

Research Report

Dysphagia and mealtime difficulties in dementia: Speech and language therapists' practices and perspectives

Aisling Egan , Carolyn Andrews  and Anja Lowit 

School of Psychological Sciences and Health, University of Strathclyde, Glasgow, UK

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Abstract

Background: There is increasing recognition of the impact that dementia has upon swallowing and at mealtimes, and the significant effect this can have on people with dementia's health and well-being. However, there remains a paucity of evidence for assessment and intervention practices for dysphagia and mealtime difficulties. Furthermore, there is a limited understanding of how speech and language therapists (SLTs) support people with these dementia-related issues and what are the barriers and facilitators to practice. Further research is therefore needed to guide policy as well as service guideline and delivery development.

Aims: To establish the current practices of SLTs managing dementia-related dysphagia and mealtime difficulties in the UK and Republic of Ireland (ROI), and to establish their opinions and experiences of what challenges or supports to practice they have encountered.

Methods & Procedures: An anonymous, cross-sectional web-based survey was developed and distributed to SLTs working in the UK and ROI. Respondents completed a questionnaire that consisted of open and closed questions across nine topic areas. Closed responses were evaluated using descriptive statistics; open-ended questions were analysed using conventional content analysis.

Outcomes & Results: A total of 310 people accessed the survey, and 125 respondents completed it fully. While respondents agreed on their role in dysphagia management, they varied in their views on the extent of their role in managing mealtime difficulties. Additionally, their self-rated knowledge of mealtime difficulties in dementia was lower than their dysphagia knowledge. The respondents predominantly based their management decisions on their clinical experience of working with people with dementia. They primarily used compensatory strategies and frequently cited the need for family and care staff training. Respondents also highlighted barriers to effective management and training provision such as inefficient referral systems, a lack of carer knowledge and lack of SLT resources.

Conclusions & Implications: The results provide valuable insight into the issues facing SLTs practising in this area. The SLTs surveyed considered dysphagia a core part of their role when supporting people with dementia; however, respondents' views on mealtime difficulties varied. This highlights the need to establish consensus guidelines on the SLT's role in order to avoid variations in service delivery that could negatively impact the health and well-being of people with dementia. Moreover, further research to develop efficient and effective training for care staff supporting mealtime difficulties and dysphagia is essential.

Keywords: dementia, dysphagia, mealtime difficulties, speech and language therapy, swallowing.

What this paper adds

What is already known on the subject

- Research indicates that people with dementia develop dysphagia and mealtime difficulties as dementia progresses. SLTs often manage these, but there is no research on the effective assessment and management procedures, or guidance on best practice.

Address correspondence to: Aisling Egan, School of Psychological Sciences and Health, University of Strathclyde, Graham Hills Building, 40 George Street, Glasgow G1 1QE, UK; e-mail: aisling.egan@strath.ac.uk

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What this paper adds to existing knowledge

- This paper provides an understanding of the variation in practice across the UK and ROI. Respondents described barriers to delivering an effective service and frequently linked these to the SLTs' resources as well as service constraints.

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

- These findings support the need for future research to develop guidelines for SLT practice in this area. They also support the need to examine resource allocation and workforce management to enable SLTs to manage dementia-related dysphagia and mealtime difficulties effectively.

Introduction

Recent figures estimate that around 850,000 people are living with dementia in the UK (Alzheimer's Society 2017). 'Dementia' is an umbrella term covering a range of neurodegenerative pathologies and is diagnosed when there is a significant impairment in at least one cognitive domain such as language, memory, visuospatial function, or executive function (American Psychiatric Association 2013). Dementia is also associated with neurological changes and movement disorders (Barbosa *et al.* 2016), both of which can impact on the swallow. As a result, people with dementia require support managing their activities of daily living, preserving their health and well-being, and maintaining their quality of life.

Dysphagia is 'a swallowing disorder usually resulting from a neurological or physical impairment of the oral, pharyngeal or oesophageal mechanisms' (Royal College of Speech and Language Therapists (RCSLT) 2014a: 3). It may result in weight loss, malnutrition, a decline in health status, aspiration pneumonia, and death (Carrión *et al.* 2015). More generally, dysphagia in the elderly carries a considerable economic cost. Westmark *et al.* (2018) reported an increase in care costs of €3677 in the acute hospital and €6192 in social care settings for people with dysphagia compared with those without, and concomitant dysphagia in dementia is associated with increased length and cost of hospital stay (Paranji *et al.* 2017). Changes to eating and drinking in dementia may also lead to increased caregiver stress (Papachristou *et al.* 2013) and reduce opportunities for socialising (Gillies 2012).

The speech and language therapist's (SLT) role in managing dysphagia to mitigate these risks varies depending on the cause. However, it typically involves the assessment and diagnosis of oropharyngeal dysphagia, the identification of aspiration, and implementing a management plan (RCSLT 2014a). Aspiration occurs when material from the oropharyngeal or gastrointestinal cavities enters the airway and lungs. If this aspirated material is pathogenic, an infection, known

as aspiration pneumonia, can develop, though not all aspiration leads to pneumonia (Carrión *et al.* 2015). The risk of aspiration pneumonia is increased by bacterial colonisation of the oral cavity due to poor oral hygiene (DiBardino and Wunderink 2015). Therefore, SLT assessment must examine a range of factors using instrumental or non-instrumental assessments. Non-instrumental assessment, also called a clinical bedside examination (CBE), integrates data on an individual's medical and social history and their presenting complaint with the findings of investigations of the structure and function of oral and pharyngeal musculature, as well as observations of food or fluid swallowing trials (Pettigrew and O'Toole 2007).

In many cases, the CBE provides sufficient information for the SLT to plan management; however, as it cannot diagnose aspiration an instrumental assessment may be necessary. The most commonly used instrumental assessments are videofluoroscopic swallow studies (VFSS) and fiberoptic endoscopic evaluations of swallowing (FEES). These allow the therapist to visualise directly the anatomical structures and physiology of the swallow, identify breakdowns in the swallow, and to confirm whether aspiration is occurring (Cichero and Langmore 2006).

Following assessment, the SLT determines an appropriate management approach, usually dichotomised into rehabilitation and compensation. Rehabilitation aims to restore the functionality of the swallow through targeted exercises, while compensation uses strategies to protect the airway during eating and drinking (Cichero 2006). Compensatory strategies provide a scaffold to a safer swallow by reducing the complexity of the swallowing task (Huckabee and Hughes 2013). Some strategies require direct input from the person with dysphagia, such as manipulating their posture or head placement while swallowing to redirect the bolus safely (Cichero 2006). Other strategies, such as modifying food texture and fluid viscosity, do not require any direct action or cognitive effort on the part of the person with dysphagia (Speyer 2017). However, while

several studies have looked at SLT dysphagia management practices (e.g., Pettigrew and O'Toole 2007), little information is available about how SLTs manage dementia-related dysphagia specifically.

As dementia progresses, cognitive challenges mean that many direct interventions and compensatory strategies are considered inappropriate or limited in scope (Alagiakrishnan *et al.* 2013, Speyer 2017). Therefore, the goals of management in dementia are typically maintenance of function and prevention of adverse outcomes (RCSLT 2014b), and management often focuses on diet modification (Speyer 2017). Some recent discussion, however, has questioned the appropriateness of this technique. In their Cochrane review, Flynn *et al.* (2018) argue that while fluid viscosity modifications may reduce a person with dementia's short-term risk of aspiration, they may also lead to adverse outcomes in the longer term, namely respiratory health and nutrition and hydration status complications. Long-term care residents on texture-modified diets also have an increased risk of malnutrition, particularly if they have concomitant feeding or cognitive issues (Vucea *et al.* 2018).

