EDS episode of care for individuals with early-stage dementia were stabilisation of EDS ability, minimising risks associated with EDS difficulty, providing support and pathways for re-referral (Table 5). These three themes are well summarised by the following response;

“When a Care Plan has been formulated and implemented that meets the client's needs across all areas that may impact the swallow. When risk is assessed as low with care plan in place. When there are no outstanding actions required as part of the episode of care. When review and data collection shows that dysphagia signs are reduced or eliminated. When an escalation plan has been shared to re-refer when the client is presenting with elevated risk again from new dysphagia signs” [participant 12].

The great majority (98%) of respondents agreed or strongly agreed that early identification of EDS difficulties allows people to increase control over their symptoms and 82% agreed or strongly agreed that early SLT input improves the individual living with dementia’s understanding of EDS difficulties. Most (96%) also agreed or strongly agreed that early SLT input helps support family members/carer. However, only 45% agreed or strongly agreed that current SLT practice supports health promotion for EDS. In addition, only 41% agreed or strongly agreed that current SLT practice supports early identification of EDS difficulties (Table 6).

Early identification of EDS difficulties in early-stage dementia was reported as a priority for 85% of SLTs. On conventional content analysis of responses from SLTs that reported that early identification of EDS difficulties in early-stage dementia was a priority, themes that were identified included prevention and preparation. On conventional content analysis of responses from SLTs that reported that early identification of EDS difficulties in early-stage dementia was not a priority, competing pressures (e.g., waiting lists, staffing, resources and higher clinical priorities) was identified as an underlying theme (Table 5).

Discussion

This study has explored evidence that comes from SLT practice in order to close research–practice gaps and support the early identification of EDS difficulties for people living with early-stage dementia (Crooke and Olswang, 2015). When a range of sources of information including referral details, person reported features and family member/carer reported features are considered by SLTs, it is coughing when eating or drinking, reduced appetite/oral intake and problems with textures that are the most frequent EDS features in early-stage dementia encountered overall.

It is recognised that in dementia difficulties may occur throughout the eating process, which encompasses all aspects of self-feeding and swallowing function (Rogus Pulia et al. 2015). SLTs were therefore asked to provide examination findings indicative of EDS difficulty in early-stage dementia across a broad range of domains including cognitive, sensory, psychological and motor findings.

The commonest EDS difficulty reported as being detected on examination of people living with early-stage dementia in the cognitive and psychological domains were lack of awareness and interest when eating. Attention deficit is a known association with EDS difficulty in people living with dementia (Hsieh et al., 2021). In previous studies carers of individuals living with dementia have reported similar problems of passivity, distraction, inappropriate feeding velocity and refusal to eat (Correia et al., 2010).

SLTs also reported that reduced ability to eat and drink independently was the one of the top three features from a list of published features of EDS difficulty to either frequently or always be encountered in people living with early-stage dementia who have EDS difficulties. Impairment of self-feeding has been observed in people living with early-stage dementia and while not linked directly to changes in swallow on videofluoroscopic swallowing studies, it raises the potential for impairment of self-feeding to be an important link or precursor to swallowing difficulties (Priefer and Robbins, 1997). A relationship has also been identified in the reverse direction with swallowing difficulty reported as an independent predictor of decreased independence in eating (Edahiro et al., 2012).

The commonest EDS difficulty reported as being detected on examination of people living with early-stage dementia in the motor domain was slowness when eating. SLTs also reported that delayed oral transit was one of the top three features from a list of published features of EDS difficulty to either frequently or always be encountered in people living with early-stage dementia who have EDS difficulties. Furthermore, when features that have been reported by people living with dementia as early of EDS difficulties were listed for SLT respondents; respondents reported rated eating slowly as the most common feature either frequently or always encountered in people living with early-stage dementia who have EDS difficulties. These responses are consistent with reports of delayed oral transit (Priefer and Robbins, 1994, Suh et al., 2009), increased pharyngeal response duration (Priefer and Robbins, 1994) and reduced hyolaryngeal elevation (Humbert et al., 2010) in videofluoroscopic swallowing studies in early-stage dementia. Again, these changes have been shown to predate aspiration and allude to the fact that slowness when eating is a potentially important precursor to swallowing difficulties (Priefer and Robbins, 1994, Humbert et al., 2010). Functional magnetic resonance imaging during swallowing has also identified decreased cortical function in areas of the brain involved in swallowing in individuals with mild Alzheimer’s disease compared to age-matched controls and is suggestive that changes in cortical control of swallowing may begin before swallowing difficulty becomes apparent (Humbert et al., 2010).

The commonest EDS difficulty reported as being detected on examination of people living with early-stage dementia in the sensory domain was taste changes. In patients with dementia, changes in taste are recognised (Broggio et al., 2001), and may adversely affect appetite (Rogus-Pulia et al., 2015), food recognition (Suto et al., 2014) and food preferences (Winchester and Winchester, 2016).

The management approaches that were most often reported by SLTs to be used either frequently or always to support people living with early stage-dementia with EDS difficulties were provision of written information, and discussion with both family members/carers and the person living with early-stage dementia. For the majority of SLTs the Covid-19 pandemic had impacted their approaches, and consistent with other surveys of the SLT profession, flexible approaches to service provision (such as remote assessment) were now more common (Chadd et al, 2021).

Nearly all respondents felt that early identification of EDS difficulties allows people to increase control over their symptoms and supports family members/carers. The vast majority of SLTs viewed early identification of EDS difficulties in early-stage dementia as a priority for SLT. Competing pressures was an underlying theme for the minority of SLTs that did not view early identification of EDS difficulties in early-stage dementia as a priority for SLT. A further theme that was identified in relation to the Covid-19 pandemic was workforce pressure. In previous surveys, SLT respondents have reported lack of resources as contributing to an inability to fulfil their role in providing assessment, management, and training in the way that they felt is necessary for people living with dementia (Egan et al., 2020). Consistent with this less than half of respondents felt that current SLT practice supports health promotion or supports early identification of EDS difficulties.

The number of SLTs able to participate in the survey was limited by stipulating current or previous experience of working with people living with dementia. Competing pressures and workforce pressures may also have impacted the response rate of the survey. Despite this the survey has captured and analysed practice-based evidence on the early identification of EDS difficulty in early-stage dementia from SLTs who have a combined experience of 566 years of working with people living with dementia and EDS difficulties. Competing clinical priorities and workforce pressures may also contribute to delayed presentation of people living with dementia. Of note some of the indicators reported by SLTs on referral and assessment are later symptoms of EDS difficulty (e.g., choking).

Importance, strengths and limitations

A particular strength of the survey design process was the involvement of people living with dementia as co-researchers. These ‘experts through experience’ optimised the process and ensured relevance to the client group. A limitation of the study is that the data is derived from clinical experience alone, and while expert opinion represents an alternative form of knowledge that can be complementary to empirical evidence, it is placed at a lower level on the overall hierarchy of evidence (Tonelli, 1999). The underlying neuropathology of dementia may also influence the specific swallow disorders observed (Rogus-Pulia et al., 2015, Alagiakrishnan et al., 2013, Suh et al., 2009). Alzheimer’s disease is the most frequent variant of dementia, although it is frequently associated with other neuropathology, which makes mixed dementia the most common form of dementia overall (Arvanitakis et al., 2019). In this study all types of early-stage dementia were therefore considered.

Conclusions

This study reports practice-based evidence from SLTs about the features, assessment approaches and management of EDS difficulty in early-stage dementia that could be used to help develop pathways to support the early identification of EDS difficulties. The new information provided by this research could be used to assist with referral criteria for SLT assessment and the provision of timely information on EDS difficulty for people living with early-stage dementia. Future research should assess for concordance between the indicators of EDS difficulty reported by SLTs, and what the people living with dementia may notice first.

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Figures and tables

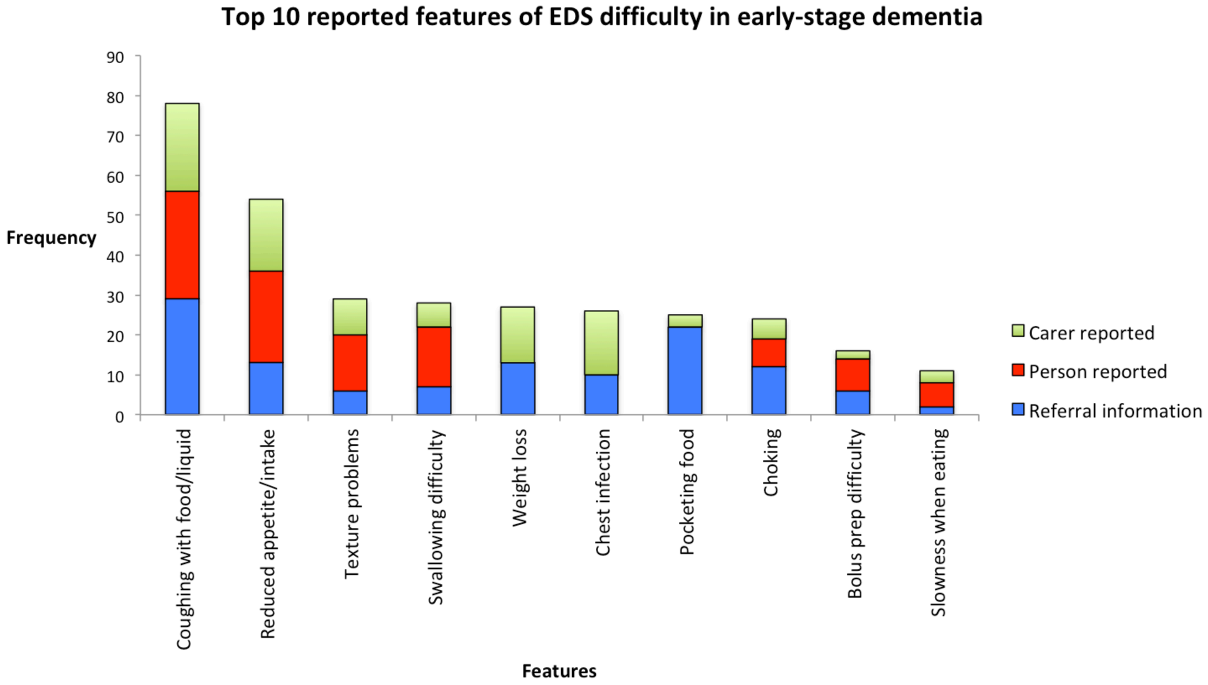

Figure 1| Top 10 reported features of EDS difficulty in early-stage dementia listed by SLT respondents when asked about information provided from three different sources (referral information, person living with dementia reported and family member/carer reported) and in decreasing combined frequency from left to right.

