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School of Psychological Sciences and Health

University of Strathclyde

'IT'S NOT JUST WHAT'S ON THE PLATE': ALLIED HEALTH PROFESSIONALS' PERSPECTIVES ON MANAGING MEALTIME AND SWALLOWING DIFFICULTIES IN DEMENTIA

Aisling Egan

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Date: 17.03.2021

Some hae meat and cannae eat

And some wad eat that want it:

But we hae meat and we can eat,

And sae the Lord be thankit.

Robert Burns, Scotland’s National Bard (1759 – 1796)

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ABSTRACT

People with dementia are likely to experience mealtime difficulties and dysphagia as their condition progresses. These changes can lead to a range of negative consequence, from dehydration and malnutrition to carer stress. Traditionally, dysphagia has been managed by speech and language therapists (SLTs), but it is unclear what their role and that of other allied health professionals (AHPs) are in managing the more wide-ranging needs of mealtime difficulties. A two-phase study was performed to explore these issues. The first phase aimed to clarify the SLTs' role in supporting dysphagia and mealtime difficulties by illustrating their current practice, defining how they see their role, and capturing their perspectives on current practices. In the second phase, the thesis aimed to conceptualise what the wider AHP workforce, including SLTs, view as the key practice challenges and the core issues in managing dementia-related mealtime difficulties. It also sought to elucidate perceptions of their roles.

The study employed an adapted explanatory sequential mixed-methods design prioritising qualitative data. The first phase used a survey design to gather qualitative and quantitative data from 125 SLTs in the United Kingdom and the Republic of Ireland. The quantitative data were analysed descriptively, and with tests of association and conventional content analysis was used for the qualitative data. The results from this phase of the study indicated that SLTs were under-resourced in their efforts to support people with dementia, and this lack of resource impacted their service and

training delivery. Some respondents indicated that they did not manage mealtime difficulties as a result of service constraints and were limited to a dysphagia focus. The results indicated that SLTs value training and consider it important for nursing staff and paid and family carers to receive training. However, workload and resource constraints meant that many SLTs could not deliver this training or follow up on its effectiveness. This was linked to issues with receiving referrals and adherence to their recommendations. The SLTs also identified communication and liaison challenges with key stakeholders.

The results of the first phase informed the development of the second phase, which used a Qualitative Descriptive approach. Interviews with 21 AHPs in Scotland were analysed using reflexive thematic analysis. Three overarching themes were identified, '*Professional Roles', 'Decision-making is Individual'*, and *'the Realities'*. The first of these themes addressed issues the AHPs faced in advocating for their role when that role was misunderstood or unknown by people with dementia and their families as well as their healthcare colleagues in the subtheme '*awareness of roles'*. Its second subtheme, '*out of the (MDT) loop'* uncovered challenges the AHPs faced in multidisciplinary team (MDT) working and the impact this had on the care of people with dementia. The second theme, '*Decision-making is Individual'* was underpinned by the concept of person-centred care, encapsulated in the subtheme '*it's not one size fits all'*. The other subthemes in this theme addressed the impact on quality of life, the management of risk, and the current state of advance care planning. The final theme, *'the Realities'* outlined the actualities of supporting people with dementia-related dysphagia and mealtime difficulties. The subtheme '*over-stretched resources'* described the challenges AHPs faced by being under-resourced and over-stretched. The second subtheme, *'workarounds'*, illustrated the ways AHPs overcame the lack of resource and other challenges by adapting their approach. The final subtheme '*culture change'* depicted the AHPs efforts to adapt the culture of dementia care and the barriers to this in their practice.

The results of the two phases of this research revealed many unique and overlapping issues. Many of the issues related to awareness of AHPs' roles, inappropriate referrals and ineffective referral systems, resource issues, and barriers to delivering training. The results of the interviews also revealed challenges the AHPs faced with risk management and advance care planning. Their drive to deliver person-centred care was evident from all data generated.

These findings provide new insights into how dementia-related mealtime difficulties and dysphagia are currently managed. They contribute significantly to our understanding of the clinical challenges faced by AHPs and the barriers to accessing service experienced by people with dementia. These findings can inform service and policy development. Future research is needed to explore AHP roles in advance care planning and risk management and support the development of these activities in relation to mealtime difficulties and dysphagia. Research also needs to evaluate AHP involvement throughout the course of dementia in order to support the expansion and development of services.

PUBLICATIONS AND PRESENTATIONS ARISING FROM THIS THESIS

Peer-Reviewed Publications

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LIST OF ABBREVIATIONS AND ACRONYMS

Acronym	**Meaning**
AD	Alzheimer’s Disease
AHP	Allied Health Professional
bvFTD	Behavioural Variant Frontotemporal Dementia
CBE	Clinical Bedside Examination
CPD	Continuing Professional Development
DLB	Dementia with Lewy Bodies
D-MAT	Dementia Mealtime Assessment Tool
DT	Dietitian
EBP	Evidence-based Practice
EdFED	Edinburgh Feeding Evaluation in Dementia Scale
FEES	Fibreoptic Endoscopic Evaluation of Swallowing
FTD	Frontotemporal Dementia
GP	General Practitioner
GPS	Global Positioning System
IASLT	Irish Association of Speech and Language Therapists
LBD	Lewy Body Dementia
lvPPA	Logopenic Variant Primary Progressive Aphasia
MDT	Multidisciplinary Team
MMSE	Mini-Mental State Examination
MND	Motor Neurone Disease
nfvPPA	Nonfluent-agrammatic Primary Progressive Aphasia
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OT	Occupational Therapist

Acronym	**Meaning**
PDD	Parkinson’s Disease Dementia
PPA	Primary Progressive Aphasia
PT	Physiotherapist
RCSLT	Royal College of Speech and Language Therapists
SLT	Speech and Language Therapist
SPA	Speech Pathology Australia
SRT	Spaced Retrieval Therapy
svPPA	Semantic Variant Primary Progressive Aphasia
UK	United Kingdom
USA	United States of America
VaD	Vascular Dementia
VFSS	Videofluoroscopic Swallow Study
WHO	World Health Organisation

1 INTRODUCTION

> *"You can tell me a secret, and I'll always keep it because I simply won't remember. But one thing I never forget is that food used to mean so much more to me than it does now."* Wendy Mitchell, *from her blog 'Which me am I today? One person's experience of* living with dementia.*'*

Eating and drinking are basic activities of daily living, and their importance to our lives cannot be overstated. In fact, *"eating and drinking are a biological necessity, a universal pleasure, and a basic human right"* (Levenson & Walker, 2019, p. 954). As such, any issues with eating and drinking or at mealtimes can significantly impact health, well-being, and social interactions. How easy it is to complete a meal depends on cognition, physical and swallowing abilities, and the mealtime environment. Dementia is a condition that can have a significant impact on these skills and abilities. This thesis investigated the practices and perspectives of allied health professionals (AHPs), particularly speech and language therapists (SLTs), who support people with dementia-related dysphagia and mealtime difficulties. This chapter will define and describe the key concepts studied before stating the study aims and providing a summary of each subsequent chapter.

1.1 Dementia

The term dementia refers to a range of neurodegenerative pathologies rather than a singular unified condition. It is *"a syndrome of cognitive impairment that affects memory, cognitive abilities and behaviour, and significantly interferes with a person's ability to perform daily activities"* (World Health Organisation [WHO], 2018, p. 6). The diagnostic criteria require significant impairment in at least one cognitive domain such as memory, executive function, language, recognition (agnosia), or visuospatial function (American Psychiatric Association, 2013). Around 850,000 people in the UK are living with dementia (Alzheimer Society, 2017), with 90,000 of those living in Scotland (Alzheimer Scotland, 2017). It is primarily, although not exclusively, a disorder of old age and has an insidious onset with gradual progression (O'Shea, 2007). Dementia is also associated with neurological changes and movement disorders (Barbosa, Teive, & Tumas, 2016). Under the umbrella term of dementia, the most common form is Alzheimer's disease (AD), accounting for 60-70% of all dementia (WHO, 2018), with vascular dementia, frontotemporal dementia, and Lewy body dementia the next most common types (Alzheimer's Society, 2017). These dementias have unique cognitive profiles reflective of various neurological pathologies, and they are progressive and irreversible. Section 2.4 describes these in more detail.

1.2 The Impact of Swallowing and Mealtime Difficulties in Dementia

The impact of dementia on the people it affects, and their loved ones, is significant (Cova et al., 2018; Gilhooly et al., 2016; Tolson et al., 2017). In addition to the changes listed above, throughout their disease, people with dementia also experience gradual changes and difficulties in eating, drinking, and swallowing (dysphagia) (Easterling & Robbins, 2008). Dysphagia is defined as "*a swallowing disorder usually resulting from a neurological or physical impairment of the oral, pharyngeal or oesophageal mechanisms*" (Royal College of Speech & Language Therapists [RCSLT], 2014a, p. 3). The risk of developing swallowing problems increases as natural, healthy ageing takes its toll on the musculature and neural controls sustaining swallowing function, discussed further in section 2.3.

Furthermore, with disease progression, people with dementia also face challenges within the mealtime (RCSLT, 2013). The term 'mealtime difficulties' encompasses these issues with eating, drinking, and other mealtime aspects. Older adults with mealtime difficulties "*require additional support and/or intervention with their mealtime skills. This includes . . . support with eating and/or drinking, with or without dysphagia, due to motor, sensory, cognitive, emotional, or behavioural issues, as well as . . . difficulties during mealtimes relating to an impoverished mealtime environment*" (Speech Pathology Australia [SPA], 2015, p. 5). These needs may manifest as changes to their ability to anticipate, prepare for, and engage at mealtimes, making it challenging to initiate eating, maintain attention on the meal, or recognise food or cutlery (C. C. Chang & Roberts, 2008; K. M. Lee & Song, 2015).

As a result of the complex cognitive, behavioural and neurological changes associated with the condition, people with dementia have an increased likelihood of experiencing mealtime difficulties and dysphagia. Changes in how a person accesses nutrition and hydration have significant implications for health and quality of life, and Priefer and Robbins (1997, p. 212) describe eating difficulties as "*the most life-threatening of all the functional impairments*" of the condition. In particular, dementia-related mealtime and swallowing difficulties can lead to malnutrition and weight loss, ill-health, the development of aspiration pneumonia, and even death (Carrión et al., 2015; Hanson, Ersek, Lin, & Carey, 2013; Manabe, Teramoto, Tamiya, Okochi, & Hizawa, 2015; Volkert et al., 2019). Dysphagia is also associated with an increased emotional burden for caregivers (Shune & Namasivayam-MacDonald, 2020), and weight loss is associated with higher caregiver burden in mild-moderate AD (Bilotta, Bergamaschini, Arienti, Spreafico, & Vergani, 2010; Kuo et al., 2017). Additionally, mealtime difficulties and dysphagia in dementia reduce socialising opportunities (Gillies, 2012) and lead to increased caregiver stress at mealtimes (Hammar, Swall, & Meranius, 2016; Papachristou, Giatras, & Ussher, 2013). There is also an economic cost to dysphagia as dementia-related dysphagia has associations with increased length of hospital stay, as well as increased resource utilisation due to poorer outcomes as compared to people with dementia who do not have dysphagia (Attrill, White, Murray, Hammond, & Doeltgen, 2018; Paranji, Paranji, Wright, & Chandra, 2017). Furthermore, hospital care costs an additional €3,677 for geriatric patients with dysphagia but without dementia and increases by €6,192 in social care settings (Westmark, Melgaard, Rethmeier, & Ehlers, 2018). It stands to reason that similar increased costs may apply to the care of people with additional mealtime difficulties.

1.3 Allied Health Professionals and Their Roles Managing Mealtime Difficulties and Dysphagia

The management of mealtime difficulties involves ameliorating swallowing issues, cognitive and behavioural changes, environmental inadequacies, and carer relationship breakdowns. It is clear from their wide-ranging nature and their significant impact on people with dementia that these issues need to be managed. As discussed further in section 2.3.4, SLTs are commonly the professionals who diagnose and manage the complex needs of dementia-related dysphagia to mitigate the associated adverse sequelae such as malnutrition, dehydration, and aspiration pneumonia (Castellanos, Butler, Gluch, & Burke, 2004). Additionally, the RCSLT (2014b) advocates that SLTs should manage aspects of mealtimes difficulties; however, the evidence base is limited, and the RCSLT do not account for the roles of other AHPs.

Moreover, there is no policy consensus. In 2012, WHO and Alzheimer's Disease International published a document entitled *"Dementia: A Public Health Priority"*. This document aimed to outline the existing knowledge, trends, and impacts of dementia in order to guide policy and decision-makers in developing strategy and systems to counteract the growing demands of this condition (WHO, 2012). The report acknowledges the impact of dementia on eating and swallowing as it suggests that carers may need to *"provide full assistance with eating and drinking"* in the later stages of the disease (WHO, 2012, p. 72). However, despite acknowledging the contributions that occupational therapists (OT) and physiotherapists can offer to people with dementia and their caregivers, the report fails to mention mealtime difficulties and dysphagia and their need for management or the role of speech and language therapy. This omission perhaps indicates a lack of awareness of these conditions' detrimental impacts at a global level, an oversight that may have significant and potentially life-threatening consequences for people with dementia worldwide. While the report states that it aims to raise awareness and champion action, it is a missed opportunity to set minimum standards of dementia care.

Similarly, in the UK, the current dementia guidelines (National Institute for Health and Care Excellence [NICE], 2018) do not provide any clarity on the management of mealtime difficulties or dysphagia in dementia. Furthermore, they do not advise which healthcare professionals should be involved in their management. For the palliative phase, the guidelines suggest "*consider involving a speech and language therapist if there are concerns about a person's safety when eating and drinking*" (p. 30); however, they do not acknowledge that mealtime difficulties and dysphagia can occur earlier in the course of the disease. They also fail to consider how the consequences of mealtime difficulties and dysphagia impact people with dementia and their place as a priority in management. Additionally, there is little guidance on the multidisciplinary team's (MDT) roles in managing dementia-related mealtime difficulties.

The defining characteristics of AHPs are their "*autonomy, specialist skill/knowledge, and control over the content of their work*" (Ong et al., 2014, p. 102). This definition underlines the professions' independence from each other, though in practice, they work most effectively when they work collaboratively (Miles, McFarlane, Kainth, & Parmar, 2014). In Scotland, there has been a particular focus on promoting AHP collaboration as core members of any MDT supporting people with dementia. In 2017, Alzheimer Scotland published guidance known as "*Connecting People, Connecting Support*" that outlines their vision of the AHP approach, shown in figure 1.1. Its vision is "*to maximise the AHP contribution to high-quality, cost-effective dementia services that are tailored to the needs of individuals, reflect the best available evidence and are delivered by a skilled AHP workforce*" (Alzheimer Scotland, 2017, p. 9). They developed this vision and guidance in collaboration with people with dementia and their carers, AHPs, and research evidence. It is clear that mealtime difficulties and dysphagia align with several aspects of this model.

Figure 1.1. The AHP Approach (Alzheimer Scotland, 2017). This image has been removed by the author of this thesis for copyright reasons.

Mealtimes are a valued activity of daily living (Watkins, Goodwin, Abbott, Hall, & Tarrant, 2017), and good nutrition is essential to maximise physical well-being. Research indicates that family members value mealtimes though they can be sources of stress (Keller, Edward, & Cook, 2007; Papachristou et al., 2013). Reducing the negative consequences of mealtime difficulties and improving the well-being and quality of life of people with dementia should be a priority for policymakers, managers, and health professionals. To that end, the purpose of this thesis is to explore AHPs' roles and practices when managing dementia-related dysphagia and mealtime difficulties.

1.4 Aims and Structure of the Thesis

Evidence-based practice is not just the application of research evidence; it also involves the *"conscientious, explicit, and judicious integration of 1) best available external evidence from systematic research, 2) best available evidence internal to clinical practice, and 3) best available evidence concerning the preferences of a fully informed patient"* (Dollaghan, 2006, p. 2). The purpose of this study is to contribute to the evidence base for the management of dementia-related dysphagia and mealtime difficulties by:

- Clarifying the speech and language therapists' role in supporting these needs by illustrating their current practice, defining how they see their role, and capturing the barriers and facilitators to practice they identify.
- Providing the basis for professional and service development by conceptualising what speech and language therapists and other allied health professionals view as the key practice challenges and the core issues in managing dementia-related mealtime difficulties.

- Providing information that can contribute to the development of guidelines on the roles of speech and language therapists and other allied health professionals in the management of these difficulties.

In order to meet the aims of the research, this thesis employs an adapted explanatory sequential mixed methods design. As such, it comprises two studies, each with its own method, results, and discussion. The thesis begins in chapter two by presenting the literature and evidence base for dementia-related dysphagia and mealtime difficulties. It also outlines the rationale for the study and the research questions.

Chapter 3 then explores the methodological considerations of this research and establishes the rationale for the research design. It describes how, in line with a pragmatic approach, the selected research design addresses the research questions.