As dementia is a progressive condition, it is also pertinent for clinicians to consider at what stage of dementia intervention for swallowing should be introduced. Typically, the SLT's role in dysphagia management is associated with dementia's later stages (RCSLT 2014b). However, research evidence suggests the presence of swallow changes in the early stages. Humbert *et al.* (2010) demonstrated early changes to the cortical control of swallowing and reduced hyolaryngeal elevation in Alzheimer's disease. Another factor that impacts the management approach is the unique dysphagia profile associated with each type of dementia (Alagiakrishnan *et al.* 2013). For instance, Suh *et al.* (2009) found that dysphagia in Alzheimer's disease is a result of sensory impairments, while in vascular dementia it is associated with motor impairment. They also found that silent aspiration was more likely to occur in vascular dementia.

Accordingly, managing eating and drinking in dementia goes beyond establishing a functional swallow, with Steele *et al.* (1997) among the first to stress the importance of considering broader mealtime issues. People with mealtime difficulties are those who 'require additional support and/or intervention with their mealtime skills [...] due to motor, sensory, cognitive, emotional, or behavioural issues, as well as [...] difficulties during mealtimes relating to an impoverished mealtime environment' (Speech Pathology Australia 2015: 5). In dementia, cognitive changes can impact on people's ability to anticipate, prepare for and engage at mealtimes including difficulties initiating eating, maintaining attention, or recognising food or cutlery (Chang

and Roberts 2008, Lee and Song 2015). Many people with dementia are, therefore, reliant on caregivers for assistance at mealtimes. Inappropriate or no support to eat can increase the risk of aspiration, leading to the development of aspiration pneumonia (Langmore *et al.* 2002). Despite recognition of the presence of mealtime difficulties in dementia, the evidence base for their management is limited, as highlighted by a recent Cochrane review (Herke *et al.* 2018). Their analysis of nine studies of environmental and behavioural strategies to increase food and drink intake among people with dementia could not provide a consensus on the best approach. One of these studies, an intervention for self-feeding skills, illustrated the potential of direct interventions that target preserved cognitive channels, namely the relatively preserved non-declarative memory system (Wu *et al.* 2014). In this study, a combination of Montessori-based activities, where activities are broken down into repeated sequential procedures, and spaced retrieval therapy (SRT), where task-related information recall requests are made at varying time intervals, resulted in a reduction in eating difficulties and an increase in the amount of food consumed at meals at 6-month follow-up. Though Herke *et al.* (2018) identified some issues with the study's methodological rigour, it suggests at least the potential for new direct approaches to compensation and rehabilitation of dementia-related dysphagia and mealtime difficulties.

Case-finding is another issue impacting on effective management of both dysphagia and mealtime difficulties. Case-finding refers to the identification of new or worsening cases by relevant persons, for example, care home staff, and is fundamental to timely referral to SLT services. However, appropriate tools that are 'simple, quick, easy to use and sensitive enough to detect changes in risk' for mealtime difficulties and dysphagia are currently not readily available to referring agents (Niezgoda *et al.* 2014: 1). Park *et al.* (2015) identified two swallow screens as appropriate for use in a care home environment, but these were developed for post-stroke dysphagia, not dementia. The best-known mealtime screen, the Edinburgh Feeding Evaluation in Dementia Questionnaire (EdFED-Q; Watson 1994), is specific to dementia but does not consider dysphagia. This lack of appropriate and comprehensive screening tools could lead to new cases not being referred early enough or high numbers of inappropriate referrals.

The significant and overlapping consequences of dysphagia and mealtime difficulties, the pervasiveness of these challenges and the impact they have on the quality of life, well-being, and mortality of people with dementia mean that effective management is essential. However, there is a limited and conflicting

evidence base for intervention. Moreover, while the position papers of professional bodies in the UK and Republic of Ireland (ROI) advocate strongly for SLT involvement, these guidelines do not detail the exact nature of the SLT's role at different stages and in various types of dementia or provide suggested models of care (RCSLT 2014b, Irish Association of Speech and Language Therapists (IASLT) 2016). Therefore, in order to guide future policy development and effective service delivery planning for people with dementia, there is a need for more information on current practices. This study aimed to identify current SLT working practices for managing dementia-related dysphagia and meal-time difficulties in the UK and ROI and to establish SLTs' opinions and experiences of the challenges and facilitators to practice they encounter.

Method

The study used an anonymous, cross-sectional survey design with a targeted sampling strategy, i.e. purposive and snowball sampling, to access SLTs with the necessary background and experience. Purposive sampling is a sample selected for its relevance to the study, and snowball sampling encourages respondents to recruit colleagues with relevant experiences (Petty *et al.* 2012). Inclusion criteria for the targeted sample were SLTs working with people with dementia and dysphagia currently or within the last 5 years in the UK or ROI, with no minimum experience specified. Sampling across the UK and ROI was considered appropriate as their healthcare systems and SLT education programmes are comparable.

Materials

Survey items were developed based on dementia, meal-time, and dysphagia literature, the authors' experiences of supporting people with dementia, and clinical discussion with SLT colleagues based in the UK's National Health Service (NHS). An online questionnaire, created using Qualtrics software (Qualtrics, Provo, UT, USA), allowed anonymous response collection, provided secure storage of responses, and had an accessible interface for respondents. The survey opened with an overview of the study, which enabled respondents to identify if this research was relevant to them, followed by the participant information sheet and the consent form. Consenting participants then viewed the dysphagia and mealtime difficulties definitions used in this study (as outlined in the introduction). The questionnaire consisted of nine sections, summarised in table 1, which aimed to cover all aspects of client contact. Each section included open and closed questions to elicit information on facts, opinions, beliefs and

Table 1. Questionnaire sections

1.	Demographics and caseload information and scope of practice
2.	Referral processes
3.	Assessment
4.	Management
5.	Training and education of carers
6.	Dementia type and stage
7.	Stakeholder liaison and fidelity to recommendations
8.	Multidisciplinary team (MDT) working
9.	Final thoughts

judgements, and behaviours (Gillham 2007). Three SLTs who met the criteria for study inclusion piloted the survey, and questions were clarified or adapted accordingly.

Data collection

The University of Strathclyde granted full ethical approval for the study. A link to the questionnaire on the Qualtrics website was distributed to professional bodies, social media, professional publications, and relevant special interest groups (ROI) and clinical excellence networks (UK) for dissemination. The survey was available online for 3 months; 310 people accessed it, and 125 SLTs completed it. The response rate cannot be determined as there is no definitive information available of the number of SLTs working with adults with dementia and dysphagia.

Analysis

Microsoft Excel was used to conduct a descriptive analysis of all closed question responses. Tests of association were completed using IBM SPSS Statistics for Windows, v.25.0. Chi-square and Fisher's exact tests analysed the associations between responses.