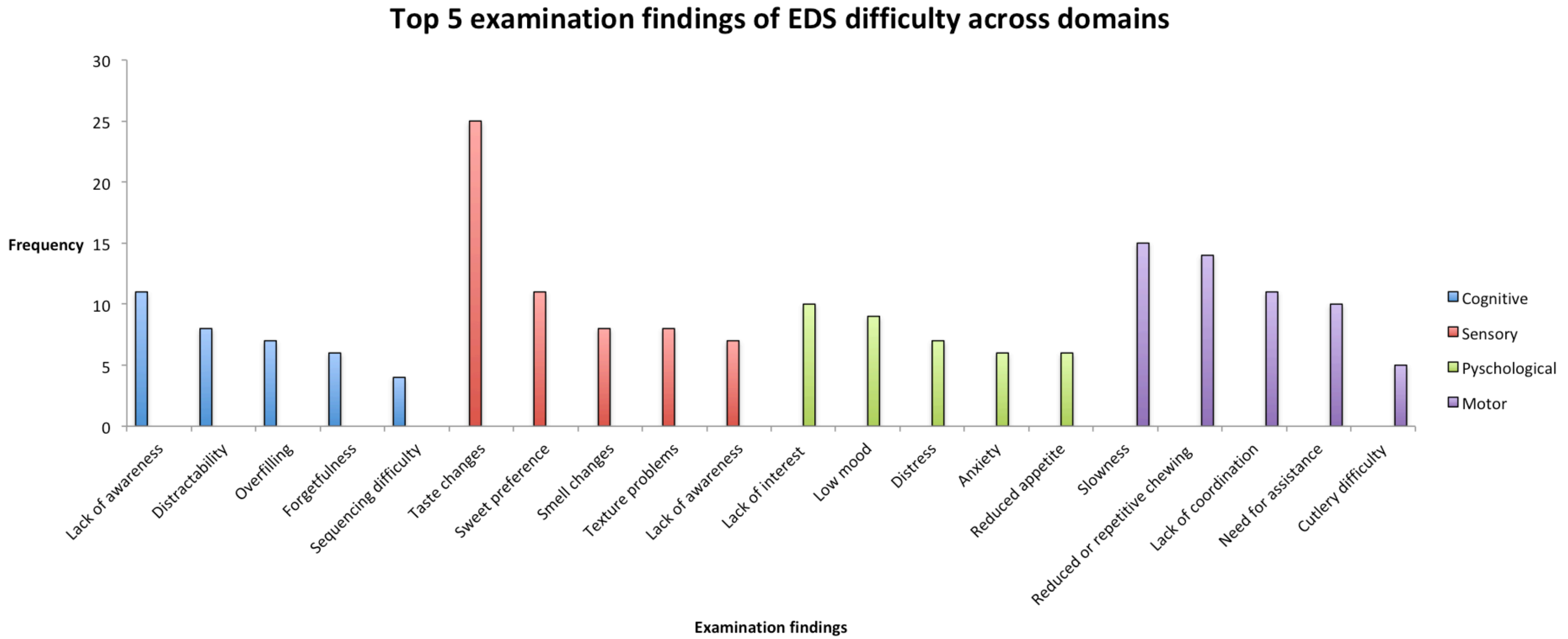

Figure 2| The top five examination findings reported to indicate that an individual with early-stage dementia has EDS difficulties across cognitive, sensory, psychological and motor domains

Code	Code description addresses	Key
Covid-19	Approach to assessing people living with early-stage dementia and EDS difficulty during the Covid-19 pandemic	C
Discharge	Closing an EDS episode of care for individuals with early-stage dementia	D
Priority	Whether EDS difficulties in early-stage dementia is a priority for SLTs	P

Table 1| Code Dictionary: showing codes with definitions derived from key concepts that emerged in conventional content analysis. Sections of text were then assigned to codes under a corresponding key.

Indicators or predictors of EDS difficulties	Never	Rarely	Sometimes	Frequently	Always	Frequently or always
Reduced ability to eat and drink independently	0%	8%	22%	63%	6%	69%
Delayed oral transit	2%	0%	29%	67%	2%	69%
Polypharmacy (5 or more medications)	4%	4%	24%	65%	2%	67%
Loss of executive function	4%	2%	29%	63%	2%	65%
Sarcopenia (age-related muscle loss)	2%	8%	39%	51%	0%	51%
Changes to taste	2%	8%	49%	41%	0%	41%
Delayed pharyngeal response	2%	4%	58%	35%	0%	35%
Decreased voluntary cough	8%	14%	47%	31%	0%	31%
Open mouth posture with reduced lip seal	4%	29%	39%	29%	0%	29%
Reduced rinsing ability	10%	12%	55%	22%	0%	22%
Reduced sucking ability	10%	27%	45%	18%	0%	18%
Apraxia impacting on eating and drinking	6%	35%	41%	18%	0%	18%
Changes to smell	6%	29%	51%	14%	0%	14%

Table 2| Frequency of detection in practice of published indicators or predictors of EDS difficulties in individuals with early-stage dementia (and mild cognitive impairment*)

Early features of EDS difficulties reported by people living with dementia	Never	Rarely	Sometimes	Frequently	Always	Frequently or always
Eating slowly	0%	4%	12%	78%	6%	84%
Coughing when eating	0%	0%	24%	76%	0%	76%
Loss of appetite	0%	0%	33%	61%	6%	67%
Need for prompting to eat or drink	8%	6%	39%	43%	4%	47%
Forgetting food is in the mouth	6%	20%	27%	47%	0%	47%
Forgetting to eat or drink	8%	4%	49%	37%	2%	39%
Choking	2%	10%	53%	35%	0%	35%
Gulping	10%	20%	39%	29%	2%	31%
Aversion to eating	6%	12%	53%	27%	2%	29%
Dry mouth	0%	18%	55%	27%	0%	27%
Loss of taste	6%	29%	45%	20%	0%	20%
Voice changes	10%	51%	31%	8%	0%	8%
Throat tightness	14%	55%	29%	2%	0%	2%

Table 3| Frequency of reporting in practice of early features of EDS difficulties reported by individuals living with dementia

Approaches to support individuals with early stage-dementia with EDS difficulties	Never	Rarely	Sometimes	Frequently	Always	Frequently or Always
Written information/guidance provided to the person and their family member/carer	0%	0%	2%	31%	67%	98%
Discussion with family member/carer	0%	0%	4%	24%	71%	95%
Discussion with the individual with early-stage dementia	0%	2%	6%	29%	63%	92%
Planned EDS follow up review	2%	0%	20%	57%	20%	77%
Therapeutic intervention (compensatory strategies)	2%	22%	37%	37%	2%	39%
Instrumental assessment of EDS e.g., videofluoroscopy or fibreoptic endoscopic evaluation of swallow	8%	37%	51%	4%	0%	4%
Therapeutic intervention (direct swallowing therapy e.g. manoeuvres)	14%	55%	31%	0%	0%	0%

Table 4| Frequency of approaches used by SLTs to support individuals with early-stage dementia with EDS difficulties

Code	Themes identified from assigned text	Sections of text assigned to code that identified theme	Example text
Covid-19	Use of remote assessment	C1-19	We have done more phone and Near Me assessments, using guidance documents they can access to refer to. We continued to do face to face when people were not shielding. We have made our training resources available on line so that people can access them independently. I agree that early identification of EDS problems is important, but a lot can be done to support prevention, self management and awareness by providing information and referral guidance rather than direct SLT intervention" [participant 29]
	Personal protective equipment	C20-31	"More time is required per-assessment, generally as the addition of PPE can be a barrier to the patient's comprehension of the assessment process therefore increased explanation required" [participant 5]
	Workforce pressure	C32-41	"Long history of short staffing issues pre-dating Covid but exacerbated by Covid has meant that waiting lists are very long and I only have capacity to respond to a crisis e.g. wait until the patient presents to hospital with aspiration and then intervene. Health promotion and education for patients at early stage would be ideal but we are in fire fighting mode at present" [participant 4]
Discharge	Stabilisation of EDS ability	D1-33	"Family / patient aware of dysphagia and dementia, progression appears stable / slow, aware how to self manage/modify pending further intervention in future, no concerns regarding chokes or aspiration, aware how to fortify food as needed, and weight stable" [participant 32]
	Minimising risks associated with EDS difficulty	D32-57	"If I feel clinical risk is well managed by patient themself, or those in their environment such as spouse, carer or nursing staff if in care home. I would feel confident if reduced risk evident in period of time elapsed with reduced signs of chronic or acute aspiration or penetration" [participant 16]
	Support		
	Pathways for re-referral	D58-70	"When thorough education has been provided to individual and their main care givers especially signs to monitor for in the future and re-referral process" [participant 14]