The following three chapters focus on the first phase of the study, whose research aims were:

- To identify current SLTs' working practices for managing dementia-related mealtime difficulties in the United Kingdom (UK) and the Republic of Ireland (referred to as Ireland).
- To establish SLTs' opinions and experiences of the challenges and facilitators to practice they encounter.

Chapter 4 describes the survey design used to establish SLTs’ practices and perspectives. Chapter 5 outlines the results of this phase, and chapter 6 discusses these results in relation to the literature.

Chapters 7 to 9 focus on the second phase of the study. The aims of this phase were based on the findings of the survey and were:

- To establish AHPs’ perspectives on their roles in managing mealtime difficulties of people with dementia
- To understand what issues and challenges impact on AHPs who support people with dementia and mealtime difficulties.

Chapter 7 provides an overview of the methods used in this qualitative phase of the study. An interview design was used as part of a Qualitative Descriptive approach to capture the views of AHPs with a specialist interest in dementia. Chapter 8 presents the results of the interviews, and chapter 9 discusses these results in relation to the literature and the findings of the first phase of the study.

The thesis closes with chapter 10, which considers the conclusions arising from both phases and discusses future directions of the research.

2 LITERATURE REVIEW

This chapter follows the introduction to dysphagia and mealtime difficulties presented in chapter one by providing the background to dysphagia and mealtime difficulties in dementia and presenting an overview of how these issues appear in different kinds of dementia. This chapter then examines the identification of dementia-related dysphagia and mealtime difficulties and the screening tools used with this population. It then considers what is known about how SLTs manage dementia-related dysphagia and mealtime difficulties before interventions targeting these issues are explored. The chapter concludes by outlining the rationale for the study.

2.1 Literature Search Strategy

This chapter provides a wide-ranging review of the literature relevant to the research. This review required a variety of search and identification processes. The review began by conducting database searches using a range of combinations of search terms. The databases searched were Web of Science, Embase, and MEDLINE. Each database was searched with a search string that included terms related to dementia (e.g., dementia, cognitive impairment, and specific dementia types) and dysphagia (e.g., dysphagia, swallow*, mastication, eat*, or drink*) or mealtime difficulties (e.g., feeding behaviour, meals, or feed*). Several key articles were identified, and the reference lists of these articles were hand searched to identify other relevant literature.

Google scholar was also used to conduct citation searches for key articles. Searches of articles related to key authors were also conducted, as well as searches related to SLTs and dysphagia and mealtime difficulties practices were also conducted. The Mixed Methods Appraisal Tool (MMAT) was used to evaluate the quality of the studies (Hong et al., 2018; Pace et al., 2012). The types of study included was not pre-determined and the quality ratings were not used to exclude studies in order to identify as many relevant articles as possible given the relatively small evidence base for dementia-related mealtime and swallowing difficulties.

2.2 Going Beyond the Swallow: Mealtime Difficulties in Dementia

Eating and drinking require complex coordination and processing, but the model of normal swallowing (discussed further in section 2.3.1) presumes that the process begins once the bolus enters the mouth. However, this is not the case, and Siebens et al. (1986) expanded the view of eating beyond these three phases to include mealtime skills. They proposed an additional two phases before food or liquid enter the mouth: *"1) the behavioural/cognitive ability to recognise that food was present and should be eaten, 2) the upper extremity function of transferring food from plate to mouth"* (p. 193). These additional phases are particularly relevant to dementia as *"generalised problems with nutrition, diet, feeding, and eating*" (Cipriani, Carlesi, Lucetti, Danti, & Nuti, 2016, *p. 706*) are frequently associated with it. Furthermore, early research noted that *"the eating difficulties experienced by patients with DAT [*dementia of the Alzheimer's type*] are not limited to difficulties of swallowing alone, but include food refusal, inability to chew, and inability to open the mouth"* (Volicer et al., 1989, p. 192). Such issues beyond the swallow have been called a variety of names, such as eating disability (Siebens et al., 1986), feeding problems (Athlin, Norberg, Asplund, & Jansson, 1989), feeding difficulties (C. C. Chang & Roberts, 2008; Watson, 1994), problem feeding behaviours (Durnbaugh, Haley, & Roberts, 1996), eating-related behavioural and psychological symptoms of dementia (Edahiro et al., 2012), eating challenges (Slaughter et al., 2020), and mealtime difficulties (Aselage & Amella, 2010; Faraday, Salis, & Barrett, 2019; Steele, Greenwood, Ens, Robertson, & Seidman-Carlson, 1997). The term 'mealtime difficulties' has increasingly become the preferred term to refer to the entire range of issues that may occur with eating and drinking. Nevertheless, definitions of mealtime difficulties still vary.

Faraday and colleagues (2019, p. 717) use the term mealtime difficulties to refer to behaviours observed in people with dementia such as "*food refusal, distractibility, visual agnosia, swallowing and feeding apraxia, pocketing food, spitting food, excessive swallows, rapid eating, absent chewing, and delayed or impaired pharyngeal swallow"*. However, their definition is narrow; it describes the presentation or appearance of mealtime issues, but it does not acknowledge the root causes of these symptoms. These root causes include changes to cognition, the emergence of behaviour changes, alterations to sensory processing that influence mealtimes, and the effects of the mealtime environment in exacerbating these issues. On the other hand, the broader SPA definition identifies that mealtime difficulties are "*due to motor, sensory, cognitive, emotional, or behavioural issues, as well as . . . difficulties during mealtimes relating to an impoverished mealtime environment"*

(2015, p. 5). This definition of mealtime difficulties is not specific to dementia, and it includes but does not require the presence of dysphagia. For that reason, this study refers to dysphagia and mealtime difficulties as two separate but related conditions that require support and management.

Dysphagia's well-established links to aspiration pneumonia and its ramifications for health and well-being mean that its need for treatment is indisputable. Aspiration pneumonia can develop if the airway is not protected from pathogenic material due to a weak or inefficient swallow (DiBardino and Wunderink 2015). However, research shows that the relationship between aspiration and the development of aspiration pneumonia is not linear (Feinberg, Knebl, & Tully, 1996), and mealtime factors influence it. Additional risk factors beyond the swallow are typically required before aspiration pneumonia develops, including having dementia, being bedbound, or dependence on others for oral care and assistance to eat (Hibberd, Fraser, Chapman, McQueen, & Wilson, 2013; Langmore, Skarupski, Park, & Fries, 2002; Langmore et al., 1998; Manabe et al., 2015). Langmore and colleagues (2002) found dependency for feeding to be the best predictor of an individual's risk of developing aspiration pneumonia. In addition to this link to feeding dependency, some preliminary research has shown a link between the caregiving approach, dementia-related behaviours, and incidents of aspiration (Gilmore-Bykovskyi & Rogus-Pulia, 2018). Inappropriate or ineffective support to eat is one aspect of an impoverished mealtime environment. Gilmore-Bykovskyi and Rogus-Pulia showed that a task-oriented approach led to greater instances of aspiration events than a person-centred one. There also appears to be a causal relationship between the presence of mealtime difficulties and independence in eating, particularly challenges to initiating the task of eating a meal (Edahiro et al., 2012).

The impact of the mealtime environment has been recognised since the eighties (Athlin et al., 1989). Athlin and colleagues' analysis of videotaped mealtime observations brought to light the significance of the mealtime dyad between the person with dementia and the carer providing mealtime support. They demonstrated that failures in communication and reciprocity between carers and people with dementia led to mealtime breakdowns. Furthermore, another videotape observation study found that the dyad's verbal interactions influenced the amount of food eaten (Liu, Perkhounkova, Williams, Batchelor, & Hein, 2020). These findings should have instigated the transformation of carers, care facilities, and health professionals' practices when managing mealtime difficulties. Unfortunately, it appears that little progress has been made in the intervening years, as research continues to highlight the impact that care pressures and carer knowledge have on meal outcomes (Watkins, Goodwin, Abbott, Backhouse, et al., 2017). The dyad's influence emphasises the necessity to consider both the factors inherent to the person with dementia and the influence of external factors on the mealtime and highlights that work in this area is still needed. These factors beyond a functional swallow, from the person with dementia's presentation to how they are supported to eat, have the potential to be as significant as the impacts of dysphagia on health and well-being. One approach that researchers and experts in the area have taken to identify and understand these issues is the development of models of mealtime difficulties.

2.2.1 Models of Mealtime Difficulties

Models of mealtime difficulties enable researchers and clinicians to conceptualise the factors that influence mealtimes and mealtime difficulties. Researchers have taken two approaches to their development; some have focused on the individual and the mealtime itself, considering mealtimes difficulties in the context of antecedents and consequences. Others have explored the wider systems and systemic issues that impact mealtimes. Both approaches are valid, though both address different issues and have different aims.

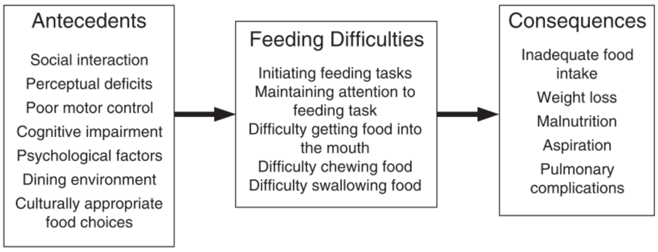


Figure 2.1 Model of Feeding Difficulty (C. C. Chang & Roberts, 2008)

Chang and Roberts (2008) developed their model based on a concept analysis of a systematic review of what they termed ‘feeding difficulties’ in dementia, shown in figure 2.1. The purpose of their model is to guide the assessment of the antecedents, or risk factors, for mealtime difficulties to support researchers to develop evidence-based interventions and for caregivers to manage them. The authors believe that mealtime difficulties result from a relationship breakdown between the person with dementia and their caregiver. They acknowledged that “*feeding difficulty of older adults with dementia is a multidimensional phenomenon that is within the purview of nursing care*” (Chang & Roberts, 2008, p. 2271). A strength of this model is the recognition that these issues are complex and multidimensional. Its development from a systematic review of the literature means that it likely reflects most issues that are faced. However, this model does not guide paid and family carers on which antecedents are likely to affect mealtime behaviour and what strategies are likely to ameliorate any issues.

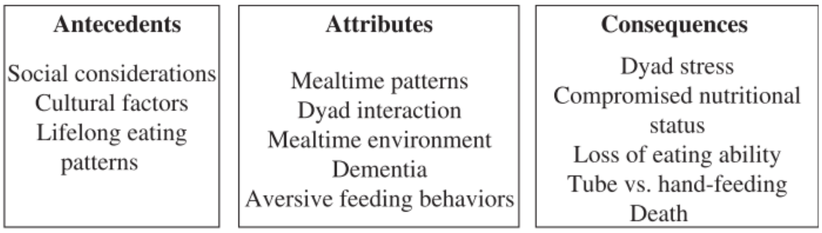


Figure 2.2 Model of mealtime difficulty (Aselage & Amella, 2010)

Aselage and Amella (2010) developed a similar model using an evolutionary concept analysis design, shown in figure 2.2. The authors view their model as differing from Chang and Roberts' as they consider this model to include broader concepts. This broadness is illustrated by their grouping of factors such as 'aversive feeding behaviours' while Chang and Roberts list individual factors. In this model, the antecedents relate to social and personal factors, and they represent elements that influenced mealtimes before dementia became a factor. The model presents attributes as the factors at play during mealtimes for a person with dementia. However, from the authors' descriptions, it requires some mental leaps to relate the antecedents and the attributes to the consequences. Moreover, the model is not easily applied clinically.

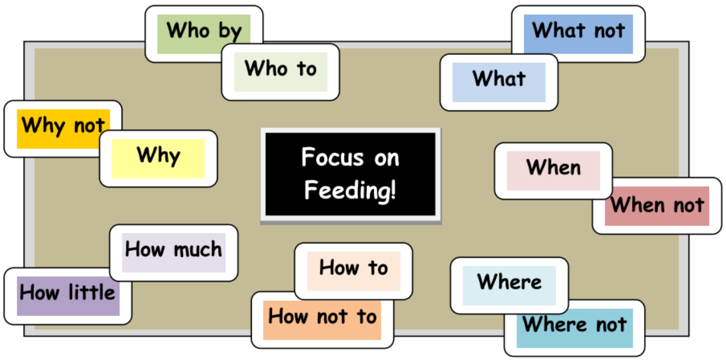


Figure 2.3. Focus on feeding! Decision-making model (Chang, Brownhill, Bidewell, Johnson, & Ratnayake, 2015)

On the other hand, the Focus on feeding! decision-making model was designed for clinical use (E. Chang et al., 2015). As shown in figure 2.3, though this model is not linear like the Chang and Roberts and Aselage and Amella models, it is also an antecedent and consequence model. This model is not theoretical but was designed as a practical template to prevent unintentional weight loss by encouraging nurses to think through the root causes of mealtime issues and determine a suitable solution from a resource book of exemplars. The pairs in the model are binary concepts, and the exemplars are based on the available evidence. This model was developed by specialist nurses and refined through application in care homes and discussion with nursing and care staff. This model is the most practical and easily applied model of mealtime management identified in the literature.

There are three models of mealtime difficulties that look beyond the person with dementia at mealtimes and examine the wider system that the people with dementia and their carers inhabit. Two models show the macro, meso, and micro influences on mealtimes (Keller et al., 2014; Liu et al., 2016). In these models, the macro levels describe policy and societal influences on mealtimes, such as funding allocation and governmental policies and regulations. The meso model represents the care or home environment and the influence its inherent care practices, such as staffing levels, food delivery options, and cultural norms have on mealtimes. The macro-level inevitably influences the meso level, and in turn, it influences the micro. The micro-level represents the individual with dementia and the qualities they bring to the picture: their preferences, their appetite, their individual needs. These models do not simply reflect top-down influences, and there is a primary focus on the interaction of meso-micro factors.

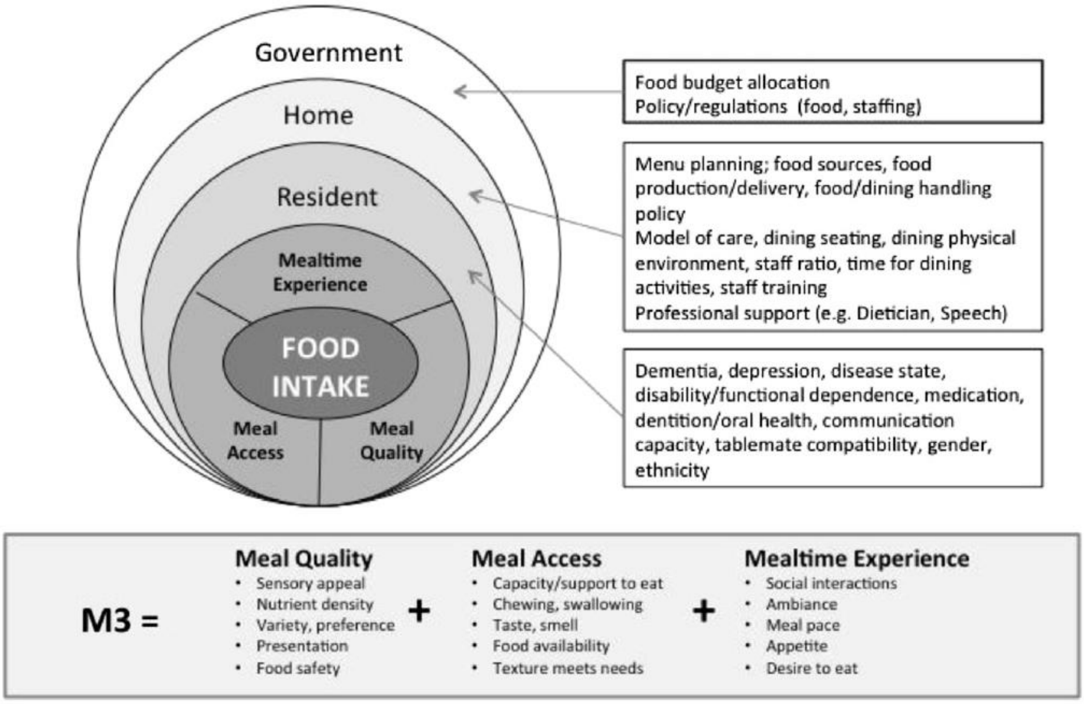


Figure 2.4 Making the most of mealtimes (M3) conceptual model (Keller et al., 2014)

This focus is explicit in the Keller model, figure 2.4, as its ‘M3’ component summarises meso and micro influences on food intake under three categories: meal quality, meal access, and mealtime experience. The ‘making the most of mealtimes’ model is a conceptual model based on expert opinion and the evidence base. This model applies specifically to care home environments, but it is not dementia-specific. The model acted as the conceptual framework of a multi-site study of Canadian care homes' mealtime practices, with the primary focus on factors that impact food and fluid intake (Keller et al., 2017). It gathered data on care home characteristics, mealtime environment factors, and resident variables. It is an extremely comprehensive model, and its division of mealtime issues into quality, access, and experience is a novel one. Dementia is one of the factors inherent to the individual; however, in a dementia-specific model, the impact of dementia on the swallow and mealtime skills would likely fall under access.