The study used conventional content analysis to interpret open-ended responses. This inductive approach generates themes directly from the data, and analysis involved data familiarisation, followed by data coding, that is, tagging units of meaning with a meaningful label or code, and then the categorisation of similar codes into descriptive themes (Erlingsson and Brysiewicz 2017). The first author completed all analyses. Single-researcher analysis was conducted in line with the researcher's ontological and epistemological position (Denkins and Lincoln 2018). Multi-researcher data analysis attempts to negate researcher subjectivity, but as a result it risks dilution of theme complexity and imitative themes (Terry *et al.* 2017). In order to ensure rigour in analysis, Tracy's (2010) criteria were followed. In some instances, if there were insufficient data to generate themes the responses were used descriptively.

Results

Respondent demographics, caseload information and scope of practice

The respondents worked primarily in the UK (81.6%, $n = 102$), and their experience working as SLTs and managing dysphagia was evenly spread. More than two-thirds of most respondents' caseloads (71.2%, $n = 89$) included dysphagia management, though 50% or less of this was dementia-related. Only 12.8% ($n = 16$) of respondents worked exclusively in one workplace, primarily acute hospital inpatient services ($n = 12$). Most respondents reported multiple workplaces, with the majority working in two (29.6%, $n = 37$), three (21.6%, $n = 27$) or more settings (36.0%, $n = 45$). For comparative analyses, these were collapsed into three categories: acute inpatients, non-acute inpatients and outpatients, and mixed settings. Table 2 provides a breakdown of respondents' demographic information and shows the settings where respondents worked most frequently.

The respondents ($n = 118$) provided their thoughts on managing mealtime difficulties and most considered these within their scope of practice (78.0%, $n = 92$). They described their role as providing self-management training and education to nursing and care staff and families (18.6%, $n = 22$), recommending compensatory strategies (17.8%, $n = 21$), offering general feeding and mealtime advice (14.4%, $n = 17$), and recommending environmental changes, such as reducing noise and distractions at meals (14.4%, $n = 17$). In some cases, respondents described making these recommendations without assessing the person with dementia (7.6%, $n = 9$). Several respondents considered themselves uniquely skilled in managing mealtime difficulties due to the breadth and scope of their training (12.7%, $n = 15$). However, the optimal system for managing mealtime difficulties was within a multidisciplinary team (MDT) (20.3%, $n = 24$). Factors that indicated the need for SLT involvement were the potential for mealtime difficulties to contribute to an unsafe swallow (14.4%, $n = 17$), and the impact of communication on the mealtime (12.7%, $n = 15$). SLT intervention was considered essential to maintaining people with dementia's quality of life (10.2%, $n = 12$).

Around one-fifth of respondents (22.0%, $n = 26$), however, had reservations about mealtime management as they did not have the resource to extend their service. Furthermore, nine respondents (7.6%) did not consider mealtime difficulties to be part of their role unless dysphagia was also present.

Table 2. Respondents' demographic information ($n = 125$)

Demographics	%	Response count
<i>Country of work</i>		
England	40.8%	51
Scotland	31.2%	39
Wales	8.0%	10
Northern Ireland	1.6%	2
Republic of Ireland	18.4%	23
<i>Geographical area of work</i>		
Urban	51.2%	64
Rural	18.4%	23
Suburban	8.8%	11
Mixed locations	21.6%	27
<i>Employer type</i>		
Public sector (e.g., NHS/HSE)	87.2%	109
Public sector and private practice	4.8%	6
Private practice	3.2%	4
Charity/voluntary sector	3.2%	4
Private practice and charity/voluntary sector	0.8%	1
Private practice and higher/further education	0.8%	1
<i>Years working as an SLT</i>		
< 1	4.8%	6
1–5	28.0%	35
6–10	20.0%	25
11–15	18.4%	23
≥ 16	28.8%	36
<i>Years managing dysphagia</i>		
< 1	5.6%	7
1–5	28.8%	36
6–10	26.4%	33
11–15	15.2%	19
≥ 16	23.2%	29
<i>Workplace setting</i>		
Care home	68.8%	86
Client's own home	60.8%	76
Acute inpatients	54.4%	68
Rehabilitation facilities	30.4%	38
Acute outpatient clinics	29.6%	37
Non-acute or long-stay inpatients	28.8%	36
Psychiatric hospital	24.8%	31
Community clinic	21.6%	27
Non-acute outpatient clinic	11.2%	14

Referral processes

Across settings ($n = 125$), nurses were the most frequent source of referrals for dysphagia and mealtime difficulties (76.0%, $n = 95$). In order to access SLT

($n = 123$), most respondents required referral agents to complete a generic form developed by their service (48.0%, $n = 59$) or a dysphagia screening tool (35.8%, $n = 44$). Around 10% (9.8%, $n = 12$) of respondents reported that they used a dementia-specific screening tool or referral form, but did not name it. Despite the reservations described in the above responses, most services ($n = 125$) accepted referrals for dementia-related mealtime difficulties (92.8%, $n = 116$).

Inappropriate referrals were common ($n = 112$), and referrals were most commonly rejected for being outside the scope of SLT practice, for instance, oesophageal issues, issues with dentition, or weight loss not linked to dysphagia (28.6%, $n = 32$). Other reasons included referrals that did not indicate the presence of dysphagia (19.6%, $n = 22$) or mealtime difficulties (4.5%, $n = 5$), the presence of behavioural issues such as food refusal (18.8%, $n = 21$), or if a patient was not fit for assessment, due to being at the end of life (12.5%, $n = 14$) or having reduced alertness (12.5%, $n = 14$). Several respondents would reject a referral if an appropriate management plan was already in place (8.9%, $n = 10$), if there had been no change in clinical presentation since their last input (15.2%, $n = 17$), or if recommendations were in place but not being followed (9.8%, $n = 11$).

Service protocols ($n = 123$) for the length of time between receiving a referral and assessment varied between settings. Respondents working in acute inpatient settings reported the shortest wait-time of 2 days (26.8%, $n = 33$). Wait-times in community and outpatient settings, however, ranged from two days to over 12 weeks, with two weeks being the most common (18.7%, $n = 23$). Just over one-third of respondents (35.8%, $n = 44$) reported using prioritisation to stream referrals. Urgent cases in acute inpatient settings were seen within 24 or 48 hours, but in the community, it was within two weeks. Overall, 87.0% ($n = 107$) of these respondents were able to meet their service's waiting list criteria. The central theme of the free-text comments ($n = 33$) was that referral processes were inefficient, and referrals often lacked essential information which was costly to their time.

Assessment

Figure 1 shows the items that respondents typically included in their assessments, with some elaborating on factors that influenced their inclusion ($n = 121$). Clinical experience was the primary influence (53.7%, $n = 65$), followed by client factors (e.g., alertness, stress and distress), and the available evidence. Factors that were less influential on respondents' decision-making were service requirements and the availability of effective interventions.

Most respondents had access to at least one form of instrumental assessment, either on- or off-site (92.0%, $n = 115$), most commonly VFSS (92.0%, $n = 115$). Those who expanded on their views on the use of instrumental assessments ($n = 124$) reported that decisions to recommend these assessments depended primarily on the person with dementia's ability to follow assessment instructions (87.9%, $n = 109$). The likely impact of the assessment on a person's well-being (85.5%, $n = 106$), the relevance to their clinical presentation (59.7%, $n = 74$), and their ability to follow recommendations (54.0%, $n = 67$) also influenced the decision. Availability of appointments was a further factor for respondents with on-site (19.4%, $n = 24$) and off-site access (12.9%, $n = 16$). The respondents with off-site access also considered the distance (16.9%, $n = 21$) and the travelling time (12.9%, $n = 16$) to attend appointments. Just under half held the view that an instrumental assessment was unlikely to change the management plan for people with dementia (43.5%, $n = 54$).