		D71-88	“When onward referral to other professions, voluntary agencies have been completed and when family and carer have been provided with education regarding swallow, signs and symptoms to monitor for, and how to seek re-referral” [participant 37]
Priority	Prevention	P1-16	“Prevention and early education is always, always, always better than advice and input at crisis point. Furthermore, if we promote and optimise eating and drinking earlier, we will see less people who are more nutritionally compromised and therefore susceptible to infections and aspiration pneumonia. Early input can provide people with an opportunity to empower themselves/their family members to promote their intake and reduce dysphagia risks where able” [participant 14]
	Preparation	P17-28	“Early identification provides an opportunity to support and advise people with early stage dementia on what to expect. It creates access to an important support service to encourage self-management of future difficulties and gives people an early opportunity to discuss their fears and wishes in relation to further deterioration of EDS” [participant 13]
	Competing pressures	P29-35	“I think seeing patients with early difficulties is gold standard, but we wouldn't have capacity as would significantly increase our waiting lists and would therefore cause harm for patients who are experiencing more significant problems that we can do something about. Education for early EDS difficulties is a good idea - but this could be in a different format than referral to SLT (e.g., SLT talking at dementia support groups etc.) [participant 4]”

Table 5| Summary of themes identified from responses analysed with conventional content analysis. Sections of text were assigned to defined codes under a corresponding key in conventional content analysis. Themes were then identified from assigned text.

Statements about EDS and individuals living with early-stage dementia	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree	Agree or strongly agree
Early identification of EDS difficulties allows people to increase control over their symptoms	0%	0%	2%	74%	24%	98%
Early SLT input helps support family members/carer	4%	0%	0%	37%	59%	96%
Early SLT input improves the individual with dementia's understanding of EDS difficulties	6%	2%	10%	53%	29%	82%
Early assessment helps predict future EDS difficulties	0%	14%	29%	39%	18%	57%
Current SLT practice supports health promotion for EDS	4%	16%	35%	35%	10%	45%
Current SLT practice supports early identification of EDS difficulties	6%	24%	29%	33%	8%	41%

Table 6| Agreement with statements about EDS and individuals living with early-stage dementia

6 Chapter 6: Experts agree greater emphasis on early identification of eating, drinking and swallowing difficulties: System wide reflections from an Expert panel

In Chapter 3, published evidence pertaining to indicators of EDS difficulties in dementia was first systematically updated and reconsidered in terms of measurability in clinical practice and applicability to people living with early-stage dementia. In Chapter 4, semi-structured interviews were then conducted with people living with dementia to gain the insight and lived experience of those affected. This provided information from a service user perspective. In Chapter 5, practice-based evidence from specialist SLTs on the early identification of EDS difficulty in people living with early-stage dementia was evaluated. In this phase, an expert panel meeting was decided upon as a means of gaining feedback on the research findings from expert stakeholders and discussing translation of the research findings into practice. To explore the current gaps in early detection of EDS difficulty, our research team met with policy makers and expert stakeholders to identify system wide barriers to early identification of EDS difficulty.

Experts agree greater emphasis on early identification of eating, drinking and swallowing difficulties: System wide reflections from an Expert panel

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Running head

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Abstract

Early identification of eating, drinking and swallowing (EDS) in early-stage dementia prevents complications, facilitates self-management and improves health. To explore the current gaps in early detection, our research team met with policy makers and expert stakeholders to identify system wide barriers to early identification of EDS difficulty referred to by people living with dementia and Speech and Language Therapists (SLT) in this research. An online expert panel meeting was used to gain feedback on the research findings and where possible, identify barriers to addressing EDS difficulties in people at early stages of a dementia journey. Accessibility of information on EDS difficulty was identified as a key issue. People living with dementia and carers reported challenges in accessing timely and reputable information from trustworthy sources. Access to information must be equitable and the timing of information provision will need to account for the difficulty of receiving a dementia diagnosis.

Introduction

Eating, drinking and swallowing (EDS) difficulty is an important issue that has been associated with dementia in all its forms (Alagiakrishnan et al., 2013) and can contribute to serious problems like choking (RQIA, 2022). A clinical response including self-management depends upon reliable identification. Review of the published evidence (O’Neill et al., 2023a, unpublished) outlines potential EDS indicators as: delayed oral transit, reduced rinsing ability, sarcopenia and polypharmacy. Interviews with people who live with a dementia highlighted a 'missed connection' between EDS difficulty and dementia, leading them to call for more information and better EDS screening in early stages of the disease (O'Neill et al., 2023b, unpublished). Experienced Speech and Language Therapists (SLT) who responded to an online survey tended to focus on more advanced and serious stages of disease. This was in the context of competing clinical priorities and workforce pressures that may contribute to delayed presentation of people living with dementia and EDS difficulty. SLTs also described a particular difficulty in delivering specialist services during the COVID-19 pandemic (O'Neill et al., 2023c, unpublished). Hence there is a pressing need to focus on early-stage disease, where problems can be identified and addressed, and worse outcomes prevented. To explore the current gaps in early detection, it is important to engage with policy makers and expert stakeholders, and to discuss translation of these research findings into practice.

Aim

The aim was to verify findings from research and explore how to address EDS difficulties in people at early stages of a dementia.

Methods

Expert panel meetings are long-established as a consensus development process in healthcare (Jones and Hunter, 1995) and are feasible to conduct online (Khodyakov et al., 2011). Experts in EDS difficulty were purposively selected then approached via email invitation and a suitable date for the meeting was agreed. The experts approached were all selected for their knowledge and experience of EDS.

Key stakeholders at the meeting included a lead for allied professionals in the Department of Health and a senior representative of Royal College of SLT. Also in attendance was Senior SLT from an integrated health and social care provider organisation and a Dysphagia Coordinator and Project Lead for a separate organisation.

A partnership was previously developed with a local charity (Dementia NI) that provide an advocacy service for people who are living with a diagnosis of dementia. People living with dementia were recruited as co-researchers and "experts by experience" to inform, influence and co-produce previous research. Attendees at the meeting included lay co-researchers, and an advocacy development officer for the charity.

Summary information was sent in advance of the meeting and a presentation followed by questions was developed by the research team. On the 18th May 2022 the expert panel meeting was held using a common videoconference platform. The meeting lasted for 2 hours and with the permission of the participants, was recorded to allow for later analysis of discussions.

Evidence summary

Across the different study phases, the main indicators of EDS difficulty in early-stage dementia have been reported as delayed oral transit or slowness when eating, taste changes, coughing, and reduced independence or need for prompting (O'Neill et al., 2023a, O'Neill et al., 2023b, O'Neill et al., 2023c, unpublished). In terms of barriers to identification of EDS difficulty, there are a number of findings that explain why people living with dementia may present late for help with EDS difficulties (O'Neill et al., 2023b, unpublished).

Firstly, most people living with dementia and their families reported not being aware of the "connection" between EDS difficulties and a dementia diagnosis.

> *"I just thought that she had a coughing incident (when eating)...however looking back this may have been a connection with her dementia"*

Secondly, people living with dementia and carers may compensate for EDS difficulties.

> *"I am just aware of her eating. I am not staring at her, I am just looking and making sure that she is doing okay. I am doing it very subtly, I am not in her face, I am just making sure that things are okay"*

Thirdly, there is limited access to information EDS difficulties for people living with dementia and carers. In the semi-structured interviews (O'Neill et al, 2023b, unpublished), 'access to timely information' on EDS difficulty to support individuals was a theme identified.

> *"I really do think being informed would be really helpful. Being informed about in the future what will happen"*

However, the source of this information also appears to be important with a reluctance of people living with dementia and carers to engage with online search engines for fear of finding untrustworthy information.

> *"You can 'google' stuff, look things up online, but you don't know if it's factual "*

Practice-based evidence from a survey of specialist SLTs about the features, assessment approaches and management of EDS difficulty in early-stage dementia found discordance between the indicators of EDS difficulty reported by SLTs (O'Neill et al., 2023c, unpublished), and what the people living with dementia may notice first (O'Neill et al., 2023b, unpublished). Of particular note, is that some of the indicators reported by SLTs on referral and assessment are later symptoms of EDS difficulty (O'Neill et al., 2023c, unpublished). Workforce pressures, exacerbated by the Covid-19 pandemic, have contributed to the delayed presentation of people living with dementia and EDS difficulty (O'Neill et al., 2023c, unpublished).

Questions for panel members

After the presentation of the evidence summary the questions asked of the panel included:

1. To what extent do you agree with the findings?
2. Does any of the evidence surprise you?
3. How can we get the evidence into practice?

Analysis

Notes were taken and a debrief took place afterwards to summarise the key outcomes. A summary of the meeting was emailed to all participants to verify that an accurate transcription of discussions was formulated by the research team and interpretation of the transcript was acceptable. Responses were grouped and summarised under the question headings below. The final question generated the most discussion and feedback was further summarised under the themes of the discussion, which included workforce challenges, multi-disciplinary approaches, and addressing barriers to identification of EDS difficulty. The focus of the results and discussion is therefore on the third question.

Results

1. To what extent do you agree with the findings?

The expert panel unanimously agreed with the findings of the research, which resonated with their own collective experience of EDS difficulty and dementia. The Senior SLT on the panel commented that the findings echoed those of the Public Health Agency 10,000 more voices project on experiences of swallowing difficulties. A key finding from the 10,000 more voices project was that people with EDS difficulty reported living with their condition for up to 18 months before seeking professional help (PHA, 2021). The Dysphagia Coordinator agreed that it was common to encounter people living with dementia who had self-managed EDS difficulty for an extended period of time and in these cases earlier access to support would have been beneficial. The Senior SLT added that lifestyle modification in response to EDS difficulty is common, but that clients aren't often aware that they are using compensation strategies.