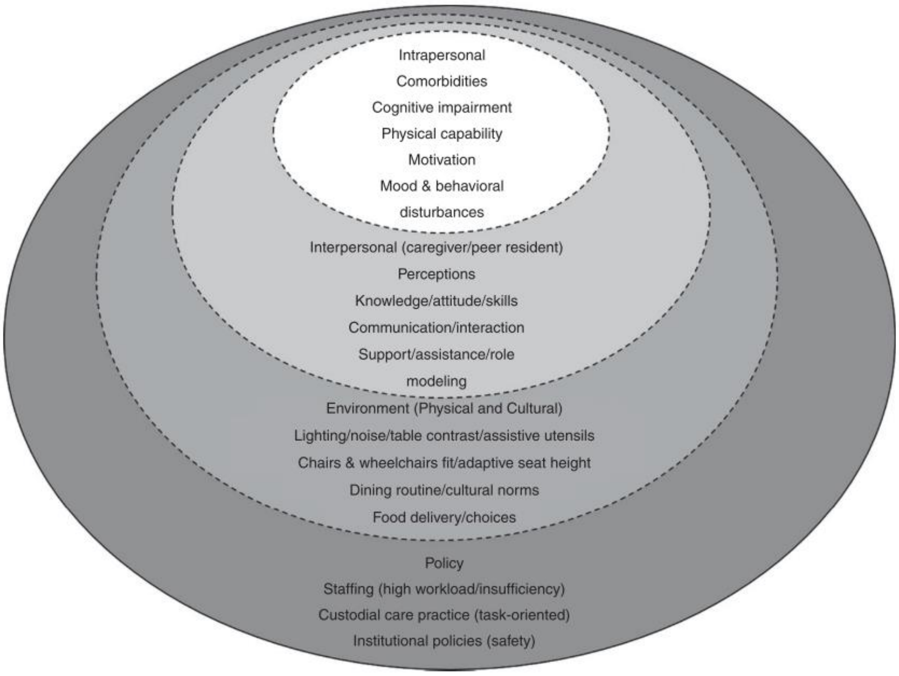
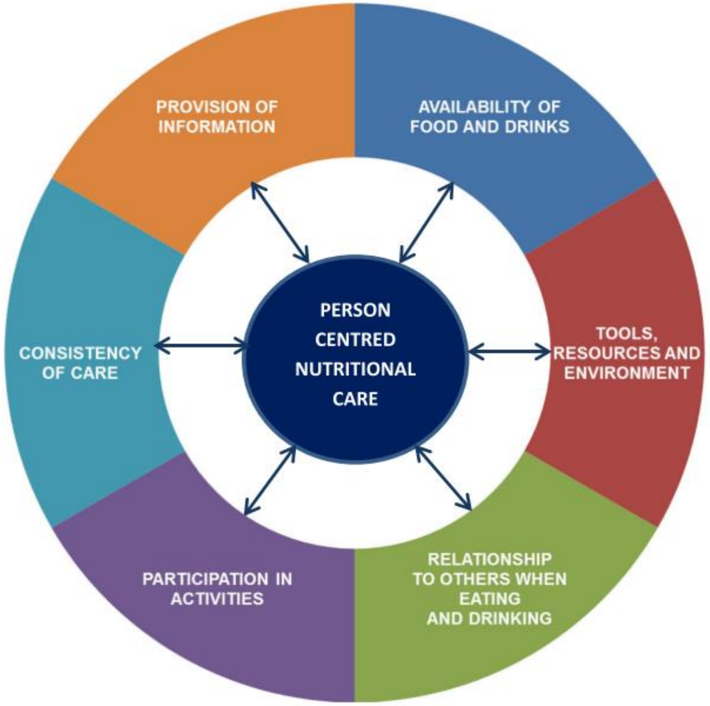


Figure 2.5 Social ecological model (Liu et al., 2016)

The 'Social ecological model of factors that influence eating performance' (SEM; figure 2.5) also illustrates these issues under the intrapersonal level, which accounts for the interactions between the person with dementia and their caregiver (Liu et al., 2016). Though this presents as an individual relationship, it is important to note that care home policies, routines, and the home's culture will influence the caregiver. This model is also specific to care homes, and here, the meso level of the Keller model is presented as the macro level. As such, it does not acknowledge the influence of governmental and structural influences beyond the care home management structures. The model was developed to illustrate the multiple factors that influence mealtimes in order to stimulate the development of interventions targeting each level.

The third complex model of mealtimes and nutritional care from Murphy, Holmes, and Brooks (2017) is not presented in this tiered manner but acknowledges many of the same issues under the theme headings and has a greater focus on the meso-micro interaction (figure 2.6). Person-centred care drives this model as it begins by considering the micro-level first and foremost, i.e., the person with dementia. The model's remaining components focus on how the meso level items can impact the meal. In the Standards of Care for Dementia in Scotland, the Scottish Government (2011, p. 51) define person-centred care as putting the person with dementia "*who uses services at the centre of their support, care and treatment. Ensuring everything that is done is based on what is important to the person from their own perspective*." In their paper, Murphy et al. (2017) indicate that Kitwood's (1997) work influenced their definition of person-centred nutritional care.



Themes	*Sub-themes*
Person-centred nutritional care	*Stage of dementia* *Psychosocial factors* *Life histories* *Health conditions* *Generational factors* *Cultural factors*
Availability of food and drinks	*Accommodating changing tastes and preferences* *Presentation of meals* *Modification of food e.g. food fortification and using food purees* *Supplements* *Prioritisation of food and drink* *Delivery, prompting and offering a drink*
Tools, resources and environment	*Nutrition screening* *Modified equipment* *Ready plated meal choice options* *Contrasting colours* *Constant prompting/encouragement/giving time to person* *Environmental factors: Setting the table*
Relationship to others when eating and drinking	*Relationship to family members* *Relationship to care staff* *Relationship to other residents*
Participation in Activities	*Create aromas to stimulate appetite and evoke memories* *Enhance appetite and sense of purpose and identity* *'Themed days'*
Consistency of care	*Prioritisation of nutrition and hydration* *Improved communication between all those involved in care*
Provision of Information	*Access to trusted information and resources* *Education and training* *Current guidelines*

Figure 2.6 Model for the provision of good nutritional care in dementia (J. L. Murphy et al., 2017)

Kitwood (1997) was the first to apply the concept of person-centred care to dementia. He developed his definition of person-centred care from psychotherapy literature and described it as a means of maintaining personhood. He defined personhood as *"a standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust"* (p. 8). As such, person-centred dementia care is delivered by "*supporting individual personhood and establishing meaningful relationships, shared decision making, and personalised care and environments, using the person's biography*" (Christensen, Lund, & Thuesen, 2019, p. 1). Murphy and colleagues' model has face validity in a UK care context as it derives from a thematic analysis of interviews exploring care staff issues in UK care homes. However, as the analysis only included the participants' responses as they directly related to the interview questions, there are potentially missing issues and resolutions that could have provided a different interpretation.

In summary, a strength of the complex macro, meso, micro models is their holistic view of how systemic and cultural issues influence mealtimes. They provide a blueprint for understanding the interconnection of structural, cultural, personal, and medical factors. One gap common to the models is the limited recognition and reference to how health professionals manage mealtime difficulties. Some of the models identify nursing staff as the healthcare professionals responsible for managing these issues, other models such as Keller's recognise the role of professionals such as SLTs and dietitians. None of these models clearly define the role and level of intervention. Furthermore, by being specific to care homes, these models fail to acknowledge that many people with dementia live at home with family carer support or paid carers coming to their home. Governmental regulations and policies also impact people with dementia and their carers living in contexts beyond the care home. Additionally, these models are not clearly applicable to different stages of dementia, where unique issues may be faced. Moreover, as dysphagia can occur as part of a syndrome of mealtime difficulties, understanding its presentation and characteristics in dementia are important considerations. Therefore, the next section will discuss the normal swallow, the impact of age, and dysphagia evaluation, before describing the presentation of dysphagia and mealtime difficulties in different types of dementia.

2.3 Dysphagia

An apt description of the swallow changes in dementia is that they occur as a result of "*neuropathology that alters both the transmission and reception of sensory information, leaving motor responsibilities without a GPS*" (Tristani, 2016, p. 108). This missing GPS (global positioning system) manifests as different swallowing challenges, from hyperphagia in frontotemporal dementia (FTD) to silent aspiration in Lewy body dementia (LBD). As a result of its varying presentation, explored further in section 2.4, dysphagia's prevalence is difficult to ascertain (Smith & Leslie, 2012). A systematic review of dysphagia prevalence in care homes found that figures ranged from 12 – 88% (McCartan et al., 2017), and estimates suggest that dysphagia's prevalence in dementia ranges from 13-57% (Alagiakrishnan, Bhanji, & Kurian, 2013). However, to recognise disordered swallowing, it is important to understand the normal swallow (Plowman & Humbert, 2018). Hence, the following section outlines the normal swallow and the impact of ageing on this process before describing breakdowns in the swallow.

2.3.1 The Normal Swallow

Swallowing is a complex process usually described as a series of stages or phases: the oral phase, the pharyngeal phase and the oesophageal phase (Groher, 2016a). Figure 2.7 illustrates these phases. A successful swallow requires the coordination of 30 muscles controlled by the cranial nerves (Shaw & Martino, 2013). The swallow's oral phase is predominantly volitional, whereas the oesophageal phase is involuntary (Shaw & Martino, 2013). Though the pharyngeal phase of the swallow is usually triggered automatically while eating, it can also be initiated volitionally (Groher, 2016a). The duration and effort needed to complete the phases depends on the consistency, the viscosity, and the amount of food or fluid (Cichero & Murdoch, 2006). This thesis will refer only to breakdowns in the swallow's oral or pharyngeal phases, known as oropharyngeal dysphagia.

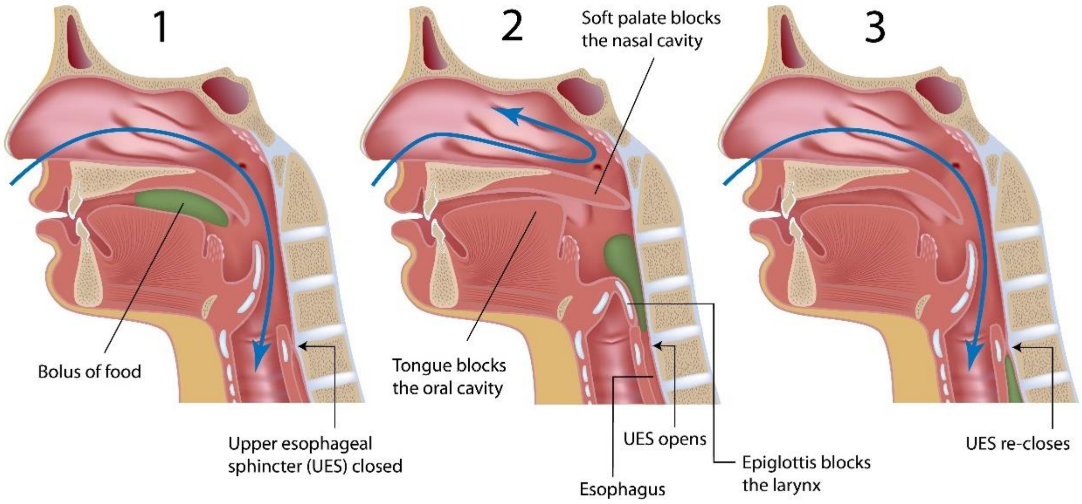


Figure 2.7 The phases of swallowing. Image ©Alila Medical Media/Adobe Stock.

The oral stage of swallowing has two parts: the oral-preparatory and oral transport phases (Groher, 2016a). The oral preparatory phase's primary goals are the breakdown of the bolus to an acceptable consistency and optimal positioning of the bolus for transport (Daniels & Huckabee, 2014). This phase requires adequate lip seal to contain the bolus, suitable dentition to masticate and break it down, good buccal tone and adequate mandible strength and range to support the masticatory process and aid bolus control, and good range, rate and strength of lingual movements to manipulate the bolus (van der Bilt, Engelen, Pereira, van der Glas, & Abbink, 2006). The oral transport phase aims to clear the bolus from the oral cavity and stimulate the reflexive swallow, thereby initiating the pharyngeal phase (Groher, 2016a). The initiation of the reflexive reactions and subsequent completion of the pharyngeal phase relies heavily on intact sensation.

The pharyngeal phase's primary objectives are airway protection through a carefully timed sequence of movements and the whole and complete transfer of the bolus into the oesophagus (Groher, 2016a). Once the tongue has moved the bolus beyond the faucal arches and the swallow initiates, the hyolarynx elevates and moves out to shorten and widen the pharynx (Shaw & Martino, 2013). The epiglottis inverts to cover the laryngeal vestibule, preventing the bolus from entering the airway (A. J. Miller, 2013). The vocal folds simultaneously close, causing a brief moment of apnoea to ensure the airway is protected (Groher, 2016a). The pharyngeal wall contracts and relaxes in a wave-like sequence known as peristalsis, which moves the bolus into the oesophagus, where it travels to the stomach (A. J. Miller, 2013). Given the complexity of coordinating these steps, there is scope for breakdown at any or all phases of the swallow. The ageing process also impacts the swallow.

2.3.2 Effects of Age on the Normal Swallow

The typical ageing process usually leads to asymptomatic functional changes in the swallow mechanism, known as presbyphagia (Ney, Weiss, Kind, & Robbins, 2009). This expected decline in swallow function is "*hypothesised to be the result of changes in the anatomy and physiology of the head and neck, muscle loss (sarcopenia), reduced functional reserve, and onset of age-related illness"* (Namasivayam-Macdonald & Riquelme, 2019, p. 229). Table 2.1, adapted from Cichero (2006a), outlines the impact age can have on the normal swallow. These changes primarily relate to decreases in power and increases in phase length, and they are largely supported by the findings of a recent systematic review (Jardine, Miles, & Allen, 2020a). However, contrary to Cichero, this review did not find an association between increased pharyngeal residue and presbyphagia. Furthermore, though the phases take longer than younger adults (Humbert et al., 2018), older adults maintain swallow efficiency (C. S. Lin et al., 2019).

Table 2.1 Impact of ageing on the normal swallow (from Cichero, 2006a)

Stage of Swallow	**Breakdown**
Pre-Oral/ Anticipatory	- Reductions in sense of smell and taste, perception of thirst (men), and regulation of fluid intake (men)
Oral Preparatory	- Ineffective mastication due to tooth loss - A reduction in masticatory strength

Stage of Swallow	**Breakdown**
Oral Transportation	- Increased time to complete the oral phase - Increased retention post swallow - Reduced tongue driving force (necessary to propel the bolus into the oropharynx) - Reduced suction pressure during straw drinking
Pharyngeal	- Delay in triggering the swallowing reflex - Increased pharyngeal transit time (women) - Increased pharyngeal residue post-swallow - Increased penetration, no increase in aspiration - More than one swallow needed to clear the bolus - Reduced laryngeal excursion reserve (men) - Reduced laryngeal and pharyngeal sensation

It is important to note that studies of age-related changes to swallowing are difficult to compare given the range of ages included, and relatively few studies include adults over the age of 85, leading to a gap in knowledge of the cumulative impact of age on the swallow (Jardine, Miles, & Allen, 2018). Interestingly, a study from New Zealand did not find a correlation between age and self-reported nutrition and swallowing challenges, suggesting that changes to the swallow should be investigated thoroughly and not just associated with ageing (Jardine, Miles, & Allen, 2020b). This finding appears to support the theory that presbyphagia and dysphagia exist on a continuum, and healthcare professionals need to be more aware of the potential for dysphagia to exist in older adults (de Lima Alvarenga, Dall’Oglio, Murano, & Abrahão, 2018). Further to this, Baijens et al. (2016) proposed dysphagia as a geriatric syndrome as its links to malnutrition and dehydration in older adults may lead to or worsen the development of frailty and sarcopenia, which can lead to further breakdowns of the swallow (Wirth et al., 2016).

2.3.3 Breakdown of the Swallow

Dysphagia can occur due to neurological changes or physical changes, for example, the presence of osteophytes (Sasegbon & Hamdy, 2017). Breakdowns in the oral-preparatory phase may include difficulties with lip seal, leading to bolus escape or issues with mastication and tongue movement, which can impact the types of food that can be eaten safely and efficiently (Malandraki & Robbins, 2013). Difficulties in the oral-transport phase may include problems with propelling the bolus to the back of the mouth, raising the velum to form a seal with the posterior pharyngeal wall to protect the nasal airway, and difficulty initiating the swallow (N Miller & Patterson, 2014).