Many respondents ($n = 105$) also provided text comments, primarily referring to VFSS. The primary themes reflected the interaction between respondents' experience and a person-centred approach. Respondents indicated that instrumental assessment referral decisions should be made on a case-by-case basis (36.2%, $n = 38$) and that VFSS is potentially distressing, frightening, or even harmful to the well-being of the person with dementia (17.1%, $n = 18$). The decontextualised nature of a VFSS and the need to consider the person with dementia in a broader context was another factor in respondents' decision not to recommend them (15.2%, $n = 16$). Three respondents specified that FEES was an inappropriate assessment for people with dementia as it is 'intrusive and does not yield the same information as VFU [*sic*, VFSS]'

Management

Similar to the choice of assessment methods, clinical experience and the available evidence were the primary drivers of clinical decision-making on management strategies. The most commonly recommended strategies were indirect or compensatory, including advising caregivers and family (100%, $n = 125$), recommending changes to food texture and fluid viscosity (both 99.2%, $n = 124$), onward referral, for example, to other allied health professionals (AHPs) (98.4%, $n = 123$), reducing distractions at mealtimes (96.8%, $n = 121$), changing quantities of food provided (e.g., finger foods or smaller meals; 95.2%, $n = 119$), recommending mealtime supervision (94.4%, $n = 118$), advising adapted utensils (93.6%, $n = 117$), making postural

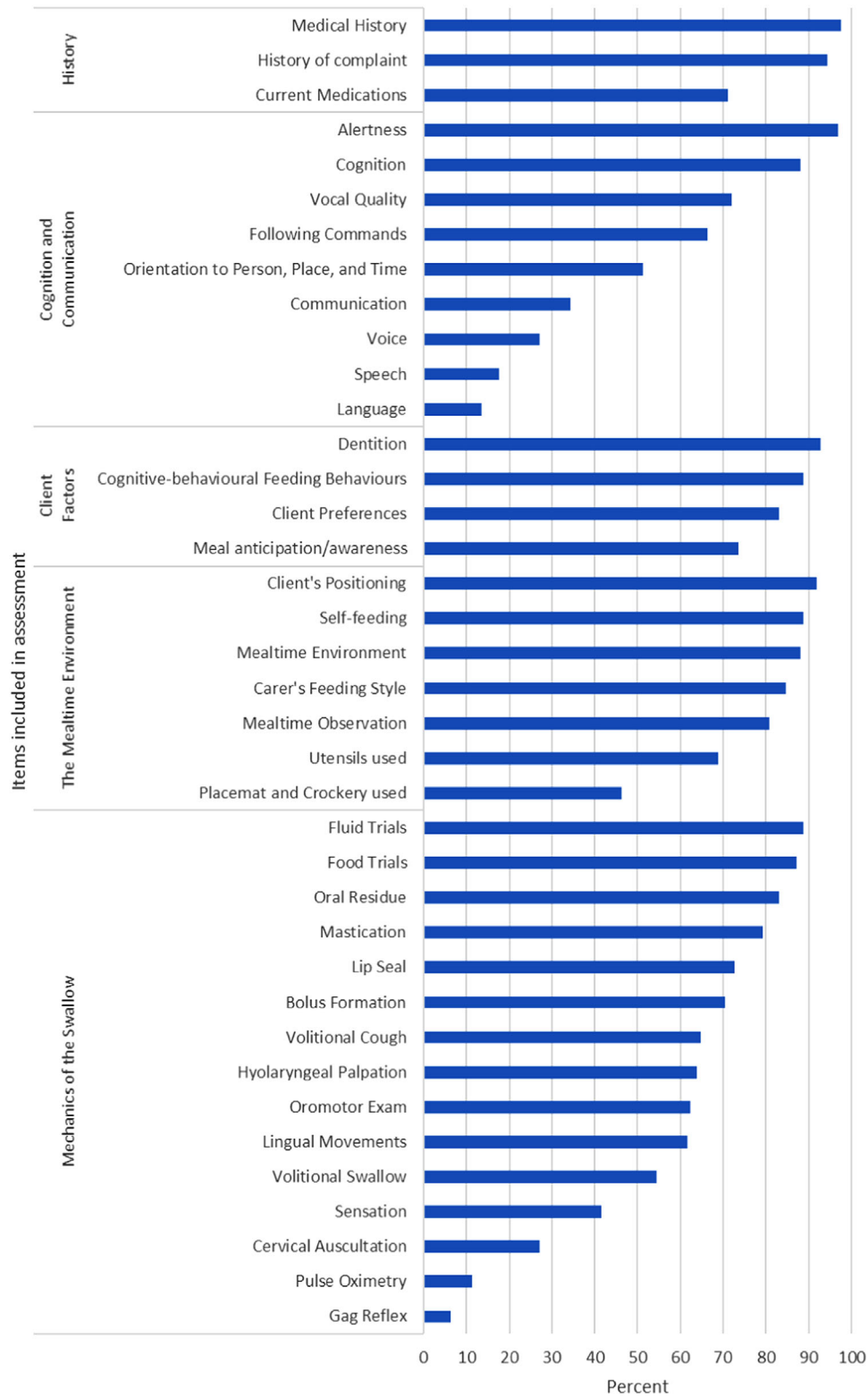


Figure 1. Items included in the assessment ($n = 125$). [Colour figure can be viewed at wileyonlinelibrary.com]