> *"People living with dementia often compensate themselves for EDS difficulty (e.g., avoiding foods, adjusting to softer textures) but they aren't aware of what they are doing"*

A Dementia NI co-researcher also commented that they personally hadn't identified the link between their own EDS difficulty and dementia.

> *“I didn’t connect my own EDS difficulty with dementia”*

This Dementia NI member also added that they were aware of other people living with dementia who before receiving help had taken it upon themselves to modify their diet and make other lifestyle changes (e.g., *“breaking up medications”*) in order to compensate for EDS difficulty.

2. Which of the research findings surprised you?

Only one expert was surprised by a single aspect that was not highlighted in the findings. That expert expected that a sense of loss (similar to bereavement) due to EDS difficulty would have been described in the interviews by carers. This was their experience as a carer of relatives who developed dementia and EDS difficulty. None of the other members of the expert panel reported being surprised by the results.

3. How can we get the research evidence into practice?

Given the potential for early onset of EDS difficulty in dementia there was felt to be a rationale for SLT or other professional involvement from an early-stage and when indicated EDS assessment. At this stage the representative from the Department of Health queried why a minority of SLTs (15%) reported that early identification of EDS difficulties in people living with early-stage dementia was not a priority. The responses focused on system level pressures related to the SLT staffing and led to one of the main themes of discussion about the SLT workforce.

Workforce challenges

The wider system level issues were acknowledged by expert panel members as a potential reason for not all SLTs reporting early identification of EDS difficulties in people living with early-stage dementia as a priority. The Senior SLT went on to explain.

> *"I think ultimately SLT triage their referrals on the basis of risk and currently only offer a clinical assessment and management service. So, when SLTs say that early identification of EDS difficulty is not a priority; I think that is in this context (clinical priority). If someone with early EDS was referred in with high clinical risk, they would be a priority."*

The Dysphagia Coordinator concurred and said:

> *"SLTs value the benefit of early identification of EDS difficulties but it is not possible as referrals are received later in the pathway"*

The focus of the discussion then moved the work force numbers needed to provide SLT assessment for or people living with dementia and whether this would be feasible with the help of multi-disciplinary support.

Multi-disciplinary approaches

In terms of providing the resources for early identification of EDS difficulty by EDS assessment, the Dysphagia Coordinator added that the potential workforce implications of a strategy involving only SLT assessment would be prohibitive given current workforce numbers of SLTs. Currently, only 33 SLT students qualify each year, which is just above the level in 2009, therefore workforce numbers are unlikely to increase significantly in the near future (Department of Health,2019).

In terms of translating the research findings into practice, the experts therefore focused on the need for accurate information and awareness. The experts reported that it was imperative to provide the right information, at the right time to those that need it. However, it was again felt unlikely that SLTs alone would have sufficient workforce capacity to provide education and advice to all people living with dementia. Such a service could potentially be achieved by involving other members of the multi-disciplinary team. The Senior SLT said;

> *"I think that there is potential for more creative thinking about providing education and advice services. I don't think every person with early EDS difficulty needs clinical assessment and management but they would*

> *definitely benefit from education and advice. I don’t think the education and advice necessarily needs to be a SLT”*

Addressing barriers to identification of EDS difficulty

The challenges and barriers discussed by the panel regarding the provision of information on EDS difficulty to people living with dementia included the timing of information and the clinical settings where information could be accessed.

From the semi-structured interviews (O’Neill et al, 2023b, unpublished), it was noted that people living with dementia would need awareness of the rationale to accept EDS assessment, and that such an assessment may be too much at the time of diagnosis. A particular concern therefore centred on whether people would accept additional information provision on EDS difficulty at the time of a dementia diagnosis. The importance of respecting the difficulty of receiving a new dementia diagnosis when providing information on EDS difficulty was emphasised. The Dysphagia Coordinator added;

> *“There is a duty to inform that needs balanced with the ability to accept and understand the information”*

A memory clinic was mentioned by a panel member as a potential clinical setting to identify people with early-stage dementia who may have EDS difficulty. A memory clinic is somewhere where people with memory problems can have their memory assessed. The 2009 National Dementia Strategy and resultant increase in memory clinics has increased the diagnosis rate of dementia in the UK (Mukadam et al., 2014). There have been calls for multi-disciplinary involvement in memory clinics so that they can effectively operate as a “one-stop-shop” to address all the needs of the patient and their significant others (Steiner et al., 2020). Memory clinics are therefore an established means of identifying people living with dementia at an early stage and there is an appetite to introduce team members capable of addressing the multifaceted needs of dementia clients.

However, other expert panel members highlighted that not everyone is diagnosed at a memory clinic and inequity of access to information could result if these memory clinics alone were specifically targeted. Inequity and variation in services was a source of frustration for the Dementia NI panel members. A Dementia NI member added that services for people living with dementia were variable depending on where people lived in Northern Ireland. A preferred approach would therefore be equitable access to information on EDS difficulty across the population.

Conclusion of meeting

Ultimately, it was agreed amongst all the panel members that an equitable, integrated system-based and multi-disciplinary approach to providing information and raising awareness of EDS difficulty for people living with dementia at a population level was needed.

Discussion

Although dementia is incurable, an early diagnosis can facilitate the provision of advice, allow for commencement of treatment and put in place support networks to empower the individual with dementia and their family. Ultimately decreasing the potential for future crises and delaying the prospect of institutionalisation (Prince et al., 2011). To date the early identification of EDS difficulty has not been well recognised as a potential benefit of receiving an early dementia diagnosis. However, the chronic care model promotes the concept of proactivity and this could be extended to the early identification of EDS difficulty in people living with dementia (Wagner, 1998). Early identification of EDS difficulty with a view to preserving usual patterns of daily living also aligns with the model for supporting people with dementia and their families (Department of Health, Social Services & Public Safety, 2011).

The question about getting the research evidence into practice generated the most discussion. The main themes of this discussion included workforce challenges, multi-disciplinary approaches, and addressing barriers to identification of EDS difficulty. Workforce challenges in the wake of the Covid-19 pandemic are a theme across the health service currently (Gillen et al., 2022). Multi-disciplinary approaches to overcome the low number of SLTs available were suggested, and in the opinion of the expert panel meeting a key strategy to facilitate earlier identification of EDS difficulty in people living with dementia is improving accessibility of information and raising awareness of EDS difficulty. The expert panel felt that people living with dementia and carers should be aware how to access information about EDS difficulty and know that the information is from a trustworthy source. Access to information must be equitable and the timing of information provision will need to be respective of the difficulty of receiving a new dementia diagnosis. An equitable, integrated system-based and multi-disciplinary approach to providing information and raising awareness at a population level was therefore felt to be needed. This would align with the chronic care model (Wagner, 1998) as it calls for transformation of acute and reactive care of people to a planned, proactive and population-based approach (Garland-Baird and Fraser, 2018). The future challenge is to develop an information provision strategy that fulfils these recommendations. Information provision would help address the issue of ‘missed connections’ between EDS difficulty and dementia, which was highlighted by interviews with people living with dementia and their carers.

The strengths of the meeting included the high level of experience of the expert panel and involvement of people living with dementia as “experts by experience”. Advocates for people living with dementia call for active involvement of people living with dementia in research (Bryden, 2015). Limitations of the meeting included the representativeness of the panel who were all interested and experienced in the field of EDS difficulty and dementia. This may have contributed to the broad consensus regarding the research findings and the lack of surprise expressed about the findings.

Only one expert was surprised by a single aspect that was not highlighted in the findings. That expert expected that a sense of loss (similar to bereavement) due to EDS difficulty would have been described in the interviews by carers. Many manifestations of loss are recognised in carers of people living with dementia as they strive to maintain continuity of the person being cared for through compensatory actions and the provision of a supportive care environment (Gillies, 2012). Therefore, a sense of loss is a recognised feature of the carer experience. This sense of loss perhaps wasn't captured in the interviews conducted in because of the emphasis placed on early indicators of EDS difficulty as opposed to loss of ability with EDS.

Finally, given that an overall informal approach was adopted for this expert panel meeting, future work could include a more formal approach. An option that could be considered is a Delphi approach, which could be used to broaden consensus across a wider range of stakeholders (McMillan et al, 2016).

Conclusions

The focus of the expert panel meeting was to verify findings from research and explore how to address EDS difficulties in people at early stages of a dementia. In terms of translating the research findings into practice, accessibility of information on EDS difficulty for people living with dementia is a key issue. People living with dementia and carers should be aware how to access information and that the information is from a trustworthy source. The timing of information provision needs to respect the difficulty of receiving a new dementia diagnosis. Access to the information also needs to equitable with considerations including the setting where dementia is diagnosed. This means that a population-based approach is preferable. It was therefore agreed amongst all the panel members that an equitable, integrated system-based and multi-disciplinary approach to providing information and raising awareness of EDS difficulty for people living with dementia at a population level was needed. Future work should focus on formally broadening consensus among a wider group of stakeholders and if applicable developing an information provision strategy that fulfils these recommendations.

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7 Discussion

In a series of papers, the previous chapters have explored EDS difficulty in dementia from published literature, experiences of people living with dementia and their carers, SLT perspectives, and the views of expert strategic leaders. Each paper has been discussed in the respective preceding chapters. This discussion chapter will now seek to put the findings into a wider context and bring the evidence together.