Pharyngeal phase issues can involve a delay in triggering its initiation, leading to the bolus entering the pharynx prematurely, reduced base of tongue to pharyngeal wall contact leading to difficulties generating sufficient pressure in the pharynx, reduced hyolaryngeal excursion to support epiglottal movement to protect the laryngeal vestibule and the airway and to open the upper oesophageal sphincter, and reduced peristaltic force of the pharyngeal muscles leading to difficulty clearing the bolus from the pharynx causing pharyngeal residue (Malandraki & Robbins, 2013; Sasegbon & Hamdy, 2017). Premature bolus spillage into the pharynx, incomplete closure of the laryngeal vestibule, and the presence of pharyngeal residue can, independently and combined, increase the risk of aspiration and penetration (Vose &

Humbert, 2019). Penetration occurs when material enters the laryngeal vestibule but does not pass below the vocal folds, and aspiration occurs when material from the oropharyngeal or gastrointestinal cavities enters the airway and passes below the vocal folds (Han et al., 2016). Typically, if laryngeal sensation is intact, any material entering the airway will stimulate a reflexive cough to protect and clear the vestibule. If laryngeal sensation is impaired, aspiration can be silent, meaning that a reflexive cough is not stimulated. If any aspirated material is pathogenic, aspiration pneumonia can develop, though not all aspiration leads to pneumonia (DiBardino & Wunderink, 2015).

2.3.4 Evaluation of the Swallow

All members of the healthcare team should be aware of and able to identify the signs and symptoms of swallowing difficulties, but it is the SLT's remit to assess and diagnose dysphagia using instrumental or non-instrumental assessments (RCSLT, 2014a). Non-instrumental assessments, also known as clinical bedside examinations (CBE), are typically the SLT's first step in diagnosing dysphagia. Before the CBE, the SLT gathers information on the individual's medical and social history, the history of the suspected swallowing issues, and their current health (Cocks & Harding, 2012). During the CBE, the SLT typically assesses cranial nerve functioning by eliciting the range, rate, and accuracy of movement of the oral and pharyngeal structures (Groher, 2016b) before observing any challenges with food or fluid swallowing trials (Pettigrew & O'Toole, 2007). The CBE is a comprehensive examination, and, in many cases, it provides sufficient information for the SLT to plan management. However, it cannot confirm silent aspiration.

Instrumental assessments, on the other hand, do allow the identification of silent aspiration as they enable direct visualisation of the anatomy and physiology of the swallow. The most commonly used instrumental assessments are the videofluoroscopic swallow study (VFSS) and the fibreoptic endoscopic evaluation of swallowing (FEES) (Cichero & Langmore, 2006). These instrumental assessments allow the SLT to observe the risk of choking or aspiration when eating and drinking. The VFSS is considered the gold standard of objective assessment as it allows observations of the oral and pharyngeal phases of the swallow, while FEES can only provide detail of the pharyngeal phase (Steele, 2015). The VFSS enables evaluation of base of tongue retraction to the pharyngeal wall, hyolaryngeal elevation and excursion, bolus clearance from the pharynx, and the success of laryngeal closure (Groher, 2016b). The presentation of dysphagia in different dementias is unique, and the following section will outline what is known about dysphagia and mealtime difficulties in the most common dementias.

2.4 Presentation of Dysphagia and Mealtime Difficulties in Different Dementias

It can be challenging to ascertain from the literature how different dementias impact on the swallow and mealtimes, as not all research clearly delineates participants' type or stage of dementia. The following sections will outline what is known about dysphagia and mealtime difficulties in the different types of dementia.

2.4.1 Alzheimer’s Disease

Alzheimer's disease (AD) typically has a gradual, progressive decline with some plateaus (Mueller et al., 2019). The initial symptom is usually episodic memory loss, which then progresses to more widespread cognitive changes in language, executive functioning and visuospatial abilities (Ramirez-Gomez et al., 2017). Specific to dysphagia and mealtime difficulties, the degree of swallowing impairment correlates to the severity of the condition (Seçil et al., 2016), and there is an association between length of time living with dementia and eating dependency (Edahiro et al., 2012; Horner, Alberts, Dawson, & Cook, 1994). The following sections discuss the presentation of these issues.

2.4.1.1 Dysphagia in Alzheimer’s Disease

Table 2.2 presents an overview of dysphagia's presentation in AD from studies where the stage of AD was identifiable. The participant numbers in these four studies were relatively low, ranging from 10 (Priefer & Robbins, 1997) to 25 (Horner et al., 1994). Two studies had aged-matched controls (Humbert et al., 2010; Priefer & Robbins, 1997), while the other two had no control group (Horner et al., 1994; Vanderwegen & Van Vlasselaer, 2013). The findings from age-matched control group studies indicate that the issues presented did not reflect age-related changes. The studies had similar methodologies, primarily using VFSS and CBEs to determine the presentation across different stages. Table 2.2 demonstrates that oral and pharyngeal phase issues present early in the disease course with progressive worsening as disease severity increases. These studies identified a prolonged oral phase as an issue across all stages and delayed swallow initiation emerging in the moderate stages (Horner et al., 1994; Vanderwegen & Van Vlasselaer, 2013). The oral and pharyngeal phase issues became more significant as the disease progressed, with pharyngeal phase issues increasing the risk of aspiration (Horner et al., 1994; Humbert et al., 2010; Priefer & Robbins, 1997; Vanderwegen & Van Vlasselaer, 2013). The Humbert et al. study had a unique methodology; they used functional magnetic resonance imaging (fMRI) to compare the cortical activation of 13 people with mild AD and 11 age-matched controls completing swallow trials (Humbert et al., 2010). Their findings showed significantly less activation in the cortical swallowing network than controls and noted reduced hyolaryngeal excursion and elevation on VFSS.

Table 2.2 Dysphagia in Alzheimer's Disease

	Oral Phase Issues	**Pharyngeal Phase Issues**
Mild AD	- Prolonged eating duration[4] - Prolonged oral phase[3]	- Prolonged pharyngeal phase[3] - Reduced hyolaryngeal excursion and elevation[2]
Moderate AD	- Prolonged oral preparatory phase[1] - Reduced mastication[4] - Oral residue[4] - Prolonged oral-transit time[4]	- Delayed swallow initiation[1] - Reduced pharyngeal clearance[1]
Severe AD	- Prolonged oral preparatory phase[1] - Absent or continuous mastication[4] - Extensive oral residue[4]	- Delayed swallow initiation[1,4] - Reduced pharyngeal clearance[1] - Multiple swallows [4] - Coughing[4] - More likely to aspirate[1]

	Oral Phase Issues	**Pharyngeal Phase Issues**
	- Food loss from the oral cavity[4] - Biting reflexes[4]	
References	1. (Horner et al., 1994) 2. (Humbert et al., 2010) 3. (Priefer & Robbins, 1997) 4. (Vanderwegen & Van Vlasselaer, 2013)	

As mentioned above, the stage of AD was not clearly identifiable from all studies, though another study from Suh, Kim, and Na (2009) had comparable findings in a study of people with AD at varying stages of the disease. From VFSS, this study identified oral residue and food pocketing as well as oral transit delays of over five seconds, delayed initiation of the swallow reflex, pharyngeal residue, and material penetration to the laryngeal vestibule. Similarly, Seçil et al. (2016) identified an increased latency in swallowing and a need for more swallows in sequential swallowing when compared to age-matched controls using submental/suprahyoid electromyography (SM-EMG; where electrodes are placed on the skin to measure sympathetic skin responses during swallowing). This study adds to the evidence base as they indicate that a significant loss of functional reserve that worsens with disease progression has implications for the assessment and management of dysphagia at all stages of this dementia.

Overall, there remain many gaps in the available knowledge about the impact of AD on the swallow. The research evidence is hampered by small sample sizes, inconsistent use of age-matched controls, and variable reporting of AD severity.

Nevertheless, what is clear from the research is that swallow changes appear early in the disease, across both phases of the swallow, progressively worsen with the condition, and they have implications for the health and well-being of people with AD.

2.4.1.2 Mealtime Difficulties in Alzheimer's Disease

Though the strength of the evidence varies, mealtime issues develop early in AD and persist throughout the disease. Durnbaugh et al. (1996) classified mealtime difficulties into four categories: resistive/disruptive behaviours (for example, attempting to leave the meal or being distracted from the meal), oral behaviours (e.g., food holding), the pattern of intake (for instance, a preference for sweet foods), and style of eating (such as the incorrect use of cutlery or crockery). These categories became the basis for the Feeding Behaviour Inventory, which measures mealtime difficulties in mid-stage dementia. They found the most common issues at mealtimes (in order) were distractibility, eating non-finger food with the hands, playing with food or non-food items, eating too-large pieces of food, and a preference for sweet food to the detriment of other food items. Though the study sample is relatively small, the scale in this study has good face validity given the efforts made to triangulate evidence from the literature and clinical practice and the endeavours to refine the scale items through expert review and consensus. Other studies identified similar issues to the ones listed by this scale; for example, several authors identified changes in taste and food preference (Aliani et al., 2013; Doorduijn et al., 2020; Easterling & Robbins, 2008; Mungas et al., 1990). However, other research has not attempted to categorise the nature of mealtime difficulties by dementia stage or type. Table 2.3 provides an overview of the mealtime difficulties identified in AD across the different stages.

Table 2.3 Mealtime Difficulties in Alzheimer's Disease

Stage of AD	**Mealtime Difficulty**
Early AD	Resistive or disruptive behaviours - Increased restlessness leading to an increased caloric need[16] - Agitation and distractibility at mealtimes[16] - Prompting and assistance to complete meal preparatory tasks[14] Pattern of Intake - Forgetting meals causing unintentional weight-loss[2] - Eating out-of-date food (may lead to illness)[2] - Anosmia leading to changes in food preference[1,3] - A preference for sweeter foods[4,5,6,13]
Moderate to Advanced AD	Pattern of Intake - A preference for eating carbohydrates[8,10] - Aversion to protein sources linked to disinhibition, agitation and irritability[8] - Changes to meal timings[11] Independence in Eating - Difficulty in initiating a meal[7,117,8] - Issues recognising and using utensils[5,7,12, 18] - Distractibility/difficulty sustaining attention during a meal[5,7,15] - Difficulty maintaining alertness[7] - Difficulty preparing meals[12] - Difficulty self-feeding[18] - Attempting to leave the meal[5,15,17]

Stage of AD	**Mealtime Difficulty**
	Food behaviours - Oral behaviours (e.g. food holding)[5,17] - Eating non-finger food with hands[5] - Playing with food or non-food items[5] - Eating too-large pieces of food[5] - Require prompting to eat[17] - Refusal to eat[17]
1. (Aliani et al., 2013) 2. (Bayles & Tomoeda, 2014) 3. (DeVere, 2017) 4. (Doorduijn et al., 2020). 5. (Durnbaugh et al., 1996) 6. (Easterling & Robbins, 2008) 7. (Edahiro et al., 2012) 8. (Greenwood et al., 2005) 9. (K. M. Lee & Song, 2015)	10. (K. W. H. Young, Greenwood, Van Reekum, & Binns, 2005) 11. (LeClerc & Wells, 1998). 12. (Mungas et al., 1990). 13. (Priefer & Robbins, 1997) 14. (Rivière et al., 2002) 15. (Rogus-Pulia et al., 2015). 16. (Volicer et al. 1989) 17. (Wu & Lin, 2015)

There is a strong correlation between dementia severity and independence in eating. Priefer and Robbins (1997) found that people with mild AD require prompting and assistance to complete preparatory tasks for meals. They found that automatic tasks like continuing to eat once the meal started presented less difficulty than controlled tasks. These controlled tasks require cognitive processing, such as opening a container to add a condiment. However, as dementia severity increases, issues such as overt signs of dysphagia, difficulty in initiating a meal, problems using utensils, trouble sustaining attention during a meal, and difficulty maintaining alertness occur more frequently (Edahiro et al., 2012). Independence and retained skill at mealtimes have both been linked to cognition and, with disease progression, multiple other factors can also impact mealtime ability. Lee and Song (2015) found that in addition to cognitive function, physical function, degree of visual impairment, duration of illness, duration of care home residence, where they ate the meal, and the type of diet were all predictive of mealtime difficulties. Rivière and colleagues' (2002) study of 244 people with AD (intervention group *n* = 150, control group *n* = 74) who lived at home with their carers demonstrated an association between mealtime difficulties, cognitive impairment and caregiver stress. Mealtime difficulties were significantly associated with the carer’s age, the severity of the cognitive change, and the person with dementia’s psychological functioning. Increased mealtime difficulties were also associated with mood and behaviour disorders. These findings are significant for managing mealtime difficulties. They identify the need to provide increased support to carers of people with dementia due to the association between their perceived burden and the development of mealtime difficulties.

Furthermore, ideational apraxia occurs more commonly in AD than other dementias (S. Ahmed, Baker, Thompson, Husain, & Butler, 2016). This apraxia influences the ability to prepare and eat meals, plan and execute purposeful movements, initiate, sequence and complete actions, and identify and use tools such as cutlery appropriately (LeClerc & Wells, 1998). From their study in a care home environment, Wu and Lin (2015) found that ideational apraxia led to issues initiating, completing, and sequencing eating tasks and affected the self-feeding ability of 25% of their sample. Ideational apraxia and self-feeding difficulties were associated with more advanced dementia. The authors hypothesised that loss of cognitive reserve enabled people with dementia to compensate in the earlier stages (Wu & Lin, 2015).

The mealtime issues in AD are variable and likely to significantly impact the person with AD’s ability to engage at a mealtime. Though there is an extensive range of issues identified, most studies have not been replicated. As such, it is not possible to build a profile of how mealtime difficulties in dementia change across the spectrum of the condition. In addition, the studies did not differentiate clearly between moderate and advanced AD. Many of the issues are related to cognitive changes, which are likely to follow a similar but not identical pattern in individuals. The main takeaway from these findings is the need to examine the person with AD in a mealtime context and to anticipate the presentation of mealtime difficulties.

2.4.2 Vascular Dementia

In vascular dementia (VaD), damage to the grey and white matter of the brain occurs as a result of vascular pathologies (Passmore, 2018). Repeated cerebrovascular damage leads to diffuse challenges, and VaD is said to have a ‘stair-step’ decline of repeated sudden decline followed by a plateau (Bayles et al., 2020). The cognitive changes are difficult to predict and depend on the location and severity of the pathological changes, though alterations in mood and behaviour are common (E. E. Smith, 2017). VaD frequently co-occurs with AD (Ramirez-Gomez et al., 2017).

2.4.2.1 Dysphagia in Vascular Dementia

Dysphagia’s presentation in VaD is under-researched, and as with the profile of its cognitive changes, also difficult to predict. Furthermore, the occurrence of cerebrovascular events may mean that dysphagia is treated as stroke-related and not associated with dementia. This may explain the dearth of research in this area. A paper from Stach (2000) described oral phase issues such as reduced rate, repetitive lingual movements and delayed oral transit, and pharyngeal issues such as the delayed triggering of the pharyngeal swallow, reduced hyolaryngeal excursion, and incomplete closure of the laryngeal vestibule. It is difficult to ascertain these findings' credibility, as no formal assessments were performed. The conclusions appear to be predominantly based on hypotheses of impairment following cerebrovascular injury and the author’s clinical experience (Stach, 2000). However, a study from Suh and colleagues (2009), which applied more reliable methods, confirmed some of Stach’s observations.

Their VFSS study of 34 people with VaD also identified pharyngeal phase issues such as delayed swallow initiation, reduced hyolaryngeal excursion, reduced epiglottic inversion, and pharyngeal residue (Suh et al., 2009). Additionally, around two-fifths of the sample had issues with mastication and bolus formation. Just over half of the sample had laryngeal penetration, and just under half aspirated, with 32% aspirating silently (Suh et al., 2009). This study's main issue is the small sample size (*n* = 34) and its singularity as a dysphagia in VaD study. Furthermore, the authors speculated that the issues observed in VaD are primarily motor, given the reduced movement in the pharyngeal phase. Although, given the incidence of silent aspiration and the delay in swallow initiation that acts as a trigger to relay sensory input to the cortex which then initiates the pharyngeal phase, a valid alternative explanation is that the deficits relate to incomplete or reduced afferent nerve functioning. Overall, there is insufficient research available to make definitive claims about the nature of dysphagia in VaD. However, the nature of the disease mechanism tells us that the probability of dysphagia occurring is high, and clinical evaluation of people presenting with VaD should be prioritised by services.

2.4.2.2 Mealtime Difficulties in Vascular Dementia

Due to the variable presentation and issues around developing subtypes of VaD, the course and presentation of symptoms can be difficult to predict. There is no research evidence available to develop a profile of mealtime difficulties in VaD.