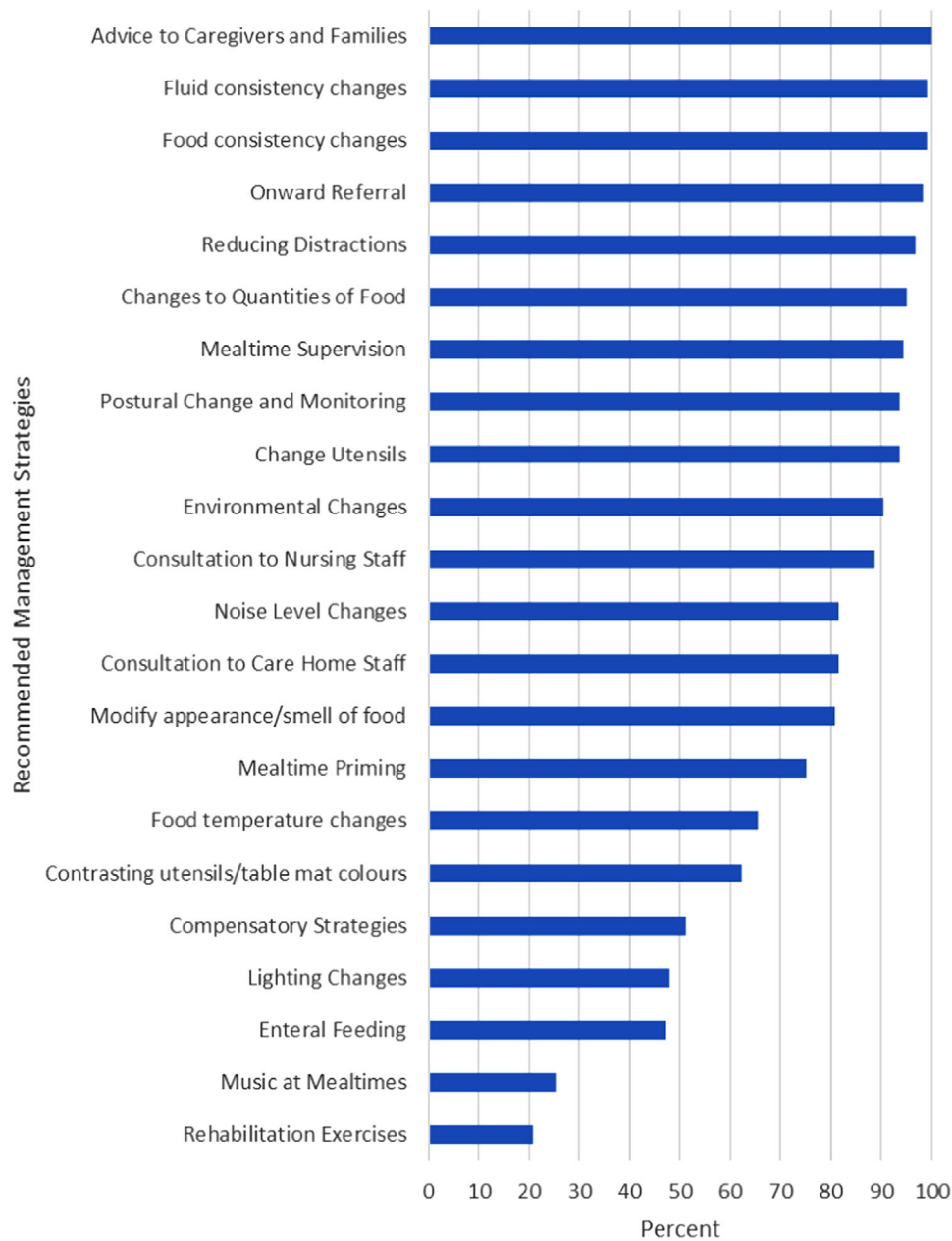


Figure 2. Recommended management strategies ($n = 125$). [Colour figure can be viewed at wileyonlinelibrary.com]

changes (e.g., seating position) (93.6%, $n = 117$), and recommending changes to the mealtime environment (90.4%, $n = 113$). The least recommended strategy was rehabilitation exercises (20.8%, $n = 26$) as respondents were concerned about the person with dementia's cognitive skills, and consequently their ability to follow directions. For enteral feeding, respondents divided equally between those who recommended this strategy (47.2%, $n = 59$), and those who did not (48.8%, $n = 61$). However, comments revealed that both groups considered it only in individual, exceptional cases. Figure 2 outlines the recommended strategies and their frequency of use.

When asked about the role of other staff in making changes to food texture ($n = 124$), around half of respondents (49.2%, $n = 61$) thought that nursing and care home staff should be able to do this without SLT input (No: 39.5%, $n = 49$; I don't know: 11.3%, $n = 14$). However, just 26.6% ($n = 33$) thought staff should make fluid viscosity modifications without SLT input (No: 60.5%, $n = 75$; I don't know: 12.1%, $n = 15$). Accordingly, most services did not allow nursing or care home staff to modify food (55.6%, $n = 69$) or fluids (60.5%, $n = 75$) without SLT input. Where this was possible ($n = 51$), it was usually the

responsibility of nursing (64.7%, $n = 33$) or medical staff (37.3%, $n = 19$). Most respondents ($n = 97$) again elaborated in open-ended comments. Around half of these respondents thought it was appropriate for others to make changes to ensure a person's safety while waiting on an SLT assessment (43.3%, $n = 42$). Furthermore, they felt that nursing and care home staff should be able to use 'common-sense' and their judgement to modify diets for patient comfort, for example, choosing softer diets for people with dentition issues (27.8%, $n = 27$). Some respondents (18.6%, $n = 18$) thought trained nursing and care home staff could make these changes, but only within the limits of their training (9.3%, $n = 9$). Respondents also felt that there should be a cap on the extent of changes made without SLT input (11.3%, $n = 11$). Where staff could make such changes, some respondents felt that follow-up and review mechanisms were needed to ensure that they did not remain in place inappropriately (10.3%, $n = 10$). They noted that without SLT follow-up, there was the risk of unnecessary and inappropriate changes to diet and fluid recommendations (19.6%, $n = 19$), which in turn could have health and quality of life implications (11.3%, $n = 11$). A further group of respondents were apprehensive about other staff making fluid viscosity changes (12.4%, $n = 12$), as they had broader concerns about the appropriateness and efficacy of using thickener. These respondents felt that the decision to recommend modified fluids required a more nuanced approach than nursing and care home staff training in dysphagia allowed. There was also a view that only appropriately trained SLTs (11.3%, $n = 11$) had the necessary knowledge and experience to balance all factors when making recommendations.

Training and education of caregivers

All respondents ($n = 125$) considered it important that caregivers had a basic knowledge of dementia-related dysphagia and mealtime difficulties, but around one-fifth (21.6%, $n = 27$) did not provide training. The respondents who offered training ($n = 98$) indicated that they did so to care home staff (67.3%, $n = 66$), family carers (66.3%, $n = 65$), hospital nurses (49.0%, $n = 48$), in-home paid carers (48.0%, $n = 47$), and hospital doctors (16.3%, $n = 16$). Information and training courses were provided to general practitioners by just 2.0% ($n = 2$) of respondents, and to members of the MDT by 7.1% ($n = 7$). Nursing and care home staff and management factors played a large role in respondents' perceptions of how easy or difficult training provision was. Motivated staff (79.6%, $n = 78$) and family members (49.0%, $n = 48$), as well as supportive ward or nursing managers (48.0%, $n = 47$) were considered facilitators to training. However, 51.0% of re-

spondents ($n = 50$) named high workloads and resource limitations in service provision as impeding their ability to provide training. Other barriers included care staff availability (88.8%, $n = 87$), as well as high care staff turnover (81.6%, $n = 80$). Almost half felt that training was not a priority for care home managers (46.9%, $n = 46$) and staff (44.9%, $n = 44$), with just 35.7% ($n = 35$) reporting that dysphagia training was mandatory for care staff. Free-text responses ($n = 23$) highlighted that respondents felt that the onus was on them to develop good relationships with care staff and management to encourage them to engage with training (21.7%, $n = 5$).

Most respondents ($n = 78$) reported a wide variation in the length of training provided, from less than one hour (7.7%, $n = 6$) to a full day (7.7%, $n = 6$), with the most common length being between one and two hours (52.6%, $n = 41$). Training sessions ($n = 98$) commonly included explanations of dysphagia (93.9%, $n = 92$), signs of aspiration (94.9%, $n = 93$) and indications to prompt referral to SLT (91.8%, $n = 90$), as well as general strategies to manage dysphagia (91.8%, $n = 90$), modify diets (93.9%, $n = 92$), modify fluids (88.8%, $n = 87$), and how to make environmental (88.8%, $n = 87$) and behavioural modifications (70.4%, $n = 69$). Most respondents (73.5%, $n = 72$) included explanations of mealtime difficulties in dementia; however, just 41.8% ($n = 41$) included explanations of dysphagia characteristics specifically associated with dementia. The follow-up to training varied as well; 38.8% ($n = 38$) of respondents did not provide any follow-up, 32.7% ($n = 32$) carried out pre- and post-training assessments, and 20.4% ($n = 20$) carried out mealtime audits of staff performance.