7.1 Clarification of the findings in context

In the wider context of public health concerns, early identification of EDS difficulty in progressive neurological and neurodegenerative diseases is a concern that has been highlighted in the recent UK-wide review of the quality of care provided to patients with Parkinson's disease (Koomson et al., 2021). At the most severe end of the spectrum, EDS difficulty can increase the risk of choking. Hence prevention of death by choking has been a high-priority public health concern in Northern Ireland since 2018 (The Public Health Agency and the Health and Social Care Board, 2021). With interest increasing since the work of this thesis began, choking has again been the subject of a recent high-profile independent review by the Regulation and Quality Improvement Authority. The key recommendations for choking prevention have included staff training, better communication between staff and shorter waiting times for swallowing assessment (RQIA, 2022). Fear of choking is significant burden for carers

(Kalkers et al., 2022). Identifying EDS difficulty is a priority specifically in the dementia population for a variety of reasons.

The prevalence of dementia among elderly people in the UK is 7.1% (Wittenberg et al., 2019) and will continue to rise (Livingston et al., 2017). Cognitive decline, altered sensorimotor function, and increased reliance on caregiver support mean that EDS difficulties are common for people living with dementia (Bayne and Shune, 2022). EDS difficulties affect up to 57% of people living with dementia (Alagiakrishnan et al. 2013) and are a risk factor for poorer outcomes (Paranji et al., 2017). Awareness of EDS difficulty early in the disease process or at preclinical stages may identify individuals at risk (Rogus-Pulia et al., 2015). Early identification of EDS difficulty has improved outcomes in Stroke (Bray et al., 2016). To manage the risks associated with EDS difficulty in dementia, SLTs can apply compensatory strategies and offer family and care staff training (Egan et al., 2020).

Literature reviews have highlighted the absence of a universal screening test for EDS difficulty (Bours et al., 2009, Kertscher et al., 2014). It may be that the complexity of established swallow decline is too multifactorial to ever be addressed adequately by a single screening tool for all conditions. A more proactive and condition specific approach, aimed at identifying EDS difficulty at an earlier stage may be more feasible and beneficial to people living with dementia. However, before early identification of EDS difficulty can be achieved, more data on the early indicators of EDS difficulty in early-stage dementia was needed.

7.2 “Extent that aim has been achieved”

The thesis aim was to inform earlier identification of EDS difficulties for people living with early-stage dementia. Accordingly, this research set out to:

1. Identify reliable and clinically measurable indicators from published literature;
2. Understand the experiences of people living with dementia and their family carers;
3. Understand SLT perspectives; and
4. Elicit the opinion of an expert panel.

In the chronic care model, the delivery system redesign element of the model endorses transformation to proactive pathways aimed at keeping the individuals healthy as possible (Wagner, 1998). The model for supporting people with dementia and their families requires services for individuals with dementia to be seamless, accessible and proactive (Department of Health, Social Services & Public Safety, 2011). In keeping with the chronic care model (Wagner, 1998), and Model for supporting people with dementia and their families (Department of Health, Social Services & Public Safety, 2011), identifying the risk of EDS difficulty at an early stage could help drive interventions that promote maintenance of swallow thus preserving individual’s independence and usual patterns of daily living.

The aim of this thesis was to inform earlier identification of EDS difficulty in dementia. In Chapter 3, published evidence pertaining to indicators of EDS difficulties in dementia was first systematically updated and reconsidered in terms of measurability in clinical practice and applicability to people living with early-stage dementia (Affoo et al., 2013, Alagiakrishnan et al., 2013). In Chapter 4 semi-structured interviews were then conducted with people living with dementia to gain the insight and lived experience of those affected. This provided information from a service user perspective, which is more applicable to the overall wellbeing of those affected when compared to published literature on indicators of EDS difficulty. In Chapter 5, practice-based evidence from specialist SLTs on the early identification of EDS difficulty in people living with early-stage dementia was evaluated. Finally, in Chapter 6, a group of experts and strategic leaders were invited to an online meeting to establish if there was consensus on the research findings, to identify system-level barriers to identification of EDS difficulty and discuss translation of the research findings into practice. The various study phases therefore provided a blended and integrated approach of multiple sources that in their totality addressed the aim of informing earlier identification of EDS difficulty in dementia.

A degree of overlap between the reported indicators of EDS difficulty in the different study phases was always possible given that each phase of the study informed and influenced the next phase. However, it is possible to appreciate indicators of EDS difficulty that were more consistently reported across the study phases (Figure 7.1). Delayed oral transit is a key indicator as it was noted by all three sources of evidence, thus indicating a shared understanding of the importance of delayed oral transit across study phases. The literature would suggest that delayed oral transit is a key feature of EDS difficulty in early-stage dementia and SLTs agreed with this. The other indicators of EDS difficulty reported in the literature were medical in nature (e.g., sarcopenia and polypharmacy), and less likely to be reported by a service user. SLTs also agreed with people living with dementia who reported slowness (consistent with delayed oral transit), taste changes, coughing and reduced independence or need for prompting as indicators of EDS difficulty in early-stage dementia. Furthermore, the expert panel were in agreement with these indicators. However, at an overall system level, there is also consensus across study phases that there are gaps in the services needed to identify these markers of EDS difficulty in a holistic and timely fashion in order to support and facilitate better self-management.

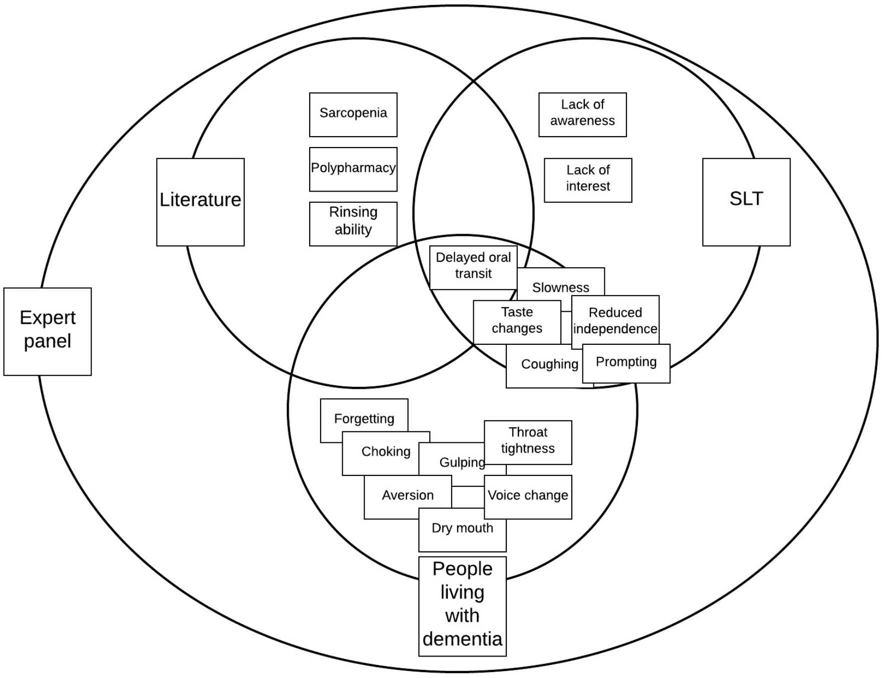

Figure 7-1 Summary of all the indicators of EDS difficulty

Showing indicators from each study phase with delayed oral transit at the centre, having been noted by all three sources of evidence and shared understanding across study phases. The expert panel were in agreement with these findings as demonstrated by outer circle.

7.3 Significance of the results

Indicators of EDS difficulty

The National Institute for Health and Care Excellence (NICE, 2006) has identified obvious indicators of EDS difficulty (difficult or painful chewing or swallowing, drooling, hoarse voice, unintentional weight loss, coughing and choking before or after swallowing) and less obvious indicators of EDS difficulty (‘wet’ voice quality, change in respiratory patterns, frequent throat-clearing, recurrent chest infection, change in eating habits and pyrexia of unknown origin). However, this guidance relates to all conditions and does not pertain specifically to dementia or to the early identification of EDS difficulty. By the time the features listed in the NICE guideline develop it is possible that a person with EDS difficulty could come to harm and participation and well-being can be impacted. A gap therefore exists for a more holistic approach to identifying EDS difficulty earlier in dementia specifically, and this thesis has investigated a range of sources (published data, personal experience, SLT opinion and expert clinical opinion) to provide new data on indicators of EDS difficulty in early-stage dementia. This provides unique insight into the perspective of people living with dementia and family carers, and provides insights into experiences of EDS, challenges faced and identifies commonalities with other sources of evidence, such as published literature and expert opinion.

Potential interventions to support intake of food and drink in people living with EDS difficulty and dementia include modification of food (Abdelhamid et al., 2016). People living with dementia often have a predictable decline in EDS, and promotion of independent self-caring for longer, as well as reduction in malnutrition should be a realistic target. The features of EDS difficulty (delayed oral transit or slowness when eating, sarcopenia, polypharmacy, taste changes, coughing and reduced independence or need for prompting, Figure 7.1) could be used to highlight those at risk and identify people with early-stage dementia that have EDS difficulty. As a result, the wellbeing of those affected could be improved and complications of EDS difficulty prevented. The significance of the indicators of EDS difficulty in early-stage dementia highlighted by this research are that they come from a range of sources and provide a holistic overview.