2.4.3 Frontotemporal Dementia

FTD refers to frontal and temporal lobe degeneration resulting in a spectrum of conditions that lead to progressive dysfunction in executive functioning, behaviour, language and motor symptoms (Olney, Spina, & Miller, 2017; Radhakrishnan & Jauhari, 2018). This syndrome has two primary subtypes: language and behaviour (J. J. Young, Lavakumar, Tampi, Balachandran, & Tampi, 2018). The behavioural variant's (bvFTD) initial symptoms are impulsiveness, apathy, disinhibition, and personality changes (Radhakrishnan & Jauhari, 2018). In the language variant, also known as primary progressive aphasia (PPA), the initial symptoms are changes to speech and language and this subtype is further divided into three variants, nonfluent–agrammatic (nfvPPA), semantic (svPPA), and logopenic (lvPPA) (Marshall et al., 2018). FTD is also closely associated with motor neurone disease (MND), progressive supranuclear palsy, and cortico-basal degeneration (Olney et al., 2017).

2.4.3.1 Dysphagia in Frontotemporal Dementia

Dysphagia in FTD is relatively understudied in comparison to the more overt presentation of mealtime difficulties. Despite this, there is some evidence to suggest that dysphagia is a likely occurrence that clinicians should consider. For instance, a study of eating behaviours in FTD (bvFTD = 23, svPPA = 25) and AD (*n* = 42) found that swallowing problems developed later in the two variants of FTD, typically as the third to fifth symptom, than in AD where they presented relatively early often as the first or second symptom (Ikeda, Brown, Holland, Fukohara, & Hodges, 2002). In the study, close family caregivers noted any changes they observed across five areas: swallowing, appetite, food preferences, eating habits, and other oral behaviours. Section 2.4.3.2 discusses the issues with mealtime aspects identified by this study. One limitation of this study is that it is based on caregiver report and not corroborated by standardised assessments. However, this could also be viewed as a strength of the method as it identified the issues the caregivers found most challenging, and it is useful for clinicians to consider the issues that carers face at different stages. It can also be helpful to compare self- and carer reports, as per a later study by Langmore and colleagues (2007).

In Langmore's study, they interviewed people with FTD and their carers and conducted CBE and FEES assessments (Langmore, Olney, Lomen-Hoerth, & Miller, 2007). Many of the people with FTD did not identify issues with eating in the interviews. However, caregivers reported behavioural feeding issues (discussed in section 2.4.3.2), and four caregivers identified swallowing issues, principally occasional choking. The researchers reported the participants as one group due to the small numbers (bvFTD = 9, nfvPPA = 7, svPPA = 5) and also assessed nine healthy similarly aged but not aged-matched older adults using FEES. From the FEES evaluation, the FTD group had excessive premature bolus leakage into the pharynx during mastication, and this appeared to be more evident in the bvFTD subgroup. Swallow initiation was also significantly delayed, and it occurred when the bolus was at the level of the valleculae or midway down the pharynx. The control group initiated swallowing when the bolus was in the oral cavity or had moved to the base of the tongue. One-third of the FTD group had pharyngeal residue after the swallow; none of the control group had residue. Bolus leakage, delayed swallow onset, and pharyngeal residue significantly increase the likelihood of aspiration. However, just one person with svPPA aspirated during the assessment, and the authors report that the three FTD groups did not vary significantly from each other. Based on the CBE findings, the authors had not anticipated the pharyngeal leakage and swallow delay issues identified by the FEES. Despite the small sample size, the dysphagia characteristics this study identified have significant implications for the management of FTD and the importance of regular objective swallowing assessment.

2.4.3.2 Mealtime Difficulties in Frontotemporal Dementia

Altered eating behaviours are often one of the first signs of FTD, and despite differing methodologies, there is substantial agreement across the literature on their presentation. These changes include an increase in appetite or impairment in satiety (R. M. Ahmed et al., 2014, 2015; Ikeda et al., 2002; Mendez, Licht, & Shapira, 2008), hyperphagia (R. M. Ahmed et al., 2015; Ikeda et al., 2002; Mendez et al., 2008; Whitwell et al., 2007), an increased preference for sweet foods (R. M. Ahmed et al., 2014, 2015; Ikeda et al., 2002; Whitwell et al., 2007), inappropriate responses if food is not available (Mendez et al., 2008), improper eating (R. M. Ahmed et al., 2014; Mendez et al., 2008), and changes to eating habits (R. M. Ahmed et al., 2014).

These changes in eating behaviours, such as the development of a sweet tooth and hyperphagia, are associated with cortical changes, such as grey matter loss (Whitwell et al., 2007). An MRI and fasted blood analysis study identified that eating changes in FTD are multifactorial from a comparison of bvFTD (*n* = 19), svPPA (*n* = 26), and AD (*n* = 30) with 23 controls (R. M. Ahmed et al., 2015). The participants with bvFTD and svPPA scored higher on questionnaires of eating behaviours indicating greater levels of difficulty, though they had no differences in most bloodwork analyses. MRI results showed that eating changes in bvFTD are partially associated with degeneration of the hypothalamus and its networks with cortical reward pathways. The svPPA group had preserved hypothalamic pathways. Though this study has a relatively small sample size, it provides some potential treatment targets to reduce these symptoms in people with FTD.

Other studies used caregiver reported measures. Mendez et al. (2008) used a food-related problems questionnaire rated by caregivers of 16 people with FTD and 16 people with AD to compare mealtime difficulties. They found that the FTD group had significantly more changes in these behaviours than the AD group. Another study using caregiver reported measures compared the eating and mealtime behaviours of people with bvFTD (*n* = 21), semantic dementia (*n* = 26), and AD (*n* = 28) to 18 age-matched controls (R. M. Ahmed et al., 2014). They weighed participants, and the participants completed measures of hunger and satiety. Again, they found that the bvFTD group had significant abnormalities. The study would have benefitted from examining caregiver stress related to these behaviours to determine if they cause undue strain but overall, it provides a comprehensive insight into the mealtime difficulties associated with the two variants of FTD. Both studies highlight the importance of using carer report to examine behaviours that may not be seen in clinical environments. Clinicians supporting people with all FTD variants must be aware of the likelihood of these individuals presenting with mealtime difficulties. Future research needs to consider the impact these challenges have on the well-being of both the person with dementia and their caregivers.

2.4.4 Lewy Body Dementia

LBD is an umbrella term that encompasses dementia with Lewy bodies (DLB) and Parkinson’s disease dementia (PDD). Though they share pathological and clinical characteristics, typically in DLB, cognitive symptoms occur early in the disease, while PDD develops in the course of an established diagnosis of idiopathic Parkinson’s disease, where motor symptoms are the initial challenge (J. P. M. Kane et al., 2018). In DLB, the primary cognitive deficits are in visuospatial functioning, attention, and executive functioning (Sanford, 2018). Memory is generally intact in the early stages, but it may decline with disease progression (Lerner, 2018).

2.4.4.1 Dysphagia in Lewy Body Dementia

The research describing dysphagia's presentation in LBD is limited by studies with small sample sizes and insufficient detail on the dementia stage and the swallow phases. However, as a five-year retrospective case review study of the post-mortem records of seven people with Parkinson's Disease and 12 with PDD found that over half of all participants had malnutrition, and 25% of the PDD group had a diagnosis of dysphagia (Bine, Frank, & McDade, 1995), there is evidence for the need to consider swallow assessment and dysphagia management for those with PDD. Although this study had a small sample, the data available varied, and the dysphagia measures were not standard across participants, it highlights the need to understand how dysphagia may present in LBD. Similarly, another study that compared Parkinson's disease (*n* = 90) with LBD (*n* = 45) found that 83% of those with LBD who aspirated on VFSS developed pneumonia within two years compared to 4% in the group who did not aspirate (Yamamoto, Kobayashi, & Murata, 2010). The LBD group's breakdown into DLB and PDD was not provided, so the impact of the differing presentation on the likelihood of developing pneumonia cannot be determined. Furthermore, though their study does not describe the oral and pharyngeal phase issues observed on VFSS, these findings emphasise the need to screen and assess people with LBD for pharyngeal phase dysphagia. Table 2.4 provides an overview of the dysphagia presentation in moderate LBD with issues noted in both the oral and pharyngeal phases.

Table 2.4 Dysphagia in Lewy Body Dementia

Stage of LBD	**Oral Phase Issues**	**Pharyngeal Phase Issues**
Moderate LBD	- Oral phase issues not otherwise specified[2]	- High rate of silent aspiration[1,2,3] - Pharyngeal residue[1,2]

Stage of LBD	Oral Phase Issues	Pharyngeal Phase Issues
	- Taking a long time to swallow[4] - Delayed swallow initiation[2] - Self-rated difficulties in swallowing food and liquids[4]	- Poorly coordinated respiration during swallowing[3] - Coughing or choking when swallowing
Unclear Stage		- High rate of aspiration, often silent[5]
References	1. (Larsson, Torisson, Bülow, & Londos, 2017) 2. (Londos et al., 2013) 3. (Monteiro et al., 2014) 4. (Shinagawa et al., 2009) 5. (Yamamoto et al., 2010)	

One notable issue to emerge is how self-rating of swallowing issues may not be a suitably sensitive screen for people with LBD. A comparison of swallowing issues among people with DLB and AD (both *n* = 29) found that the DLB group scored significantly higher than the AD group for self-rated difficulties in swallowing food and liquids, coughing or choking when swallowing, and taking a long time to swallow (Shinagawa et al., 2009). However, the participants' dementia stages ranged widely, and it was unclear whether this would have an impact. Yamamoto et al.'s (2010) study found that 55% of the LBD group presented with silent aspiration, and many did not self-report any swallowing difficulties. Further investigation is needed to determine specific patterns and profiles of people with LBD who do or do not self-report issues. The specificity of the questioning used also needs to be considered. For instance, another study used self-report in both subtypes of LBD to screen their participants for

VFSS referral (Londos et al., 2013). They asked: "*Are you experiencing any kind [*sic*] swallowing difficulties? Do you have coughing problems (daytime or nighttime)?"* (p. 2). This design was likely chosen for ethical reasons, i.e., minimising unnecessary radiation exposure, but this question is likely not sensitive enough to uncover swallowing concerns. A thorough case history and a CBE may have been more sensitive measures and identified more subtle issues. As a result of the insensitive screening measure, though their study recruited 82 participants with LBD, just 26 self-identified as having swallowing difficulties and were assessed by VFSS (DLB: *n* = 20, PDD: *n* = 6) (Londos et al., 2013). Had they used a more sensitive measure or a broader approach to enrolment in the VFSS strand, a more detailed picture of swallowing in LBD could have been developed and allowed more significant insights into how dysphagia develops in this population.

The Londos study does, however, provide some insights. Notwithstanding the disparity in number between the two groups, both groups presented with similar issues during VFSS, and there were no statistically significant differences between the groups (Londos et al., 2013). Two participants had no dysphagia following VFSS. Pharyngeal issues were common (88%, *n* = 23), with participants presenting with delayed swallow initiation (62%), pharyngeal residue (50%), and aspiration or penetration (42%). Twelve participants (46%) had oral and pharyngeal issues on VFSS, and only one had solely oral phase issues. Oral phase issues were not broken down in reporting. On follow-up, the researchers found that 12 of the 24 participants with dysphagia had died. Pneumonia was the cause of death in nine of these cases. This finding was statistically significant compared to the 56 participants without dysphagia as 13 had died, but pneumonia was the listed cause of death for just four. A study by some of the same researchers retrospectively reviewed VFSS footage and found that 40 of their 48 participants had confirmed dysphagia on VFSS, 34 had pharyngeal phase issues, and 14 did not self-report any swallowing problems (Larsson et al., 2017). Again, the study found that both subtypes (DLB: n = 38, PDD: n = 10) had similar swallow profiles, with around 50% presenting with pharyngeal residue and 27% observed to aspirate, some silently.

The regularity with which these studies identified pharyngeal issues, particularly silent aspiration, suggests that dysphagia in both DLB and PDD may be over-looked if objective assessments are not a routine assessment. The occurrence of silent aspiration has significant implications for people with LBD's health and well-being, given the likely development of aspiration pneumonia among those who aspirate (Yamamoto et al., 2010).

2.4.4.2 Mealtime Difficulties in Lewy Body Dementia

There is limited evidence from the research on the mealtime issues in LBD. Shinagawa et al. (2009) identified that the primary issues were loss of appetite and requiring assistance at the meal. Like AD, idiopathic Parkinson’s disease and LBD are associated with loss of smell and taste in their early stages, impacting the desire to eat and food preferences (DeVere, 2017; Doty, 2018). These findings indicate that more research is needed, and practitioners should consider the impact on mealtimes when supporting people with LBD.

2.4.5 Summary

The presentation of mealtime difficulties and dysphagia demonstrates significant variation and variability across the dementias. For instance, the literature illustrates the significant impact that AD has on mealtimes, with mealtime issues related to attention and cognitive changes such as the development of apraxia. On the other hand, the mealtime issues in FTD relate to the executive functioning changes experienced in this condition, with impulsive eating and over-eating dominating the presenting symptoms. The tables included in several sections also highlight the variation of dysphagia across the stages of dementia. The literature points to early changes in swallow processes in AD, while the evidence for LBD highlights that this group is at particular risk of silent aspiration. Unfortunately, outside of AD, the available literature does not allow clinicians to draw definitive conclusions on when swallowing issues emerge. However, the silent changes in FTD and LBD should make this a priority issue for researchers. This overview of the challenges associated with each dementia highlights the need to consider the differential dementia diagnosis when exploring assessment and management with this client group. Nevertheless, before management can begin, healthcare professionals need to have effective referral systems in place that can identify when support is needed. The next section will look at the screening tools that are used to identify dementia-related mealtime difficulties and dysphagia.

2.5 The Identification of Dysphagia and Mealtime Difficulties

Family carers and care and nursing staff must have the means to identify issues with swallowing and mealtime skills, also known as case finding, and seek appropriate support from relevant health professionals. For the family carer, this involves educating them about issues that may develop and ensuring they have an appropriate point of contact, such as a General Practitioner (GP) or nurse specialist, to support them with an onward referral. For care and nursing staff, there is an expectation that they would receive training around these issues in order to recognise and manage them (discussed further in section 2.7.1). However, how they identify which issues they can manage intramurally or if they need to seek support is unclear. The need for appropriate tools that are "*simple, quick, easy to use and sensitive enough to detect changes in risk*" for mealtime difficulties and dysphagia is clear (Niezgoda, Keller, Steele, & Chambers, 2014, p. 1). There is also an acknowledged need for standardised onward referral protocols for at-risk people with dementia to receive further evaluation (Park, Bang, Han, & Chang, 2015). It is important to note that a screen cannot diagnose a particular condition or impairment; instead, it evaluates the likelihood of such a condition being present (Walshe, Ryan, & Regan, 2017). Daniels and Huckabee (2014, p. 55) define a screen as "*a brief assessment that is easy to administer and minimally invasive"*. Still, it is uncertain how screening and onward referral occur in clinical practice and which, if any, tools are used.

One issue is that the literature around mealtime and dysphagia screening tools in dementia is limited, and often tools developed for one population are applied to others without further validation. For example, most dysphagia screening literature comes from an acute stroke population whose needs vary significantly from those of a typically more medically stable population with dementia. Additionally, though the evidence shows that post-stroke dysphagia screening decreases pneumonia risk, even when adjusted for stroke severity (Hinchey et al., 2005), the evidence for the efficacy of screening in reducing complications and improving access to services for dementia populations is lacking. The primary goal of screening with an acute stroke population is to reinitiate oral feeding as soon as possible post-stroke and allow the intake of medications (Daniels & Huckabee, 2014). However, the goals of care in dementia are less immediate, though early identification is essential to ensure that management strategies are put in place to prevent or reduce the negative impacts of dysphagia before they become detrimental to the individual’s health, well-being, and quality of life.

Furthermore, people with dementia often reside at home or in home-like environments such as care homes where access to specialist dysphagia services may be limited (O’Loughlin & Shanley, 1998; Park et al., 2015; Steele et al., 1997), while there is usually quick and efficient access to SLT services for those recovering post-stroke in hospitals. Moreover, the approach to post-stroke screening is not appropriate for dementia. Post-stroke swallow screens tend to be binary; allow oral feeding or place the individual nil by mouth until acute post-ictal effects resolve. This binary approach is inappropriate for dementia due to the progressive nature of swallowing and cognitive impairment and the guidance that non-oral feeding is not recommended in dementia (Harwood, 2014; Lacey, 2004; Palecek et al., 2010). In addition, it is inappropriate to instigate nil by mouth status pending SLT or specialist follow-up if there is no access to immediate follow-up. This reinforces the need to use dysphagia screening and case-finding tools that are developed with a dementia population in mind.

Regrettably, this is not a straightforward task, as exemplified by the findings of a review of dysphagia screening tools suitable for care home environments (Park et al., 2015). This review of 29 screening tools concluded that the Gugging Swallowing Screen (Trapl et al., 2007) and the Standardised Swallowing Assessment (Perry, 2001a, 2001b) were the most appropriate for a care home population. However, both of these tools were developed for post-stroke dysphagia in acute hospitals and are not validated on care home populations. They recommend placing people nil by mouth pending further assessment when a cut-off is reached, and neither screen considers mealtime difficulties. Consequently, these screening tools do not meet the basic requirements for a dementia or care home environment screening tool.