Additional free-text comments ($n = 42$) highlighted indicators of training working well (23.8%, $n = 10$) with comments such as: 'Increase in confidence and appropriate creativity regularly seen and reported after the course' and 'In areas where I have had to fight to do one I often find staff ask for more.' However, respondents also stressed the need to adapt training for care staff to account for their limited time (28.6%, $n = 12$). Some of these respondents described successfully piloting new approaches, for example, delivering training in bite-size blocks and conducting pre-training visits to tailor information to identified needs. However, they faced barriers in fully implementing this, for example: 'this seemed a more effective way of working, but we could not justify the staffing/time commitment to role [*sic*] this out across the region'.

Dementia type and stage

The availability of information on dementia type and stage varied across all respondents ($n = 125$). Some

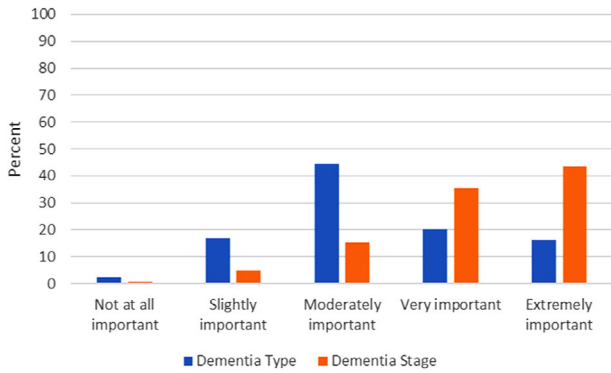


Figure 3. Importance of tailoring management to dementia type and stage ($n = 124$). [Colour figure can be viewed at wileyonlinelibrary.com]

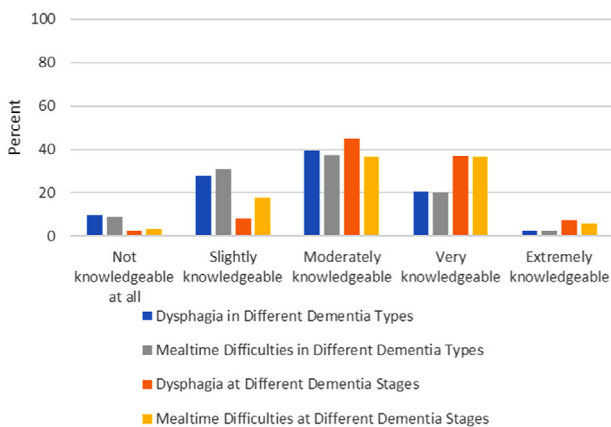


Figure 4. Self-rated knowledge of difficulties in different dementia types and stages ($n = 123$). [Colour figure can be viewed at wileyonlinelibrary.com]

had access to information on both (36.8%, $n = 46$), whereas others could only access information on type (26.4%, $n = 33$) or stage (7.2%, $n = 9$). Other respondents reported no, or sporadic, access to this information (29.6%, $n = 37$).

Views on the importance of tailoring management to dementia type and stage differed ($n = 124$). Most respondents (79.0%, $n = 98$) considered it very or extremely important to tailor management to the stage, whereas only 36.3% ($n = 45$) felt the same about the type (figure 3).

These results mirrored the self-reported knowledge of these factors (figure 4). That is, respondents viewed themselves as more knowledgeable about variations in presentation across different stages than types of dementia. Furthermore, respondents felt more knowledgeable about dysphagia than mealtime difficulties across dementia stages, whereas for dementia type, these differences were absent. Chi-square tests identified a significant association with small effect sizes between the respondents' views on how important they consid-

ered tailoring management to dementia type and their knowledge of dysphagia ($\chi^2(4) = 21.34$, $p < 0.001$ (two-tailed), $\phi_c = 0.30$) and mealtime difficulties in dementia types ($\chi^2(4) = 18.39$, $p = 0.001$ (two-tailed), $\phi_c = 0.27$). This outcome indicates that SLTs who rated their knowledge of dysphagia and mealtime difficulties as moderate or higher were more likely to consider it important to tailor the intervention to dementia type. When investigating the relationship between knowledge of the dysphagia and mealtime difficulties in different dementia stages and the importance of tailoring management to dementia stage, the Fisher's exact test showed a significant association for knowledge of dysphagia ($p = 0.006$), but not mealtime difficulties ($p = 0.281$).

A subset of respondents ($n = 64$) described their methods of continuing professional development (CPD) which most commonly included attending professional study days (29.7%, $n = 19$), in-service talks from colleagues (9.4%, $n = 6$), or general dementia training (e.g., dementia champion training or other general courses, both 4.7%, $n = 3$). None of the respondents reported attending training specific to dementia and dysphagia or mealtime difficulties.

Finally, respondents provided a list of resources they had found useful in their clinical practice (table 3). The respondents described resources in a variety of formats, for example, books, videos, and mobile applications. They used these resources for their own learning, to communicate with people with dementia and to share information with carers.

Stakeholder liaison and fidelity to recommendations

The respondents ($n = 122$) identified challenges liaising with, and providing feedback to, key stakeholders involved in caring for people with dementia, such as family members, care staff or medical colleagues. A high percentage reported issues liaising with the person with dementia (83.6%, $n = 102$), citing their cognitive ability (42.2%, $n = 43$), ability to comprehend the feedback (40.2%, $n = 41$), and ability to retain and act on this information (19.6%, $n = 20$). Providing feedback to the client's family was a challenge for 57.4% ($n = 70$), with the availability of family members (34.3%, $n = 24$) cited as a common issue. Liaison with care home staff was problematic for 45.9% ($n = 56$), mainly due to staff turnover and availability issues (32.1%, $n = 18$). The dissemination of information amongst care home staff was also a concern for respondents (23.2%, $n = 13$). They described worries such as 'not always sure that feedback is interpreted and/or passed on the way I intend it to be' and 'difficulty with information being disseminated to all care home staff who need it'. Liaison with doctors was challenging for 36.1% ($n = 44$) due

Table 3. Clinical resources ($n = 58$)

Resource	%	Response count
<i>Resources used by SLTs</i>		
Book: Kindell, J., 2002, <i>Feeding and Swallowing Disorders in Dementia</i> . Speechmark	32.8%	19
Information guide: National Patient Safety Agency, <i>Dysphagia Care Plans</i>	10.3%	6
CPD: Accessing journal articles and evidence-based practice information	5.2%	3
<i>Resources used with people with dementia</i>		
Toolkit: <i>Talking Mats</i> (available at https://www.talkingmats.com/)	3.4%	2
<i>Resources for carers</i>		
Information guide: NHS Dumfries and Galloway, <i>The Communication and Mealtimes Toolkit</i> (available at http://www.nhsdgs.scot.nhs.uk/Departments_and_Services/Speech_and_Language_Therapy/Adult_SLT/Documents/Communication_Mealtimes_Toolkit_for_Dementia_2013.pdf)	22.4%	13
Video: Watchman, K., Wilkinson, H., and Hare, P., 2010, <i>Supporting People with Learning Disabilities and Dementia Training Pack: A Training Pack for Support Staff</i> (based on the Supporting Derek film and guide) (available at https://www.pavpub.com/learning-disability/supporting-people-with-learning-disabilities-and-dementia-training-pack)	8.6%	5
Leaflet: NHS/own information leaflets	6.9%	4
Video: Typical and disordered swallowing	6.9%	4
Information guide: The Caroline Walker Trust, <i>Eating Well: Supporting Older People and Older People with Dementia</i> (available at https://www.cwt.org.uk/wp-content/uploads/2014/07/EW-Old-Dementia-Practical-Resource.pdf)	5.2%	3
CPD: E-learning modules	5.2%	3
Information guide: <i>Dementia Care—Support with Eating and Drinking</i> (available at http://www.dementiacarers.co.uk/documents/dementia-eatinganddrinking.pdf)	3.4%	2
Apps: Dysphagia apps	3.4%	2

to difficulties with access to doctors, their availability and their degree of engagement. Still, a smaller number of respondents reported an established system of feedback to the medical team that was working well (4.9%, $n = 6$).