As identified in Chapter 3, research studies assessing the reliability of indicators of EDS difficulty in early-stage dementia typically utilise either a videofluoroscopic swallowing study or fibreoptic endoscopic evaluation of swallow as the comparative reference (i.e., ‘gold standard’) for detecting aspiration and therefore formally diagnosing EDS difficulty (Priefer and Robbins, 1997, Humbert et al., 2010, Özsürekci et al., 2020). However, these approaches are not part of routine clinical practice since only 4% of SLTs responded that they frequently or always use instrumental assessment in people with early-stage dementia (Chapter 5, Table 4). Outside the research setting, these investigations are typically reserved for people with more advanced EDS difficulty picked up by either screening or clinical assessment and may not be in the best interests of those with early EDS difficulty.

The limitations of these instrumental tools in clinical practice include time constraints, expense, lack of access, limited reproducibility, and in the dementia population behavioural and psychological barriers to administering the tests effectively (Sato et al., 2014, Lancaster 2015, Schröder et al., 2019). Therefore, from a clinician’s perspective reliable indicators of EDS difficulty are highly desirable from the point of view of avoiding late presentations of EDS difficulty, thus minimising or rationalising the future need for these more expensive and invasive investigations. This aligns with elements of the chronic care model, such as decision support and delivery system redesign (Wagner, 1998).

In summary, holistic and condition specific indicators of EDS difficulty in early-stage dementia could be used to highlight those at risk and identify people with early-stage dementia that already have EDS difficulty. By identifying these people earlier, late presentations of EDS difficulty could potentially be avoided with the need for expensive and invasive investigations to diagnose EDS difficulty minimised.

Barriers to identifying EDS difficulty

The semi-structured interviews have highlighted the importance of identifying EDS difficulty early in dementia because there is a lack of awareness of the connection between EDS difficulty and dementia in people living with dementia and their carers. This coincides with lack of identification of EDS difficulty by people with dementia, families and health care professionals (Chapter 5). Lack of awareness and identification could result in delayed presentation to health professionals for assessment of EDS difficulty and ultimately lead to poorer outcomes (Paranji et al., 2017). The semi-structured interviews and the literature base also highlight that people living with dementia and carers report compensatory changes that may mask problems or allow individuals to cope (Priefer and Robbins, 1997). Reduced awareness of the connection between EDS difficulty and dementia could exacerbate this issue of compensation and further delay presentation to Health Care Professionals. A key finding from the 10,000 more voices project was that people with EDS difficulty reported living with their condition for up to 18 months before seeking professional help (PHA, 2021). Previous qualitative research supports this finding as it has been identified before that EDS problems are not discussed with people living with early-stage dementia as they are felt to be unrelated to them or irrelevant (Anantapong et al., 2021).

The systematic review offered potential early indicators of EDS difficulty in dementia (Chapter 3), but in the survey conducted (Chapter 5) competing pressures on SLT time, meant that less than half of respondents felt that current SLT practice supports early identification of EDS difficulties. The survey uncovered that a standardised way for identifying EDS difficulty in early-stage dementia is not in use, and clinical priorities are typically focused on people with established EDS difficulty. Specialist SLTs in the survey reported symptoms of EDS difficulty on referral and assessment that were typical of later stages of dementia (e.g., choking); suggesting SLTs specialising in EDS are seeing people for initial assessment who have been living with the condition in the community for a considerable time. This is well illustrated in the comment by one SLT that reflected the broader sentiment of the respondents that competing clinical priorities were a barrier to early identification of EDS difficulty;

> *“I think seeing patients with early difficulties is gold standard, but we wouldn't have capacity as would significantly increase our waiting lists and*

> *would therefore cause harm for patients who are experiencing more significant problems"*

This suggests a focused role and function in the later stages of the disease but with reduced resources for earlier intervention and education. Therefore, there is discord between presenting features of EDS difficulty in clinical practice, and what the people living with dementia notice as early symptoms (e.g., slow eating, taste changes, coughing and reduced independence or need for prompting). In people with dementia and EDS difficulty, SLTs use compensatory strategies and provide family and care staff training in mealtime support (Egan et al., 2020). The chronic care model describes the benefits self-management and community support (Wagner, 1998). To enable this to happen, more awareness of EDS difficulty in early-stage dementia is needed in order to initiate these measures in a timely fashion. SLT literature in the area of oncology describes a move away from a "reactive" approach, which involves waiting for either overt signs or symptoms of EDS difficulty to develop before referring for assessment and considering recommendations for intervention (Kristensen et al., 2020).

In a previous survey (Egan et al., 2020), SLT respondents reported lack of resources contributing to an inability to fulfil their role in providing assessment, management, and training in the way that they felt is necessary for people living with dementia. The survey conducted herein provides additional insights to the professional challenge specific to the population living with early dementia; in this survey, competing pressures (e.g., waiting lists, staffing, resources, and higher clinical priorities) was an underlying theme for the minority of SLTs that did not view early identification of EDS difficulties in early-stage dementia as a priority for SLT considering their competing priorities. Experts focused on system level pressures related to the SLT staffing to explain this minority opinion.

The Covid-19 pandemic has impacted the clinical operations of SLTs and service provided to those with Dementia. There is increased workforce pressure (e.g., due to staff absence). Only 45% of SLTs agreed or strongly agreed that current SLT practice supports health promotion for EDS, as summarised in the following response;

> *"Health promotion and education for patients at early stage would be ideal but we are in firefighting mode at present"*

Service demand may impact health promotion approach, and this has been exacerbated by the Covid-19 pandemic.

7.4 Limitations

Research to inform clinical practice development is demanding of expertise and resources, leading to recognition of the wide extent of work needed: across reviews of published evidence, gathering patient and carer perspective, eliciting professional experience and leadership opinion. A single PhD researcher can open discourse, but more development is needed. There are a number of limitations to the findings from each study phase that have previously been discussed in each Chapter. For example, in Chapter 4 it was discussed that

Zoom was used for semi-structured interviews as per guidance issued during the Covid –19 pandemic, all types of dementia were grouped together and there may have been selection bias in the cohort of participants from Dementia NI. This was mitigated by presenting the research project at a Dementia NI engagement event and opening the invitation to participate to all Dementia NI members. In Chapter 5, it was also discussed that there was difficulty recruiting SLTs to the survey in the context of workforce pressures during the Covid-19 pandemic. Although the fact that only SLTs with experience of working with people living with dementia were included, meant that a limited sample of specialist SLTs were surveyed. The data obtained in the survey was also from clinical experience alone, which represents a lower level of evidence.

To help inform future survey work, the systematic review in Chapter 3 was conducted with the specific purpose of uncovering indicators of EDS difficulty only in early-stage dementia. This narrowed the scope of the systematic review and a review of all stages of dementia could be considered in future work. Given the limited number of indicators of EDS difficulty in early-stage dementia from the systematic review, the survey also listed for SLT participants indicators of EDS difficulty in early-stage dementia from published expert opinion articles (Rogus-Pulia et al., 2015, Winchester and Winchester, 2016). These EDS indicators would therefore be from a lower level of evidence (SIGN, 2015). In addition, while data on the earliest EDS changes were gathered from semi-structured interviews and included in the survey of SLTs, the data may be subject to recall bias by the participants who went on to develop further EDS difficulties (Althubaiti, 2016).

Furthermore, in Chapter 6, lay members attending the expert panel meeting were co-researchers from Dementia NI which could have introduced agreement bias when research findings were discussed.

7.5 Covid-19 as a limitation

During this research the impact of covid-19 pandemic was considered both in terms of social distancing and reduced capacity for healthcare professionals on the frontline to partake in research. This was carefully considered. The inevitable increase in delayed routine work in the aftermath of the crisis period was also factored into the project timeline. The survey was released between December 2021 and January 2022, which coincided with the Omicron wave. While hospitalisations were less during this wave, Covid-19 was impacting workforce and changing clinical practice which was evident in this survey. Many staff were off, and departments were short of cover. Indeed, a theme that was identified in relation to the Covid-19 pandemic was workforce pressure on SLTs (Chapter 5), which was a theme across the health service at the time (Gillen et al., 2022).

To ensure the safety of researchers and participants, up to date guidance from the Public Health Agency was adhered to when planning or organising interviews (https://www.publichealth.hscni.net/covid-19-coronavirus). As such, interviews were conducted online. The feasibility of this approach in people living with dementia was demonstrated. The input of co-researchers was invaluable in terms of pre-interview logistics, the research protocol, participant information sheet, consent process, introduction by researcher to interview questions and the content of interview questions.

7.6 Cohesion between the preceding chapters in the context of frameworks

This research has identified the need for a holistic EDS screen to provide early identification of the onset of EDS for people living with dementia to incorporate; (i) the lived experience of those with dementia, (ii) indicators from the evidence base and (iii) learning from clinical expertise. In the context of proactively identifying EDS difficulty in early-stage dementia, more knowledge is needed of the earliest signs of decline in EDS ability and standardised approaches to care are needed to reduce variability and the risk of poorer health outcomes associated with EDS difficulty. This thesis has addressed that need.

A systematic review was first conducted prior the semi-structured interviews, so that published evidence pertaining to EDS difficulties in dementia had been updated and considered (Affoo et al., 2013, Alagiakrishnan et al., 2013). A previous research priorities exercise in Ireland stated the need for more systematic reviews in SLT (Mc Kenna et al., 2014). In the chosen framework for design of the semi-structured interviews, the systematic review provided a prerequisite for semi-structured interview use in terms of having prior knowledge of the phenomenon under investigation (Kallio et al., 2016).

In the survey, a list of published features of EDS difficulty in dementia was provided to SLTs as derived by updating systematic literature reviews from previous publications (Affoo et al., 2013, Alagiakrishnan et al., 2013). When derived from direct clinical experience, expert opinion represents an alternative form of knowledge that may be complementary to empirical evidence (Tonelli, 1999). In addition, the systematic methods for combining evidence and expert opinion described usually identify evidence prior to expert opinion (Campbell et al., 2002). Therefore, a rationale existed for conducting the survey to elicit the professional expert opinion in order to complement the previous evidence-based review.