Clinicians must also ensure that their routinely used screening tools are valid, reliable, and feasible (Campbell et al., 2015; Daniels & Huckabee, 2014; Leder & Suiter, 2014), although the available battery profile makes this challenging (Aselage, 2010; Park et al., 2013). Validity appraises whether tools evaluate what they purport to, while reliability measures how precisely the screen works (Navarro, 2014). Feasibility allows the user to determine how easy a tool is to use and is a paramount concern when examining the multi-faceted nature of dysphagia and mealtime difficulties. In dysphagia screening, the desired outcomes are measures of the risk of dysphagia or aspiration (Daniels & Huckabee, 2014). This viewpoint has limitations for a dementia population whose feeding, eating, drinking and swallowing difficulties often go beyond the physiological and are impacted by cognitive and sensory factors (Alagiakrishnan et al., 2013; Easterling & Robbins, 2008), and as such, mealtime screening is complex.

Furthermore, for a screening tool to be effective, it needs to be comparable to the gold standard diagnostic tool, sensitive enough to avoid false negatives and specific enough to avoid false positives (Campbell et al., 2015). There is no gold standard assessment for mealtime difficulties, but for dysphagia, the accepted diagnostic gold standard instrumental assessments are VFSS and FEES (Bours, Speyer, Lemmens, Limburg, & De Wit, 2009). However, given what is known about the cognitive, sensory and motor impairments associated with dementia, the limitations of rehabilitative approaches (Alagiakrishnan et al., 2013), and the current guidelines advocating against enteral feeding (Royal College of Physicians, 2010), it may be inappropriate, intrusive, and ethically dubious to perform an invasive exam such as these in individuals with cognitive impairment (P. A. Smith & Leslie, 2012). As such, in the dysphagia screening literature, there has been limited validation of screens against an objective assessment in vulnerable populations. Additionally, there has been a shift in the dementia literature towards functional, observation-based assessments in the individual’s environment and context to document mealtime difficulties in a more naturalistic context (Lambert, Gisel, Groher, & Wood-Dauphinee, 2003). The Irish Association of Speech and Language Therapists (IASLT, 2016a, p. 2) emphasise that “*there is currently only evidence to support the use of* *swallow screening in stroke in acute care settings*". The heterogeneity and variability in the screens available support this standpoint.

In line with this, table 2.5 presents the dysphagia and mealtime difficulties screens designed for use with older adults or a dementia population examined under these criteria. The purpose of reviewing these screens was to determine, from the available literature, whether a suitable screening tool exists to identify mealtime difficulties and dysphagia in dementia in order to instigate an onward referral. As can be seen from the table, there is a dearth of well-developed, validated screens suitable for mealtime and dysphagia identification in dementia. The reviewed screens lack robust validity, reliability, and feasibility measures, and no screen was suitable for both mealtime difficulties and dysphagia. It remains unclear whether any of these screening tools have made the transition to use in practice.

From these tools, the Dementia Mealtime Assessment Tool (D-MAT) (Martin, 2016), the Edinburgh Feeding Evaluation in Dementia (EdFED) (Watson, 1994; Watson, MacDonald, & McReady, 2001), the Pre-Feeding and Swallowing Assessment Checklists (O'Loughlin & Shanley, 1998), and the Feeding Behaviour Inventory (Durnbaugh et al., 1996) demonstrated potential as mealtime screeners. However, they all lacked robust psychometric testing and considerations of dysphagia and aspiration risk. Strengths of the DMAT (Martin, 2016) and the Pre-Feeding and Swallowing Assessment Checklists (O'Loughlin & Shanley, 1998) were their 'recipe book' approach that provided staff with recommendations for immediate environmental or individual modifications. Though the EdFED (Watson et al., 2001)

Table 2.5. Screening Tools for Mealtime Difficulties and Dysphagia

Name	**Setting**	**Developed for:**	**Dementia-specific**	**Validated: VFSS/FEES**	**Validity**	**Sensitivity & Specificity**	**Reliability**	**Feasibility**
Mealtime Difficulties								
Eating Behaviour Scale (Tully, Matrakas, Muir, & Musallam, 1997)	Care home	Nursing and Care Staff	✓	×	✓	×	✓	×
Pre-feeding Assessment Checklist; Swallowing Assessment Checklist (O’Loughlin & Shanley, 1998).	Care home	Nursing and Care Staff	×	×	×	×	×	×
The Level of Eating Independence Scale (Coyne & Hoskins, 1997)	Care home	Care staff	✓	×	×	×	✓	×
EdFED	Care home	Nursing Staff	✓	×	×	×	✓	×

Name	**Setting**	**Developed for:**	**Dementia-specific**	**Validated: VFSS/FEES**	**Validity**	**Sensitivity & Specificity**	**Reliability**	**Feasibility**
(Watson, 1994, 1997; Watson et al., 2001)								
The Feeding Behaviour Inventory (Durnbaugh et al., 1996)	Care home	Nursing Staff	✓	×	×	×	×	×
Structured Meal Observation (Reed, Zimmerman, Sloane, Williams, & Malaz, 2005)	Care home	Care Staff	✓	×	✓	×	✓	×
D-MAT (Martin, 2016). Commercially available;	Any	Nursing and Care Staff	✓	×	×	×	×	×

Name	**Setting**	**Developed for:**	**Dementia-specific**	**Validated: VFSS/FEES**	**Validity**	**Sensitivity & Specificity**	**Reliability**	**Feasibility**
not published in peer-reviewed journals.								
Dysphagia								
Simple Bedside Swallowing Test (Sitoh, Lee, Phua, Lieu, & Chan, 2000)	Acute hospital	Doctors	×	×	×	×	✓	×
Dysphagia Screening Questionnaire (Kawashima, Motohashi, & Fujishima, 2004)	Community-dwelling	Self-administered or carer-completed	×	×	×	×	✓	×
Patients' Awareness of Symptoms of Dysphagia (Boczko, 2006)	Long-term care and sub-	Any healthcare staff	×	×	×	×	×	×

Name	**Setting**	**Developed for:**	**Dementia-specific**	**Validated: VFSS/FEES**	**Validity**	**Sensitivity & Specificity**	**Reliability**	**Feasibility**
	acute facilities							
The 3-ounce water swallow test (Suiter & Leder, 2008)	Acute Hospital	Any healthcare staff	×	FEES	✓	✓	✓	✓
Yale Swallow Protocol (Leder & Suiter, 2014)	Acute Hospital	Any healthcare staff	×	FEES	✓	✓	✓	✓
EAT-10 (Belafsky et al., 2008)	Any setting	Self-administered	×	×	✓	×	✓	×

is simple to administer, it might be more useful as a grading or outcome measure as it has limited functionality past identifying features of mealtime difficulties. It does not outline directions for management or onward referral. The Feeding Behaviour Inventory (Durnbaugh et al., 1996) has potential as a tool to evaluate feeding behaviour though consideration of dysphagia and aspiration risk and quantifying these behaviours beyond present or absent would strengthen this tool.

From the dysphagia screens, the Yale Swallow Protocol (Leder & Suiter, 2014), based on the Water Swallow Test (Suiter & Leder, 2008), is validated against standardised measures. It claims to be appropriate for dementia, though it has a low threshold for recommending nil by mouth and a high false-positive incidence. Following their procedure faithfully would mean placing people nil by mouth until SLT assessment (Leder & Suiter, 2014), which has ethical implications for a population with dementia. The assessment methods are also decontextualised and removed from the patient’s functional performance and ability in their natural environment.

In order to appropriately screen this population and redirect for further assessment, caregivers and professionals involved in the provision of mealtimes and feedings must have appropriate tools available. This lack of appropriate and comprehensive screening tools could lead to new cases not being referred early enough or high numbers of inappropriate referrals. Given the complex nature of mealtime and swallowing difficulties and the varied nature of the lived experience of people with dementia, it is evident that individuals caring for and supporting them require clear guidelines and directions for identifying signs and symptoms of aspiration and dysphagia. A screen cannot be an endpoint in management. Carers must be aware of indicators for onward referral to AHPs and practical, evidence-based strategies to manage dysphagia and mealtime difficulties for people with dementia. The next section discusses what is known about interventions to manage these issues.

2.6 The Speech and Language Therapist’s Role in Managing Dysphagia and Mealtime Difficulties

When dysphagia is present, its management tends to be a priority issue for healthcare teams due to its direct impact on health and well-being. However, it is generally uncertain how these healthcare professionals manage these issues in practice. The most efficient way to determine if and how clinicians apply research evidence and developments to their clinical practice is by surveying them. This enquiry enables researchers to gain a snapshot into work practices and conventions. Though a relatively small body of literature exists that allows an insight into SLTs’ general approach to dysphagia management, no identified research provides insights into how they manage mealtime difficulties. The majority of surveys provide broad-strokes overviews of dysphagia management, except for a few studies examining specific conditions more closely, for example, stroke (Archer, Wellwood, Smith, & Newham, 2013; Jones, Cartwright, Whitworth, & Cocks, 2017), Parkinson’s Disease (N. Miller, Deane, Jones, Noble, & Gibb, 2011), and head and neck cancer (Krisciunas, Sokoloff, Stepas, & Langmore, 2012; Roe et al., 2012).

An examination of the literature revealed ten general surveys into SLTs’ dysphagia practices and two survey studies with a dementia focus, though both provide minimal insight into how these difficulties are managed (Cocks & Ferreira, 2013; Hopper, Cleary, Donnelly, & Dalton, 2007). Cocks and Ferreira (2013) looked at oral versus non-oral feeding decision-making, discussed later in this section. Hopper et al. (2007) looked at speech and language therapy service delivery for people with dementia in Canada. Three-fifths of their respondents felt that people with dementia would benefit from SLT involvement; however, caseload demands limit their ability to be involved. The majority of respondents believed that they were not receiving referrals for people with dementia that would benefit from SLT services (Hopper et al., 2007). They also felt there was an over-focus on dysphagia in their workloads, and they were under-resourced to address communication issues. Their survey found that 75% of respondents ‘always’ or ‘often’ provided swallowing interventions. However, the authors included rehabilitation and direct and indirect compensatory strategies under one item, and, as such, this does not allow a clear interpretation of how SLTs manage dysphagia in people with dementia. SLTs who never complete rehabilitation exercise, such as the study’s exemplar of thermotactile stimulation, may have responded affirmatively to this item as it also included mealtime or dining room management strategies that they do recommend or vice versa. Nevertheless, this survey does begin to establish the barriers that SLTs face when providing services to people with dementia while also uncovering some beliefs the clinicians hold about dementia.

Most of the remaining surveys evaluated SLTs’ CBE practices. McCullough, Wertz, Rosenbek, and Dinneen's (1999) survey of 61 SLTs working with adults with neurogenic disorders in the United States of America (USA) identified variation in the items viewed as important to include in CBE and VFSS, particularly around the inclusion of oromotor assessment tasks and swallow trials. They also found that clinicians included CBE measures without a supporting evidence base, suggesting a reliance on clinical expertise, though they used evidence-based guidelines and measures during VFSS.

Four of the studies used variations of the same survey to provide insights into CBE and VFSS practices in the USA (Mathers-Schmidt & Kurlinski, 2003), the UK and Ireland (Bateman, Leslie, & Drinnan, 2007), Ireland (Pettigrew & O'Toole, 2007), and Australia (Vogels, Cartwright, & Cocks, 2015). These surveys identified similar issues with variation in what items SLTs include in CBEs and their decision-making. Mathers-Schmidt and Kurlinski (2003) found inconsistencies in the items that clinicians included or excluded from their assessments, though they consistently did not include gag reflex assessment, cervical auscultation, and indirect laryngoscopy. They used clinical case vignettes to understand how and why clinicians decide to refer for objective assessment. They found that access to objective assessment and their clinical experience were not associated with their management decisions. However, there was significant variation across the six vignettes and consensus on recommendations in just two cases. The survey responses included SLTs who work across paediatric and adult caseloads and are therefore likely to have different practices and clinical experience that would influence their assessment choices and decision-making. The decision to present the results as a homogenous group ignores this influence. Pettigrew and O'Toole (2007) also found that equipment access, caseload, experience, or dysphagia training did not influence SLTs' decisions to recommend VFSS. Furthermore, their survey also identified variability in clinicians' clinical decision-making and the items they frequently used or never used in assessment. One particular issue they identified was that clinicians did not include communication assessment as standard. This is a recommendation of the American Speech-Hearing Association and SPA, but not the RCSLT. In their adaptation of the survey, Bateman et al. (2007) did not include the vignettes. They found that their respondents used cervical auscultation more frequently than the USA study, although they inconsistently completed sensory assessments. Their respondents also had more classroom and supervised dysphagia training and greater access to VFSS than their American counterparts. These three surveys did not collect any qualitative data from their respondents. This omission is a limitation of the studies as the clinicians' rationale for including or excluding items cannot be determined.

Vogels et al. (2015) repeated the Mathers-Schmidt survey and conducted follow-up interviews with eight SLTs. Though their methodology indicated that they included qualitative questions in the survey, the results do not describe the findings, limiting their insight. They also found that their respondents were inconsistent in the items they included in assessments, and their findings were similar to the Mathers-Schmidt and Bateman studies. The survey results showed that Australian SLTs' oromotor examinations examined motor aspects more frequently than sensory aspects. Interview participants identified clinical factors as the reason they did not evaluate sensation. One reason for the variation in findings could be the generic nature of the study. The survey was not specific to one condition and, as such, does not allow interpretation of practice variation in response to various client presentations. A condition-specific questionnaire may make preference patterns in certain neurological conditions more apparent. The questionnaire also did not include demographic information on workplaces which may have influenced the variability in practice preferences.

Using a different survey in a Canadian service context, Martino, Pron, and Diamant (2004) also found variation in the assessment items. Very few SLTs assessed sensation though all respondents assessed involuntary cough and wet voice. They found that clinicians' experience was associated with the assessment of mandibular and labial range of movement and that respondents disagreed on which items were highly important to include. On the other hand, they described their participants' objective assessment decision-making as systematic. One issue with the survey is that though the authors endeavoured to ensure the sample was random and had adequate statistical power, the sample size is small (*n* = 34). This issue is particularly relevant when looking at the sample’s composition as it includes both adult and paediatric therapists. The reporting does not take this into account, and it is unclear whether there is a difference between adult and paediatric practices.

Furthermore, there is no clear assessment protocol for mealtime difficulties, with just one comprehensive mealtime assessment tool, the McGill Ingestive Skills Assessment (MISA), available (Lambert, 2003; Lambert, Abrahamowicz, Groher, Dauphinee, & Gisel, 2005; Lambert, Gisel, Groher, Abrahamowicz, & Wood-Dauphinee, 2006). The MISA can evaluate the mealtimes skills of older people living in long-term care. It was developed from reviewing the research literature and by expert discussion. It is a holistic mealtime assessment consisting of 50 items, each with a four-point scale, and the developers consider it an evaluation of a person’s abilities, not their impairments. It has good intrarater reliability for several of the scales and excellent reliability for the overall score. However, an OT developed it for use by OTs, not for SLTs, and it is unclear whether this assessment is used in clinical contexts as it takes a long-time to complete. Additionally, the assessment does not consider dysphagia as it is an observational tool, and the developers considered dysphagia to require a direct assessment. Given the limited information available in the literature, it is unclear if, in practice, SLTs, OTs or other healthcare professionals are the ones evaluating mealtimes skills or if this role is fulfilled at all.

In addition, most of the surveys do not provide a breakdown of where the SLTs see people with dysphagia, which is a significant limitation. As such, they do not account for how practice is likely to vary across clinical settings. Just one survey focused on a specific location, community-based services (Howells, Cornwell, Ward, & Kuipers, 2019). Moreover, people accessing services for dysphagia identify a need for support adjust to the changes brought on by the diagnosis, its psychosocial impact, and its impact on quality of life (N. Miller, Noble, Jones, Deane, & Gibb, 2011; Moloney & Walshe, 2019; Nund et al., 2014). However, just one survey considered these factors (Howells et al., 2019), and it is uncertain if or how practice addresses them.

While the variation in practice identified by the surveys makes it challenging to determine how SLTs conduct assessments with particular client groups, variability may be an inherent part of SLTs' practice. Variability in CBE practice has been identified as a result of SLTs' complex clinical reasoning, and this variability is responsive to heterogeneities in client diagnosis, presentation, and available resources (McAllister, Kruger, Doeltgen, & Tyler-Boltrek, 2016). Dysphagia experts suggest this variation is in-line with diagnostic reasoning models and establishes a need for robust dysphagia training that supports analytical and intuitive decision-making, rather than adherence to strict assessment protocols (Doeltgen, McAllister, Murray, Ward, & Pretz, 2018). However, the development of such diagnostic reasoning for dementia-related dysphagia would benefit from understanding how practising clinicians make such decisions. The trial of a standardised dysphagia assessment in an acute hospital in Australia demonstrated that adherence to a strict protocol constrained SLTs' clinical decision-making (McAllister et al., 2016). They found that decision-making in dysphagia assessment is a non-linear process impacted by the clinician's experience. Further to this, a recent study of SLT clinical decision-making in dysphagia found that variability in assessment reflects a hypothesis-testing approach to assessment (McAllister et al., 2020). By examining expert SLTs' clinical reasoning in a live situation, this study demonstrates a novel approach to how SLTs' practices are understood. It reflects the value of the SLTs' clinical experience and flexibility in decision-making in refining hypotheses from an original referral to incorporating new information from the notes and history review. This information influences their on-line decision-making at the moment of the task. The authors propose that strict adherence to standardised assessment protocols may not always be appropriate due to its impedance of the SLT's reasoning. They also highlight that SLTs who are novice to working in dysphagia should focus on developing clinical decision-making skills.