Other difficulties ($n = 125$) included clients or caregivers not following recommendations (93.6%, $n = 117$). Close to half the respondents who commented further ($n = 103$) identified issues with following diet and fluid modification recommendations (43.7%, $n = 45$). They attributed this to a lack of understanding of the rationale for and the scope of the recommendations (46.6%, $n = 48$). Other reasons for not following recommendations included the person with dementia (20.4%, $n = 21$) or the family or paid carer (9.7%, $n = 10$) disliking the modified texture. Many of these respondents viewed training and education as the best strategy to improve adherence to their advice (52.4%, $n = 54$), followed by being available for and involving stakeholders in discussions (31.1%, $n = 32$). They also described reinforcing ethical and legal ramifications for care home and nursing staff and management to increase their fidelity to the recommendations (14.6%, $n = 15$). For example, they reminded care home staff of their regulators' care standards (e.g., the Care Quality Commission in England), their obligations to residents under these, and the consequences of not meeting these standards. Compromising with people with dementia

and their family members in order to tailor management to individuals was also viewed as an essential step (13.6%, $n = 14$). As one respondent described: 'I speak with clients and carers to help them to make an informed decision about their care, not necessarily to increase compliance but to ensure they make the decision that is right for them with the information they need.'

Multidisciplinary team (MDT) working

Most respondents (81.6%, $n = 102$) reported working as part of an MDT. Of those who described their team ($n = 95$), the most common team members were occupational therapists (89.5%, $n = 85$), physiotherapists (78.9%, $n = 75$), nursing staff (78.9%, $n = 75$) and dietitians (75.8%, $n = 72$). When asked ($n = 92$) about who from the team they worked most closely with, they identified dietetics and nursing (both 62.0%, $n = 57$). Many respondents ($n = 119$) considered being part of the MDT as being extremely important (65.5%, $n = 78$) or very important (24.4%, $n = 29$).

Final thoughts

In the final section, respondents provided additional thoughts on barriers ($n = 87$) and facilitators ($n = 81$) to their practice. These thoughts echoed the issues raised earlier in the questionnaire.

Care staff issues (52.9%, $n = 46$) were a significant barrier, with some respondents linking this to gaps in their knowledge, of dementia, dysphagia, and the SLT's role as a result of limited training (39.1%, $n = 34$). Some respondents felt that their services' capacity (e.g., time and resource; 29.9%, $n = 26$) impacted their ability to providing training and an effective service.

Good-practice facilitators were a robust referral system with timely referrals (42.0%, $n = 34$) and a collaborative approach to management with paid carers, the MDT, and families (24.7%, $n = 20$).

Discussion

The purpose of this study was to establish SLT practices when supporting people with dementia-related dysphagia and mealtime difficulties in the UK and ROI. As expected, the range of responses and comments indicated that procedures vary between SLTs and services. The issues raised by respondents reflected challenges in awareness of the scope of the SLT role, issues with referrals, challenges to management decision-making, and the need for care/medical staff training.

Scope and awareness of the SLT role

The health and well-being implications of dysphagia and its links to aspiration pneumonia mean that its need for treatment is well established. However, research shows that additional factors are required before aspiration pneumonia develops, including being bedbound or dependent on oral care and feeding (Langmore *et al.* 1998, 2002). These factors beyond the swallow highlight the need to support individuals with mealtime difficulties, as well as dysphagia. There was a consensus amongst the current respondents that dysphagia treatment is an integral part of their role in supporting people with dementia. However, they provided contradictory responses concerning their role in the management of mealtime difficulties. While respondents generally agreed that these fell within the SLT's scope, some sentiments expressed in the open-ended question indicated that this did not always translate into practice. Some respondents indicated that they could only offer over-the-phone advice, while others stated that they would not accept the case unless dysphagia was present. These views seemed to be, at least partly, driven by the SLTs' perceived resource as just a small percentage of respondents (7.6%, $n = 9$) did not consider mealtime difficulties to be part of their role.

Such variability in practice could potentially lead to inequitable access to services for people with dementia. Furthermore, it makes it more challenging to demonstrate the value of SLT intervention in dementia that is necessary to support the commissioning of SLT services.

For instance, the current National Institute for Health and Care Excellence dementia guidelines (2018), despite covering the period from diagnosis to palliation, only recommend SLT management during the palliative stages. This oversight indicates that commissioners do not recognise the fact that SLTs can support factors beyond the swallow across the course of dementia. It also stands in contrast to respondents' wish for more timely referrals, perhaps indicating their view that referrals were coming too late when SLT management was most limited. In addition, it does not take account of research evidence, such as Humbert *et al.*'s 2010, which demonstrates early-stage swallowing changes. There is, therefore, a clear need to develop a consensus on the SLT's role in managing the pervasive impact of mealtime difficulties and dysphagia across dementia types and stages both within the profession and at a policy level.

Referral issues

The survey respondents highlighted referral issues such as inappropriate referrals or referrals lacking in information as negatively impacting their time and resource, and as a consequence, their service delivery. As most respondents indicated that they use open referral forms which do not specify criteria or prompts for SLT referral, the ongoing referral issues could indicate that referrers lack a clear means of identifying appropriate cases. The use of generic forms is not surprising given that the currently available evidence does 'not clearly define the elements and processes needed for valid and reliable case-finding during mealtime[s]' (Niezgoda *et al.* 2014: 296). Additionally, evidence for the efficacy of screening tools in reducing complications and improving access to services for dementia populations is lacking, and one of the issues in developing this evidence is that available tools have varying levels of reliability and usability (Park *et al.* 2015). With the often-gradual onset of dysphagia in elderly and care populations, care home carers must have the means to identify and quantify risk in order to generate appropriate onward referrals. Park *et al.* (2015) concluded that nurses are in a prime position to do this due to their visibility and constant availability in the care home, yet Niezgoda *et al.* (2014) and the present study suggest that many care home staff are ill-equipped to recognise and manage the signs of dysphagia. Current respondents felt that where training was delivered, learning was not being acted upon or disseminated by recipients across their services, leading to ongoing issues with the identification of cases and SLT referrals. In the absence of standardised referral and screening tools for people with dementia, there is an increased likelihood of inappropriate referrals, which negatively impacts on SLT time and resource. However, more

worryingly, there is an increased risk of services missing people with dementia in need of treatment.