Furthermore, in the survey a list of features of EDS difficulty reported by people living with dementia was derived from semi-structured interviews of living with dementia and carers for people living with dementia. Co-researchers were involved in both semi-structured interview and survey design, which provided continuity and cohesion in terms of the applicability of both phases of this research to people living with dementia.

The semi-structured interviews had a particular focus on the experiences of people living with dementia when accessing services in their EDS journey. The connections between EDS changes and dementia not made previously and thus the final theme became ‘missed connection’ between EDS difficulty and dementia, and subthemes of ‘access to information’ and ‘compensatory changes’ were in the final theoretical framework. Individuals or processes reported to be helpful or unhelpful in the person living with dementia or their carer's journeys were dramatically framed into symbolic roles of *heroes* and *villains* (Wagner-Egger et al., 2011). Examples of heroes included community psychiatric nurses, General Practitioners, SLTs, family, the organisation Tied, and simple solutions (e.g., aids for eating and drinking). Examples of villains included Google, missing hospital records, lack of access to information about yourself, lack of information at time of diagnosis, and too much time between hospital check-ups.

In terms of identifying barriers to early identification of EDS difficulty and translating the research findings into practice, an expert panel was convened to give system level oversight to key connected and related issues. The expert panel focused on the need for information. It is imperative to provide the right information, at the right time to those that need it, whilst respecting the difficulty of receiving a new dementia diagnosis. This information would empower people living with dementia and family carers at the earliest stage. The wider system level issues (for example staffing pressures described in the survey) were acknowledged. An equitable, integrated system-based and multi-disciplinary approach to providing information and raising awareness at a population level was recommended. This aligns with the aim of the chronic care model (Wagner, 1998), which is transformation of acute and reactive care of people to a planned, proactive and population-based approach (Garland-Baird and Fraser, 2018).

7.7 Suggestions for further work

There are unmet needs and gaps in health care services provided to people living with dementia and EDS difficulty that have been exacerbated by Covid-19. There is a need to standardise and reduce variability in the support provided for people with early-stage dementia experiencing EDS difficulty. Future work should focus on the recommendations of designing an equitable, integrated system-based and multi-disciplinary approach to providing standardised information and raising awareness of EDS difficulty in dementia at a population level. Overall, it is felt that the timing of information provision will need to consider the setting where dementia is diagnosed and on how the individual responds to their initial diagnosis. The source of information is another important consideration and the reliability of the source is a prime concern to people living with dementia. An initial next step could be to standardise the information about EDS difficulty that people living with dementia receive. Timelines for information and format of delivery would also need considered. The approach to breaking bad news, explaining that EDS difficulty can be a life limiting factor in the future, and communicating options for advance care planning are important considerations.

There are also other areas where the work of this thesis could be taken forward. In keeping with the need expressed during scoping meetings with the SLT department from the South Eastern Trust at the outset of the PhD (Chapter 2), the new information provided by this research could be used to assist with referral criteria for SLT assessment for people living with dementia. In my own clinical practice as a SLT the indicators of EDS difficulty identified in this research, particularly delayed oral transit, help to appropriately triage referrals for assessment of people living with dementia. Resources permitting, people with early indicators of EDS difficulty can be appropriately triaged to receive support with EDS. The evidence from this research could also be widened to include holistic indicators of EDS difficulty within models of disability (Üstün et al., 2003).

Recommendations from the recent NCEPOD review of the quality of EDS care provided to patients with Parkinson's disease included the need for documentation of swallow status and swallow screening for patients with Parkinson's disease (Koomson et al., 2021). It is likely that similar recommendations will follow for other conditions where EDS difficulty is common, such as dementia. The new information on early indicators of EDS difficulty in dementia could assist with that anticipated work by highlighting worrying symptoms and signs to hospital staff.

The work in this thesis is presented "with papers" in the format of the International Journal of Language and Communication Disorders. Four substantive manuscripts are presented with the intention that they may be submitted for wider dissemination in appropriate academic or professional journals. If published the new information on indicators of EDS difficulty in dementia specifically will therefore also help other researchers that are seeking to develop mechanisms for identifying pre-clinical EDS difficulty in community settings (Madhavan et al., 2018). Further dissemination of the research has included presentations to Dementia NI and there is intention to submit the work to academic conferences.

Accessibility of information on EDS difficulty was identified as a key issue in the expert panel meeting (Chapter 6). The need for provision of timely information on EDS difficulty for people living with early-stage dementia has been uncovered. There are various pathways to disseminate this need for information and future work should involve the Royal College of SLT and other allied health professional groups. The link to Dementia NI could be used to raise awareness of EDS difficulty.

In terms of information, personal information was also important for those that had received help. And it was a source of frustration that not everyone (including the person affected and health care professionals) had access to the same information.

> *"There are so many people but they don't talk to each other, so you are only getting jigsaw pieces sent through and you know there is no way you are going to understand it"*

This situation could be improved by Encompass, which is a Health and Social Care Northern Ireland wide initiative that will introduce a digital integrated care record to Northern Ireland. Using this system, patients and their carers should be able to book appointments, review test results and correspondence, and communicate with those providing their care.

In terms of prioritising the next steps, the needs of people with dementia need to put at the forefront of any future plans. As such, the initial focus should be on design of an equitable, integrated system-based and multi-disciplinary approach to providing standardised information and raising awareness of EDS difficulty in dementia at a population level using public health expertise.

7.8 Future research studies

Further good quality research in the area of EDS difficulty in early-stage dementia is needed. A prospective study of diagnostic accuracy and evolution over time of indicators of EDS difficulty in early-stage dementia could be considered. Research participants could be identified through early diagnosis memory clinics. The expectation is that items on the candidate list of indicators of EDS difficulty may predate established or advanced EDS difficulty. It would therefore be useful to identify a measurement of EDS difficulty that can easily be repeated on an ongoing basis in a study population in order to evaluate the evolution of EDS difficulty over a study period. If swallowing were repeatedly evaluated by videofluoroscopic swallowing studies a cumulative effect of radiation exposure would result. For fibreoptic endoscopic evaluation of swallow it is unlikely that study subjects would consent to repeated invasive testing of this nature. The options are then clinical assessment tools or questionnaires. In order to avoid study subjects repeatedly having to return to the research clinic for clinical assessment, a questionnaire via telephone or postal follow up may be most suitable. A limitation of this approach is the lack of gold standard diagnosis of aspiration that would be provided by videofluoroscopic swallowing studies or fibreoptic endoscopic evaluation of swallow, but an advantage of a questionnaire is the increased ability to monitor the evolution of each study participants swallow over time in an acceptable and time efficient manner.

7.9 Conclusion

By employing an integrated approach this thesis has used published data, personal experience, and expert opinion to provide insights to inform early identification of EDS in dementia and provide new knowledge on indicators of EDS difficulty in early-stage dementia. Lack of awareness and service pressures, may explain why people living with dementia may present late for help with EDS difficulties. A population-based intervention for providing information and raising awareness of EDS difficulty and dementia is necessary in the opinion of experts. This thesis has therefore addressed the intended knowledge gaps showing how EDS difficulties might be identified. Further practice development plans will require careful facilitation, taking full account of post-pandemic clinical context. The duty to better inform people living with dementia about EDS difficulty has been exposed.

Take away points

- The connection between potential EDS difficulties and a dementia diagnosis may not be made, even though EDS changes are present.
- This may be explained by behaviours that mask problems or allow individuals to cope or compensate. Reduced awareness may also be due to inadequate access to information and lack of specialist services.
- Workforce pressures, exacerbated by the Covid-19 pandemic, have contributed to the delayed presentation of people living with dementia and EDS difficulty. SLTs are reporting indicators of EDS difficulty on referral and assessment that are later symptoms of EDS difficulty.
- Lack of awareness and service pressures, may therefore explain why people living with dementia may present late for help with EDS difficulties.
- In the opinion of experts, service users would benefit from a population-based intervention for providing information and raising awareness of EDS difficulty and dementia.

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8.1 Introduction

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9 Appendices

9.1 Scottish Intercollegiate Guidelines Network grading system

1++ High quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias.

1+ Well-conducted meta-analyses, systematic reviews, or RCTs with a low risk of bias.

1- Meta-analyses, systematic reviews, or RCTs with a high risk of bias.

2++ High quality systematic reviews of case control or cohort or studies.

2++ High quality case control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal.

2+ Well-conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal.

2- Case control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal.

3 Non-analytic studies, e.g., case reports, case series.

4 Expert opinion.

It should be noted that in Scottish Intercollegiate Guideline Network guidelines that cross-sectional studies are rated in a similar fashion to cohort studies (SIGN, 2015).

Based on the level of evidence, grades of recommendation can be made.

A At least one meta-analysis, systematic review, or RCT rated as 1++, and directly applicable to the target population; or a body of evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results.

B A body of evidence including studies rated as 2++, directly applicable to the target population, and demonstrating overall consistency of results; or extrapolated evidence from studies rated as 1++ or 1+.

C A body of evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results; or extrapolated evidence from studies rated as 2++.

D Evidence level 3 or 4; or extrapolated evidence from studies rated as 2+.

Key points with regard that are applicable to the current study are the emphasis on the applicability to the target population and consistency of results. A good practice point is that recommended best practice is based on the clinical experience of guideline development groups.