Management of dysphagia divides roughly into two strands, rehabilitation and compensation. Usually, the SLT will formulate a rehabilitation programme and identify appropriate compensatory strategies based on evidence from a VFSS of the underlying physiological breakdowns in the swallow (East, Nettles, Vansant, & Daniels, 2014). Rehabilitation exercises aim to strengthen muscles and recover movement patterns (Huckabee & Macrae, 2014). Their completion typically involves complex sequencing, and they require the person with dysphagia to follow directions, maintain attention to the task, and have adequate recall to complete the steps regularly (Robbins et al., 2008). Compensatory strategies aim to maximise the swallow's safety by offsetting physiological or sensory changes and reducing the swallowing task's complexity (Lazarus, 2017). These may be used in conjunction with or instead of a rehabilitation programme. Some compensatory strategies require the person with dysphagia to remember to perform an action such as turning the head or tilting the chin while swallowing to protect the airway (Cichero, 2006a). Other strategies rely on educating the carer to modify the environment, food texture and fluid viscosity, or food delivery, as they require little cognitive effort or direct action by the person with dysphagia (Speyer, 2017).

Some interesting findings related to this come from the surveys that included case vignettes. These surveys found significant variation in management selection from respondents (Carnaby & Harenberg, 2013; Mathers-Schmidt & Kurlinski, 2003; Pettigrew & O'Toole, 2007). For example, the USA-based Carnaby study concluded that there is no "usual care" in dysphagia management because of the variability in SLTs' practice patterns (Carnaby & Harenberg, 2013). Most notably, from their case vignettes, the respondents suggested 47 different dysphagia treatment options for one case, with just 4% identifying an appropriate rationale based on disordered physiology. This may relate to findings that clinicians struggle to identify and differentiate normal and disordered swallowing (Plowman & Humbert, 2018). Their results suggested a lack of uniformity in treatment schemes and strategies and that the utilisation of research-supported assessment techniques, exercise-based interventions, and patient follow-up were limited (Carnaby & Harenberg, 2013). A later survey of treatment selection decision-making for adults and children with dysphagia found that variation in treatment selection related to experience (McCurtin & Healy, 2017). In this survey, 116 Irish SLTs rated the frequency of their clinical use of a non-exhaustive list of 32 dysphagia therapies. On average, respondents used 6.93 techniques, self-rated experts used 7.7, and those with a predominantly dysphagic caseload used 8.1. McCurtin and Healy (2017) found that three interventions dominated their survey responses: food texture modification (83%), thickening fluids (72%), and posture changes (72%). This finding is similar to surveys from an Australian context. Rumbach, Coombes, and Doeltgen (2017) found that around 70% of respondents indicated their management only consisted of compensatory strategies, with diet modification as the most common strategy. This survey did not explore why and when clinicians recommend compensatory or rehabilitation strategies, though this would be beneficial. From Howells, Cornwell, Ward, and Kuipers' (2019) survey of community-based dysphagia therapists, the majority of respondents (84.1%) used a combination of compensatory and rehabilitation strategies, with just a small number indicating they only provide compensatory strategies (15.9%). Notably, almost three-quarters of respondents indicated their clients required food modification (73.5%), while 42.4% required fluid modifications. The respondents ‘often or always’ collaborated with dietitians (77.1%), though over 50% reported they did not work with other professionals. Over half the survey respondents indicated that dementia accounted for up to a quarter of their caseload, while 40.3% indicated they had no dementia cases in their caseload. This study did not provide a breakdown of the aspects of a CBE that community clinicians included or excluded from their assessments which would provide useful comparisons to surveys of practice in other settings, but they did note that these therapists had issues accessing objective assessment. A strength of this study is the focus on the practices of SLTs working in one clinical setting. However, the analysis would have benefitted from comparing differences in practice between rural and metropolitan areas. Though none of these studies reported findings specific to dementia, it is noteworthy how common the recommendations of food and fluid modifications were.

The primary rationale the SLTs in the McCurtin and Healy (2017) study used for treatment decisions were client suitability and clinical experience. Practice-evidence accounted for 41% of their reasoning, and client factors accounted for 35%. In order, lack of training, lack of suitability, and lack of knowledge were the primary reasons SLTs did not include a particular technique. There was little variance among respondents in their rationale for choosing or rejecting dysphagia therapies. As respondents were only recruited from special interest groups, these findings may reflect the opinions of SLTs engaged with their professional development, and non-members may have different reasoning processes. Furthermore, variation in clinicians' reasoning due to client group, workplace setting, et cetera, are not captured by this study. However, as few studies have examined decision-making in this manner, this study provides a good starting point in evidence development and is a foundation for future research. They suggest that practice evidence determines clinicians' decision-making, including their experience and beliefs, their colleagues' experience, and client factors (McCurtin & Healy, 2017). A such, there are concerns that SLTs rely on anecdotal evidence, and decisions may be automatic and perfunctory (McCurtin & Carter, 2015). However, McCurtin and Carter (2015, p. 1148) go on to suggest that SLTs' approach to treatment decision-making in dysphagia "*may reflect an understanding of the limits of science in practice and the equating of science with research evidence*", particularly in relation to concerns with the limitations of research evidence and its generalisability. Other research suggests that SLTs with additional qualifications identify as more autonomous and scientific in their decision-making, and they consider themselves less influenced by client preferences, experience, and discipline influences (McCurtin & Clifford, 2015).

These findings suggest that there are two schools of thought regarding the value that clinicians place on client values and preferences and that further education influences this outlook. As such, research cannot determine if clinicians are choosing their techniques and therapies from reliable integration of the three elements of evidence-based practice. These elements, external research evidence, evidence internal to clinical practice or clinician expertise, and client preferences (Dollaghan, 2004), have particular relevance to dementia-related mealtime difficulties. There is minimal research evidence for the management of dysphagia in dementia and less for the management of mealtime difficulties. In a clinical culture where SLTs rely on their colleagues' expertise and their own experience, there is a risk that people with dementia may not be considered a management priority. Furthermore, with the influence of clinical culture and without appropriate guidance for management, there are likely to be pockets of excellent care and patches of no service.

One notable issue in dementia management is that SLTs must also contribute to decisions on the continuation of oral feeding or transitions to non-oral or enteral feeding alternatives as part of an MDT. Though enteral feeding options are widely accepted as inappropriate for use in advanced dementia (Goldberg & Altman, 2014; Royal College of Physicians, 2010), experts suggest that they are appropriate as an interim measure in likely reversible health crises in mild-moderate dementia (Volkert et al., 2015). Discussions with family members and the decision-making process for enteral feeding recommendations can be complex (Askren & Leslie, 2019). It requires SLTs to balance concerns about aspiration and nutritional risk with the comfort of the person with dementia and their families (Berkman, Ahronheim, & Vitale, 2019). A UK hospital service evaluation demonstrated that this decision-making is a dynamic and ongoing process involving multiple parties that requires the decision-makers to balance the risks, burdens and benefits, treatment goals, ethical values and the interests of the individuals involved (G. Clarke, Galbraith, Woodward, Holland, & Barclay, 2015). This finding reflects the best practice recommendations of a group of SLT dementia experts who advocate that those making management decisions for people with dementia use "*an approach which considers the individual and not solely the diagnosis*" (H. A. Smith, Kindell, Baldwin, Waterman, & Makin, 2009, p. 546).

As a result of expert consensus on the inappropriateness of enteral feeding in dementia, there is a move to support ‘comfort’ or ‘acknowledged risk’ feeding (Fong, Tsai, Wong, Yiu, & Luk, 2019; Kelly, Cumming, Kenny, Smith-Merry, & Bogaardt, 2018; Palecek et al., 2010; Sommerville, Lang, Archer, Woodcock, & Birns, 2019), though this is ill-defined and guidance is limited. Feeding with accepted risk is “*an approach that affords comfort, dignity and autonomy . . . for patients with an unsafe swallow unlikely to improve in whom tube feeding had been ruled out*” (Sommerville et al., 2019, p. 554). While comfort feeding has been described as “*continued attempts at careful hand feeding as long as the patient is not in distress; reframing feeding tube discussions with families; and . . . the comfort of the patient during feeding is of primary importance, even in the setting of weight loss*” (Palecek et al., 2010, p. 583). Pertinently, there is limited information on the outcomes of people with dementia following these approaches, and there is limited evidence to support hand-feeding as an alternative to enteral feeding. One small-scale study compared three hand-feeding techniques – direct hand, overhand, and underhand – and found that these techniques did not take significantly longer to complete than usual care and did encourage increased oral intake (Batchelor-Murphy et al., 2017). However, the study's outcomes did not consider weight loss or gain, or provide any prognostic measures of follow-up with participants, there was no control group, and the trained staff had no guidance on when to select each technique. The study also lacked a follow-up evaluation to consider what practice changes could support the recommendation of hand-feeding as a suitable alternative to enteral feeding. Findings from a recent retrospective study showed no significant differences between care home residents with advanced dementia who received nutrition via a nasogastric tube or by hand-feeding (Chou, Tsou, & Hwang, 2020). However, feeding tube placement in advanced dementia is a risk factor for six-month mortality (K. C. Lee et al., 2018), and the Chou et al. (2020) study showed a non-significant mortality trend in the enteral feeding group. Given the uncontrolled, retrospective nature of the study, and the noteworthy difference in sample size between the two groups, it is possible that the findings do not provide a valid comparison of these measures. It is also not clear how recommendations on hand-feeding and alternatives to enteral feeding are delivered in clinical practice.

A UK survey looked at how SLTs make oral versus non-oral feeding recommendations in dysphagia generally (*n* = 68) and across four conditions, including dementia (*n* = 25) (Cocks & Ferreira, 2013). They found that independent of diagnosis (*n* = 68), the factors most influential on the decision were alertness, amount of aspiration, frequency of aspiration, patient wishes, cough ability, acuity of the condition, history of pneumonia, nutritional status, history of respiratory infections, prognosis, and incidence of silent aspiration. In dementia, the ten most influential factors, in order, were: the desire to eat, amount of aspiration, alertness, cognition, acuity of any medical condition, patient wishes, history of pneumonia, nutritional status, family wishes, and frequency of aspiration. The study built on an earlier study from the USA (Logemann, Rademaker, et al., 2008) and asked respondents to rate the items they identified. If this study had generated items, it might have led to other, novel factors emerging. Furthermore, the study reportedly collected some qualitative data where respondents explored the rationale for these items' selection; however, they do not report this analysis in the study, which is a limitation. Another study examining SLTs' decision-making in recommending oral feeding with risk found that they recommended it when the person's preferences were known, that they saw it as providing greater quality of life near the end of life than enteral feeding, and when the aspiration risk was accepted by the person and family (Berkman et al., 2019). This study did not seek to examine the SLTs' perspectives of risk feeding in dementia, though that is an important consideration and an area of developing practice for SLTs (Soar, Birns, Sommerville, Lang, & Archer, 2020).

This section has shown the variation in SLTs' assessment practices and the influences of clinician values and clinical expertise. It has also found that food and fluid modifications dominate SLTs' dysphagia management practices. This section also highlights the limited evidence available on how SLTs manage dementia-related mealtime difficulties and dysphagia in practice. The following section will consider the evidence for interventions for dementia-related dysphagia and mealtime difficulties.

2.7 Managing Mealtime Difficulties and Dysphagia in Dementia

Typically, management goals in dementia are maintenance of function and prevention of adverse outcomes (Royal College of Speech and Language Therapists, 2014b). Logemann and Pitts (2013) acknowledged that a return to baseline is not always a realistic outcome for people with dysphagia, which is undoubtedly the case for dementia-related dysphagia. Furthermore, with disease progression and its impact on cognition and behaviour, rehabilitation and direct interventions are often ruled out for people with dementia (Alagiakrishnan et al., 2013; Speyer, 2017). However, the significant and overlapping consequences of dysphagia and mealtime difficulties mean that it is essential that health professionals have effective management strategies to ameliorate these issues. Nevertheless, there is a limited and conflicting evidence base for intervention in dementia-related mealtime difficulties and dysphagia. This section will examine training interventions, dysphagia interventions, and mealtime interventions.

2.7.1 Caregiver Training Interventions

Niezgoda and colleagues describe the development of dysphagia in older adults and care populations, with the exception of acute illness or stroke, as insidious and usually identified at mealtimes by the individual, care and nursing staff or family (Niezgoda et al., 2014). As such, carers at the forefront must have the means to identify and quantify risk and issues in order to generate an appropriate management plan and onward referral. Park and colleagues (2015) concurred with this finding, concluding that nurses in care homes are in a prime position to identify and manage swallowing difficulties due to their visibility and constant availability. Niezgoda et al. (2014) posited that although most care home staff will have had basic training on feeding techniques, it is likely that many are ill-equipped to recognise and manage the signs of dementia and their impact on the meal. Steele and colleagues (1997, p. 43) advocate for caregivers to receive *"education and/or training for the multiplicity of elderly needs at mealtimes"*, however, formal training opportunities are not always available to care home staff or in-home and family caregivers. Furthermore, there is little information available about the type and content of dysphagia and mealtime training delivered in practice.

A recent review identified that nursing and care staff have four primary training needs when supporting people with dementia and mealtime difficulties: i) providing person-centred mealtime care, ii) dealing with uncertainty, particularly as it relates to managing end of life issues, iii) learning strategies, skills and knowledge to manage mealtime difficulties, and iv) being supported to create the right mealtime environment (Faraday et al., 2019). The first of these needs links back to Murphy and colleagues (2017) model of nutritional care, which identified person-centred care as the cornerstone for managing nutritional needs. This also links to the research that suggests that caregivers' interactions with the person with dementia at mealtimes impact the meal (Gilmore-Bykovskyi, Roberts, Bowers, & Brown, 2015). The British and Irish speech and language therapy professional bodies advocate for the SLT's role in training carers to manage dysphagia but do not specify effective strategies to manage uncertainty. The RCSLT consider the role to involve *"advising, supporting and training carers in effective ways to promote safe swallowing, reduce risk of aspiration and enable nutrition and hydration needs to be met"* (2014, p. 16), while the IASLT recommend SLTs *"train carers to support safe swallowing"* (2016, p. 16). However, it is less clear whose responsibility it is to train carers to manage dementia-related mealtime difficulties and provide them with the strategies, skills, and knowledge they need. The available research on training also offers limited guidance. Table 2.6. provides an overview of the training programmes available.

Of the dementia and older adult training studies presented in table 2.6, three studies focused on dysphagia training (Benati, Coppola, & Delvecchio, 2009; Davis & Copeland, 2005; O'Loughlin & Shanley, 1998), while the others looked at mealtime function (Batchelor-Murphy, Amella, Zapka, Mueller, & Beck, 2015; C. C. Chang & Lin, 2005; Faxén-Irving, Andrén-Olsson, Geijerstam, Basun, & Cederholm, 2002; Mamhidir, Karlsson, Norberg, & Kihlgren, 2007; S. Roberts & Durnbaugh, 2002). The majority of the studies focused on care home or supported care environments' staff, with just one study based in an acute hospital (Davis & Copeland, 2005). None of the studies provided training to family carers or paid carers who support people with dementia in their own homes.

Table 2.6. Dysphagia or Mealtime Difficulties Training Programmes

Authors	**Setting**	**Trainer's Background**	**Dementia Specific**	**Training Type**	**Training Content**
Training Focus: Dysphagia					
(O'Loughlin & Shanley, 1998)	Care home	SLT, OT, Dietitian	No, but it includes an extensive section on dementia	A train-the-trainer design. Senior nurses received three four-hour workshops, each one-month apart. Once trained, the nurses deliver an in-service to their colleagues within two-months.	- The normal swallow, - Dysphagia signs and symptoms, - Effects of dementia on swallowing, - Management of dysphagia - Nutritional guidance.
(Davis & Copeland, 2005)	Acute hospital	SLTs	No	A 30-minute web-delivered 45 slide PowerPoint presentation.	- The normal swallow - Dysphagia risk factors - Guidelines for administering nutrition, hydration and medication
(Benati et al., 2009)	Care home	Nutrition team members	Yes	Not specified	- Physicians and nurses were trained to use a malnutrition screen and a swallowing screen.