Further to referral issues, a worrying finding was the routine waiting times for people with dementia. In community settings, it was standard to have to wait at least 10 days before being seen by an SLT. Langmore *et al.* (2002) noted that while care home residents have conditions that can cause gradual decompensation in the swallow, sudden acute episodes, such as the onset of an infection, can lead to abrupt deterioration of the swallow. Waiting lists of 10 days or longer could potentially compromise the care of people with dementia. Another unsettling finding was that a small number of respondents appeared to make over-the-phone recommendations to care homes without assessing the individual. It was unclear whether they based these recommendations on sound clinical judgement (e.g., prior knowledge of the individual), or if this reflected workload or training issues that need to be addressed at a service level to ensure adequate care of individuals with dementia. Further exploration of the impact of delays in treatment is needed, alongside investigations of the impact of SLT understaffing on waiting lists in order to develop guidelines on optimal waiting times, particularly in community settings.

Management decision-making

Given the relatively limited evidence base available, it is perhaps not surprising that therapists' responses indicated that they prioritised clinical expertise, or 'knowing how' (McCurtin and Clifford 2015: 1183) in decision-making over the research evidence. However, reliance on clinical expertise could result in inconsistent practice, particularly in the absence of clear protocols. Although variability in practice does not necessarily equate to poorer outcomes, it could have negative consequences in some instances. For example, despite some SLTs flagging concerns about the use of thickened fluids, this intervention, alongside modifying diets, was the most utilised management strategy, indicating that SLTs may feel it is the only strategy they can effectively use with this client group. Reliance on thickened fluids could be concerning, however, considering that the research indicates that the short-term benefits in reducing aspiration risk may have longer term impacts on health and well-being (Flynn *et al.* 2018). Further exploration of the longer term effects of modified food and fluids is necessary if SLTs wish to continue using them with this population. In addition, few respondents reported using direct approaches. It is unknown to what degree this was due to a conscious decision in view of the insufficient evidence base for techniques such as SRT (Wu *et al.* 2014), a lack of awareness of or restricted access to the literature, or if service pressures, understaffing and

lack of resource may be preventing SLTs implementing effective, yet time-consuming, interventions in the interests of serving a wider number of referrals.

As is the case with many areas of SLT practice, the above identifies an urgent need to widen the evidence base for effective interventions and its dissemination. One approach to extending the evidence base, as suggested by Dobinson and Wren (2019), is supporting SLTs to develop their practice-based evidence into research evidence. This practice development could link to further exploration of the SLT and MDT roles in dysphagia and mealtime support for people with dementia to effectively guide the development of future policy.

A lack of dementia-specific training available to SLTs might further impact the provision of evidence-based practice. This is suggested by respondents rating themselves less knowledgeable of dysphagia in different types of dementia than its stages, and the related view that tailoring management to dementia type is of less relevance. Whilst intervention should be tailored to the unique needs of each individual, the research evidence describing dementia-related differences in response to dysphagia interventions, and varying dysphagia profiles associated with different types of dementia (Flynn *et al.* 2018, Alagiakrishnan *et al.* 2013) highlights the need to consider type and stage in management decisions. While SLTs did not detail their pre-registration training on the topic, it was interesting to note that no SLT reported receiving additional training in managing dysphagia and mealtime difficulties associated with dementia. SLT practice was further limited by a lack of readily available evidence-based resources, as those suggested by respondents were few in number and often several years old. Further pre- and post-registration training in dementia-related dysphagia and mealtime difficulties, as well as the development of evidence-based resources, must, therefore, be a priority in order to drive practice development and improved outcomes for people with dementia.

Care/medical staff training requirement

The respondents expressed a clear need for paid carer training to support the SLT role and viewed themselves as playing a part in delivering it. Despite unanimously agreeing on its importance, they identified several systemic issues preventing the provision of this training and education. These issues included high care home staff turnover, and nursing and care home staff's limited understanding of the SLT's role. The variability in training approaches, as well as the inconsistency in follow-up methods, provides evidence for a lack of clear guidance on what information and techniques are suitable for an effective training programme, and what the

preferred training outcomes are. While there are several dementia-specific training programmes reported in the literature (e.g., Batchelor-Murphy *et al.* 2015, Chang *et al.* 2006), they do not provide information on longer term outcomes of their training. Such outcomes could be changes to referral patterns, reductions in feeding-related adverse events, or improvements in well-being and quality of life. Proof of change is essential to justify providing a staffing resource for training and follow-up.

Even if evidence-based training provision were available and adequately resourced, it could only be effective if it is accessible to those who need it, and if the systems surrounding people with dementia can initiate change. However, SLTs described several barriers in this regard, including recommendations not being followed due to paid carers' poor understanding of the rationale for SLT advice, breakdowns in communication between care staff, as well as a lack of interest in training from care home management. Such systemic barriers to change have a direct impact on the care of people with dementia, as well as negatively affecting the SLTs workload, which further compounds the resource limitations they are already facing. These issues thus demonstrate a need for further research into paid carer and medical staff training, training outcome measurement, and consolidation of training recommendations and policies for the care sector.

Study limitations

Although all efforts were made to minimise the impact of limitations to the study design, some were unavoidable, and therefore need to be acknowledged.

Without specific information available from governing bodies of the number of SLTs working with dysphagia, and dysphagia and dementia in particular, across the UK and ROI, it was impossible to determine a meaningful representative sample and thereby a response rate. For this reason, the survey was disseminated via several networks and professional bodies to capture as wide a range as possible. The current sample has a relatively even spread across SLT experience, dysphagia experience, and geographical area, thereby increasing the likelihood but not guaranteeing the applicability of the results. As the questionnaire was purposefully developed for this study, it was not standardised before its use. One issue that emerged was that more SLTs than anticipated worked across multiple settings, making it impossible to link their responses to their work setting. Future research may wish to consider targeting SLTs in specific settings to mitigate this issue.

Additionally, as respondents self-selected, there may have been a positive response bias as people who met the study criteria but had a negative view of SLT involvement in supporting with dementia may be less in-

clined to spend time completing a questionnaire. However, as the survey examined a broad range of issues and responses reflected a wide range of views, it is likely that the results presented here validly reflect the realities of practice. Therefore, the researchers feel that the study has raised some crucial issues that future discussions and research on dementia care must consider.

Conclusions

The results of this study demonstrate that, in addition to a limited evidence base to guide effective management of dementia-related dysphagia and mealtime difficulties, there is a need to clarify and establish guidance around the SLT's role in their management. In order to avoid variations in service delivery that could impact negatively on the health and well-being of people with dementia, future guidelines should be more specific on the SLT's role across dementia stages while taking into account the need for protocols to vary across care settings. Furthermore, such guidance needs to align with those provided to other professions involved in the care of people with dementia, including other AHPs whose roles might overlap. The availability of CPD for SLTs managing dementia-related mealtime and swallowing difficulties also requires further consideration.

It is also clear from responses that the respondents viewed themselves as under-resourced and unable to fulfil their role in providing assessment, management, and training in the way that they felt is necessary. The highlighted gaps in education and training of family and paid carers further exacerbated these issues. In addition to developing AHP-focused practice guidelines, greater collaboration with the care sector to develop materials and ensure adequate training in dysphagia and mealtime difficulties for all carers is necessary. These measures will support the effective management of people with dementia from all perspectives and enhance their quality of life.

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