9.2 Risk of bias tools

9.2.1 Newcastle-Ottawa scale

The Newcastle-Ottawa scale (Wells et al., 2013) is a risk of bias tool that has been recommended for use by the Cochrane Collaboration (Higgins and Green, 2011). It can be applied to case-control and cohort studies. The Newcastle-Ottawa scale assigns points or stars in three domains: 1) selection of study groups (four stars); 2) comparability of groups (two stars); and 3) ascertainment of exposure and outcomes (three stars). There is a maximum score of nine for the least risk of bias. The number of stars allocated to the study can be converted to the Agency for Healthcare Research and Quality standard of study quality as follows (Borge et al., 2017):

Good quality: 3 or 4 stars in selection domain AND 1 or 2 stars in comparability domain AND 2 or 3 stars in outcome/exposure domain.

Fair quality: 2 stars in selection domain AND 1 or 2 stars in comparability domain AND 2 or 3 stars in outcome/exposure domain.

Poor quality: 0 or 1 star in selection domain OR 0 stars in comparability domain OR 0 or 1 stars in outcome/exposure domain.

Criticisms of the Newcastle-Ottawa scale have included an overly general definition of quality criteria (Stang, 2010) but the counter argument is that this allows for wide applicability of the tool (Borge et al. 2017).

9.2.2 National Heart, Lung, and Blood Institute Quality Assessment Tool

For cross-sectional studies the National Heart, Lung, and Blood Institute Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (NHLBI, 2014) was selected as the evaluation tool for assessing risk of bias. There are 14 questions on the form. The intention is not for a score to be added up in order to arrive at a summary judgment of quality. The questions are designed to focus the reviewer on the key concepts for evaluating the internal validity of a study. As such the tool allows for a broad classification of studies as good, fair or poor. A "good" study has the least risk of bias, a "fair" study is susceptible to some bias and a "poor" rating indicates significant risk of bias.

9.2.3 Quality Assessment of Diagnostic Accuracy Studies

QUADAS-2 is a tool that was published in 2011 (Whiting et al., 2011) as an update of the original QUADAS tool (Whiting et al., 2003) for assessment of diagnostic accuracy studies. This tool comprises four domains that are assessed for risk of bias: patient selection, index test, reference standard, and flow and timing. The first three domains are also assessed in terms of applicability to the particular review question that is posed. The tool has been widely adopted and is the current standard tool for evaluating studies of diagnostic accuracy (Venazzi et al., 2018). Although no cut-off scores are used with QUADAS-2 for classifying study quality each domain is rated individually as low, high or unclear risk of bias, and an overall impression of study quality is obtained.

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9.3 Survey

Early Identification of Eating Drinking and Swallowing difficulties for people living with early-stage dementia

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Start of Block: Introduction to survey

Q0 Hello, thank you for opening this survey which aims to understand the potential for **early-identification of EDS difficulties** for people living with **early-stage dementia** from the perspective of the SLT. We are keen to gain from your clinical knowledge and expertise. In-depth responses are encouraged. This survey should take no more than 20 minutes to complete. **It has been co-designed with people living with dementia. E**thical approval has been granted by Ulster University.

“EDS” refers to Eating, Drinking and Swallowing. **“SLT”** refers to Speech and Language Therapist. **"People living with early-stage dementia"** have either a formal diagnosis of early-stage dementia (by General Practitioner or Specialist) or a clinical dementia rating no greater than 1 (i.e., mild dementia). Early-stage symptoms of dementia include problems with memory, speed of thought, language, perception or EDS. Many people at the early-stage of dementia stay independent and only need a small amount of assistance with daily living. Please note:
* Completion of the survey will be taken as your consent to participate.
* Some answers can only be approximated, so don't worry if you can't provide exact figures.
* Honest answers are important. Please answer according to what happens in current clinical practice, not what you would do in an ideal world.
* Your responses are anonymous.
* A progress bar at the bottom of the page will show you how close you are to completion.
* You can stop the survey; your responses will be saved and you can return to complete it where you left off.

End of Block: Introduction to survey

Start of Block: Practical and clinical experience

First some questions about referral, assessment and management

Q1.1 Based on your experience, please list **3** of the **most frequent pieces of information** on a referral for a SLT EDS specialist assessment for people living with early-stage dementia

○ 1. ______________________________

○ 2. ______________________________

○ 3. ______________________________

Q1.2 Person reported difficulties: Please list **3 of the most frequent EDS difficulties** that people with early-stage dementia **report themselves**

○ 1. ______________________________

○ 2. ______________________________

○ 3. ______________________________

Q1.3 ASSESSMENT: Describe **your examination findings** that indicate that an individual with early-stage dementia has EDS difficulties (please consider domains such as cognitive, sensory, psychological, and motor)

○ Cognitive (e.g., thinking)
____

○ Sensory (e.g., senses)
____

○ Psychological (e.g., emotions)
____

○ Motor (e.g., movements)______________________________

○ Other ______________________________

Q1.4 MANAGEMENT: Please indicate how often you would use the approaches listed to support individuals with early stage-dementia with EDS difficulties?

	Never	Rarely	Sometimes	Frequently	Always
Discussion with the **individual** with early-stage dementia	○	○	○	○	○
Discussion with **family member/carer**	○	○	○	○	○
Written information/guidance provided to the person and their family member/carer	○	○	○	○	○
Instrumental assessment of EDS e.g., videofluoroscopy or fibreoptic endoscopic evaluation of swallow	○	○	○	○	○
Therapeutic intervention (**compensatory strategies**)	○	○	○	○	○
Therapeutic intervention (**direct swallowing therapy** e.g. maneuvers)	○	○	○	○	○
Planned EDS **follow up review**	○	○	○	○	○

Q1.5 DISCHARGE: Based on your experience, please explain when you are able to **safely close an EDS episode of care** for individuals with early-stage dementia

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____

____

____

____

Q1.6 CARERS: Please list the **3 most important pieces** of **supporting information** that a **family member/ carer** could provide that indicates that an individual with early-stage dementia is presenting with current EDS difficulties

○ 1. ____

○ 2. ____

○ 3. ____

Q1.7 Given what you know about EDS difficulties in mild dementia, please rate how **strongly you agree or disagree** with the following statements about individuals with early-stage dementia

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
Early assessment helps **predict** future EDS difficulties	○	○	○	○	○
Early **identification** of EDS difficulties allows people to **increase control** over their symptoms	○	○	○	○	○
Early SLT input improves the **individual** with dementia's **understanding** of EDS difficulties	○	○	○	○	○
Early SLT input helps **support** family members/carer	○	○	○	○	○
Current SLT practice **supports early identification** of EDS difficulties	○	○	○	○	○
Current SLT practice **supports health promotion** for EDS	○	○	○	○	○

Q1.8 Please describe how your **current approach to assessing** people living with early-stage dementia and EDS difficulty has changed as a result of **the Covid-19 pandemic** in your setting

____

____

____

____

____

Q 1.9 Please describe how Covid-19 has **impacted** service users with early stage dementia and EDS difficulty as a result of the Covid -19 pandemic.

Q1.9 Do you think early identification of EDS difficulties in early-stage dementia is a priority for SLT?

Yes (please explain why below) ____

No (please explain why below) ____

End of Block: Practical and clinical experience

Start of Block: Reported Features

Q2 Listed are some features that have been reported in **published literature** as identifiers or predictors of EDS difficulties in individuals with early-stage dementia and mild cognitive impairment (a condition that can precede dementia). How **often do you identify** the features listed in people living with early-stage dementia who have EDS difficulties?

	Never	Rarely	Sometimes	Frequently	Always
Delayed oral transit	○	○	○	○	○
Delayed pharyngeal response	○	○	○	○	○
Reduced rinsing ability	○	○	○	○	○
Reduced sucking ability	○	○	○	○	○
Open mouth posture with reduced lip seal	○	○	○	○	○
Sarcopenia (age-related muscle loss)	○	○	○	○	○
Polypharmacy (5 or more medications)	○	○	○	○	○
Loss of executive function	○	○	○	○	○
Decreased voluntary cough	○	○	○	○	○
Weight loss	○	○	○	○	○
Reduced ability to eat and drink independently	○	○	○	○	○
Apraxia impacting on eating and drinking	○	○	○	○	○
Changes to smell	○	○	○	○	○
Changes to taste	○	○	○	○	○

Q3 Listed are some **features** that have been **reported by people living with dementia** as early features of EDS difficulties. **How often** do people with EDS and early-stage dementia tell you that they occur?

	Never	Rarely	Sometimes	Frequently	Always
Eating slowly	○	○	○	○	○
Forgetting food is in the mouth	○	○	○	○	○
Dry mouth	○	○	○	○	○
Voice changes	○	○	○	○	○
Throat tightness	○	○	○	○	○
Aversion to eating	○	○	○	○	○
Forgetting to eat or drink	○	○	○	○	○
Need for prompting to eat or drink	○	○	○	○	○
Loss of taste	○	○	○	○	○
Loss of appetite	○	○	○	○	○
Gulping	○	○	○	○	○
Coughing when eating	○	○	○	○	○
Choking	○	○	○	○	○

End of Block: Reported Features

Start of Block: Information about you

Q4.1 In which **area do you work?** If you work in more than one area please select the one in which you are based

○ England

○ Scotland

○ Northern Ireland

○ Wales

○ Other (please specify)

____

Q4.2 How **many years** have you been **working** with **people living with dementia and EDS difficulties**?

	0	4	8	12	16	20	24	28	32	36	40
EDS difficulties ()											

Q4.3 Do you work as part of a **specialist dementia assessment centre**?

☐ No

☐ Yes

Q4.4 Please estimate what **percentage** of your **caseload** that you have worked with in the past year that has been people living with **dementia and EDS difficulties**?

0 10 20 30 40 50 60 70 80 90 100

0% ()	

End of Block: Information about you