Authors	**Setting**	**Trainer's Background**	**Dementia Specific**	**Training Type**	**Training Content**
Training Focus: Mealtime Difficulties					
(S. Roberts & Durnbaugh, 2002)	Care home	Nursing	Yes	Two training programmes - Nurses received a two-hour session - Care assistants received 1.5 hours of training	Nurses: - Use of the Feeding Behaviours Inventory - Food presentation - Staff behaviour - The dining room environment. Care Assistants: - Observed videos of mealtime difficulties in dementia - Discussion of interventions - Intervention role-play
(Faxén-Irving et al., 2002)	Supported group living	Clinical Nutrition	Yes	An in-person 12-hour educational programme, combining lectures and practical workshops.	- Nutrition and diet for older adults - Malnutrition in older adults - Dental care

Authors	**Setting**	**Trainer's Background**	**Dementia Specific**	**Training Type**	**Training Content**
					- Identifying dysphagia - Modifying diets - The impact of dementia and other age-related conditions on mealtimes.
(C. C. Chang & Lin, 2005)	Care home	Nursing	Yes	Three hours of in-service classes and one-hour of hands-on feeding skills training.	- About dementia - Mealtime difficulties in dementia - Management strategies, e.g. environmental adaptations environment, caregiver interactions, and feeding skills.
(Mamhidir et al., 2007)	Care home	Nursing	Yes	A one-week training course	- Erikson's theory of eight stages of man - Focus on relationships - Normal ageing

Authors	**Setting**	**Trainer's Background**	**Dementia Specific**	**Training Type**	**Training Content**
					- Communication - The environment - Integrity - Dementia - Mealtimes as opportunities for task and relationship activities.
(Batchelor-Murphy et al., 2015)	Care home	Nursing	Yes	A 20-minute web-based training of a narrated PowerPoint presentation followed by a four-minute video demonstration. Additional coaching sessions were offered.	- Feeding techniques and strategies

SLTs developed two of the dysphagia training studies (Davis & Copeland, 2005; O’Loughlin & Shanley, 1998), nutrition and dietetics researchers created two training programmes (Benati et al., 2009; Faxén-Irving et al., 2002), and nursing researchers designed the other studies (Batchelor-Murphy et al., 2015; C. C. Chang & Lin, 2005; Mamhidir et al., 2007; S. Roberts & Durnbaugh, 2002).

The content and delivery of the training programmes also varied significantly. Training provided information on the normal swallow, dysphagia and dementia’s impact on the swallow (Davis & Copeland, 2005; Faxén-Irving et al., 2002; O’Loughlin & Shanley, 1998), feeding skills (Batchelor-Murphy et al., 2015; C. C. Chang & Lin, 2005; Durnbaugh et al., 1996; Faxén-Irving et al., 2002), the use of specific screening tools (Benati et al., 2009; O’Loughlin & Shanley, 1998; S. Roberts & Durnbaugh, 2002), or in one case, in-depth learning on a psychological theory of ageing and its application to mealtimes (Mamhidir et al., 2007). Two of the studies involved online training (Batchelor-Murphy et al., 2015; Davis & Copeland, 2005), while the others were delivered face-to-face. The two online studies demonstrated that web-based learning effectively changes knowledge, though neither study provided sufficient evidence that it changes practice. All studies used lecture-based learning, and some also offered concurrent, practical workshop sessions (C. C. Chang & Lin, 2005; Faxén-Irving et al., 2002) or video vignettes (Batchelor-Murphy et al., 2015; S. Roberts & Durnbaugh, 2002). The length of time spent training varied from 24 minutes (Batchelor-Murphy et al., 2015) to one week (Mamhidir et al., 2007).

The outcome measures used to judge the efficacy of the training interventions varied widely between studies. Five of the studies provided before and immediately after training measures of knowledge change (Batchelor-Murphy et al., 2015; C. C. Chang & Lin, 2005; Davis & Copeland, 2005; O’Loughlin & Shanley, 1998; S. Roberts & Durnbaugh, 2002), with one study completing an eight-week follow-up (Batchelor-Murphy et al., 2015) and one completing a three-month follow-up (O’Loughlin & Shanley, 1998). The measures used by the studies were not sufficient to determine if the staff retained the knowledge and if it changed practice and outcomes for people with dementia. For example, though the O’Loughlin and Shanley (1998) study found significant knowledge improvement was maintained at the three-month follow-up, their study included no resident outcome measurements or identified changes in referral patterns or adverse events that could indicate that the training had made a positive change. Three studies did not measure knowledge changes (Benati et al., 2009; Faxén-Irving et al., 2002; Mamhidir et al., 2007). These studies used outcome measures to evaluate the impact on the people with dementia, primarily measures of resident weight (Benati et al., 2009; Faxén-Irving et al., 2002; Mamhidir et al., 2007). Several studies considered changes to the amount of food eaten during meals (Batchelor-Murphy et al., 2015; C. C. Chang & Lin, 2005; S. Roberts & Durnbaugh, 2002). One issue is that the studies did not adequately control for other factors that might influence weight. For example, the Faxén-Irving (2002) study included a supplement regime alongside the training programme and did not include any measures of change in staff knowledge. As such, it is inappropriate to link the changes in weight to the effectiveness of the training programme.

Other studies used measures of the person with dementia's mealtime behaviours (Batchelor-Murphy et al., 2015; C. C. Chang & Lin, 2005), though the Batchelor-Murphy study had incomplete data collection and did not report between-group analyses of scores. Furthermore, they did not report the control and experiment groups' similarity at baseline. Again, this makes it challenging to judge the effectiveness of the intervention. Additionally, despite the participants in Chang and Lin's study demonstrating a reduction in adverse mealtime behaviours, this did not translate to an increase in the amount of food eaten. The application of a broader range of outcome measures may have demonstrated other positive gains. For instance, if the reduction in behaviours also reduced carer stress or whether fewer mealtime behaviours led to reduced mealtime-related adverse events. Just one study examined the impact of staff training on the occurrence of adverse events; in this instance, hospital admission for aspiration pneumonia (Benati et al., 2009). The omission of this measure from most studies' outcome measures makes it challenging to evaluate the contribution of training to the maintenance of people with dementia's health and well-being.

The variation and variability in content, design, delivery, and outcome measurement make it challenging for health professionals supporting people with dementia to determine what appropriate and effective training in the management of dementia-related dysphagia and mealtime difficulties should include. There is also no available evidence on how clinicians currently deliver this training. From their review, Faraday and colleagues (2019) identified the training needs of nursing and care staff, but further research is needed to address the gaps in training development and provision. A clear gap exists in training and educating family carers of people with dementia, and research is needed to establish the areas where they require support.

2.7.2 Dysphagia Interventions

In the UK context, SLTs are the healthcare professionals primarily in charge of managing dysphagia, though they usually perform this role as part of an MDT. Unfortunately, very few interventions target dementia-related dysphagia, and management tends to focus on compensation, primarily diet and fluid modification (Speyer, 2017). The most well-known study of dysphagia management in dementia is a randomised control trial that used VFSS to evaluate the effectiveness and acceptability of three conditions, (i) nectar-thick fluids, (ii) honey-thick fluids, or (iii) thin liquids with a chin-down posture (Logemann, Gensler, et al., 2008). The study included 711 people with various dementias, and the researchers built on this study by randomising 515 participants to implement one of the three conditions based on the results of the VFSS (Robbins et al., 2008). The first study found that participants aspirated more significantly on thin fluids with chin-tuck compared to nectar- or honey-thick fluids and more significantly on nectar-thick than honey-thick fluids (Logemann, Gensler, et al., 2008). No condition was effective for participants with advanced dementia. However, the sequencing of the trials may have impacted participants' fatigue levels as there was some evidence that this impacted performance. The study also elicited the participants' preference which was for chin-tuck position followed by nectar-thick fluids. Though the study provided comparisons of Parkinson's disease, PDD, and the other dementia groups combined, an analysis considering AD and VaD individually would have been a worthwhile addition, particularly as this study is well-powered.

In the second phase, the researchers followed up with the participants after three months and noted the onset of aspiration pneumonia or other respiratory complications (Robbins et al., 2008). The three-month cumulative incidence of pneumonia was 11% though this was lower for the chin-down posture group than for the thickened liquid groups. The incidence of pneumonia was higher in the honey-thick group than in the nectar-thick. No definitive conclusions can be drawn as these findings were not statistically significant. It is important to note that this study did not control for fidelity to the intervention in the three months between allocation and review. As such, it is unclear if the participants adhered strictly to the recommended group for the duration of the study or if there was variation in their observance. However, these findings provide the often-missing follow-up of an intervention's impact and demonstrate the potential for adverse outcomes.

Both studies show that fluid modification is not an entirely neutral treatment option, and its use should be treated with caution. In addition, a qualitative descriptive study analysing the perspectives of adults with dysphagia post-stroke indicated that the prescription of thickened fluids is a detested, “*burdensome intervention”* that may lead people to reject the treatment (McCurtin et al., 2018, p. 37). Further to this, a Cochrane review that included unpublished data from these studies (Logemann, Gensler, et al., 2008; Robbins et al., 2008) found that thickening fluids may reduce the risk of aspiration in the short-term but risks respiratory health complications and negative impacts on nutrition and hydration in the longer term (Flynn, Smith, Walsh, & Walshe, 2018). It is also important to note that this review did not identify any food modification studies that met their criteria.

O’Keeffe (2018) argued that the limited evidence base for modified diets as an intervention for dysphagia of any origin makes their prolific use questionable, and therapists need to weigh up their impact on quality of life with the perceived benefits. Modified texture foods are also associated with malnutrition in long-term care facilities, particularly if residents have a cognitive impairment or require assistance at mealtimes (Vucea, Keller, Morrison, Duizer, et al., 2018). Furthermore, research with older adults suggests that maximally modified or puréed meals do not contain appropriate nutritional value, specifically micronutrients (Vucea et al., 2017; Vucea, Keller, Morrison, Duncan, et al., 2018). A systematic review of the use of texture-modified foods and thickened drinks in dementia found that their use was associated with lower daily food and fluid intake and that there is limited evidence that these interventions improve clinical outcomes, such as reducing the development of aspiration pneumonia or malnutrition (Painter, Le Couteur, & Waite, 2017). Additionally, an Australian study that examined how healthcare professionals monitor thickened fluid prescriptions found that two-thirds of respondents only monitored thickened fluid consumption when they felt there was a clinical need, and over half believed people with dysphagia on thickened fluids were not drinking enough (J. Murray, Doeltgen, Miller, & Scholten, 2014). The potential for a thickened fluid prescription to reduce liquid consumption leading to dehydration is a serious issue. Dehydration has implications for mood and functioning (Pross, 2017) and mortality in older adults (El-Sharkawy et al., 2017), as well as associations with worsening cognition and well-being (Mantantzis et al., 2020). Moreover, a study of the effects of thickened liquids compared to carbonated liquids on swallowing function in people with LBD found that thickened liquids worsened pharyngeal residue in four participants compared to thin liquid, thereby increasing the risk of aspiration (Larsson et al., 2017).

Given these adverse outcomes, some experts assert that "*the routine use of thickened liquids to prevent pneumonia in patients with dementia should be avoided, and diet should involve a comprehensive approach rather than a reflexive diet modification*" (Wang, Charlton, & Kohlwes, 2016, p. 736). However, a recent expert review that acknowledges these critiques argues that modified diets do have a role and proposes a battery of considerations for prescribers before making their recommendation (Ballesteros-Pomar et al., 2020). Given these conflicting views and the limitations of the evidence, the appropriate management of dysphagia in dementia is likely to be unclear to clinicians.

Furthermore, there is minimal evidence for alternatives to food and fluid modification in dementia-related dysphagia, though two studies with promising treatments have been identified. One study was a randomised control trial with a crossover design that examined the impact of cervical mobilisation on dysphagia limit in severe AD (Bautmans, Demarteau, Cruts, Lemper, & Mets, 2008). The study randomly assigned participants ($n = 16$) who met the criteria to two groups. One group received cervical spine mobilisation from a physiotherapist three times a week for one week, followed by a wash-out week, and one week as a control. The second group followed this protocol in reverse. Each participant acted as their own control, and no complications occurred. The participants' dysphagia limit (the amount of thin fluids they can drink in one go) increased significantly after one session and after the treatment week. The intervention was feasible and acceptable to people with dementia. However, it would have benefitted from a pre- and post-objective assessment that evaluated the swallow and follow-up measures examining the impact on diet, nutrition, and well-being as dysphagia limit is not a functional outcome measure.

The other study looked at the use of spaced retrieval therapy (SRT) with visual aids as a tool to teach compensatory dysphagia strategies (Benigas & Bourgeois, 2016). The study had a multiple baseline design where the effectiveness of compensatory strategies, such as a chin-tuck, double swallow, or a lingual sweep, were evaluated on VFSS and during mealtime observation. The participants (n = 5) were trained on strategy cue cards one at a time, ordered according to the individual's needs with gradual delays in the presentation schedule. This approach led to functional improvement of 2-3 targeted strategies for all five individuals with training effects for one individual lasting to the four-week follow-up. However, this intervention is time-consuming to complete, and it requires participants to have oral reading skills limiting its applicability. The study also used a somewhat artificial mealtime environment, and it is unclear if the skills would transfer to a routine dining room environment in a care home. As such, it is a suitable technique for teaching the use of compensatory strategies to people with dementia, but further research is needed to evaluate its generalisability. Despite small sample sizes, the findings of the Bautmans et al. (2008)

and Benigas and Bourgeois (2016) studies suggest the potential for new and developing techniques to be applied to dementia-related dysphagia management.

The evaluation of the available interventions for dementia-related dysphagia suggests that providing appropriate and person-centred management is not a clear-cut process. SLTs managing this condition are offered little guidance from the literature, and the usual techniques do not appear to be appropriate. It is uncertain how these issues are managed in clinical practice and what interventions are used.

2.7.3 Mealtime Interventions

In addition to SLTs, AHPs with a potential interest in mealtime management are the OT, physiotherapist, and dietitian. SLTs have taken a role in managing mealtime difficulties largely due to the impact of environmental, cognitive, and behavioural factors on the process of eating and drinking. However, eating and drinking are a process and an activity of daily living; therefore the OT has scope for involvement in their management. Paul and D'Amico (2013, p.30) argue that "*occupational therapy is crucial to motivate, remediate, educate, restore, modify, and adapt this daily activity to achieve a more successful outcome*" while acknowledging the SLT's role in managing dysphagia. What is unclear is where the SLT and OT diverge in their responsibilities in managing mealtime difficulties. For instance, ideational apraxia and activity sequencing issues suggest the need to involve occupational therapy. However, none of the identified studies have been developed by occupational therapy researchers, and it is unclear if practising clinicians consider these issues within their role.

Furthermore, although the physiotherapist’s role in dementia care is primarily associated with maintaining muscle function and enabling safe mobilisation, their training means there is scope for overlap with mealtime management. For example, physiotherapists support the maintenance of strength and enable appropriate seating posture, potentially impacting a person with dementia’s ability to self-feed and swallow safely. Similarly, the direct impact of mealtime difficulties and dysphagia on nutritional intake (Keller, Beck, & Namasivayam, 2015) indicates that dietetic services have a clear role. SLTs and dietitians are typically seen as a complementary partnership in the management of dysphagia (Heiss, Goldberg, & Dzarnoski, 2010), as it is vital to consider not just how people eat but what they are eating (Amella, Grant, & Mulloy, 2008). However, Cammer and colleagues (2019) found a lack of specificity in staff roles in managing nutritional care in dementia which hampers how dietitians advocate for good nutritional care. How, or even if, AHPs liaise with each other to ensure appropriate, safe, and sufficient intake through a social and supportive mealtime environment is unknown. There is no available evidence of AHP or MDT practices in managing mealtime difficulties, and this notable gap needs to be addressed.

Multiple systematic reviews have considered the impact of mealtime interventions. Several of these reviews have focused on the nutritional impact of mealtime interventions (Abdelhamid et al., 2016; Bunn et al., 2016; Douglas & Lawrence, 2015; Herke et al., 2018), while others have looked at the impact on behaviour (Whear et al., 2014), eating performance (Fetherstonhaugh, Haesler, & Bauer, 2019; Liu, Galik, Boltz, Nahm, & Resnick, 2015), interventions targeting mealtime difficulties (Liu, Cheon, & Thomas, 2014), and the mealtime experience (Vucea, Keller, & Ducak, 2014). The consensus of the available systematic reviews is that mealtime interventions show some benefits for individuals with dementia, though methodological issues and small sample sizes make the generalisation of the findings challenging and prevent researchers and clinicians from identifying an optimal treatment option. Table 2.7 provides an overview of the potential effects of the available mealtime interventions in the areas of impact of food presentation, the mealtime set-up, the mealtime environment, the provision of music at mealtimes, aquarium contemplation, mealtime assistance, and directly intervening with individuals with dementia.

Table 2.7 Mealtime Interventions

Intervention	**Study and Main Findings**
Food Presentation	- People with cognitive impairment consume greater amounts of oral supplements delivered by glass or beaker (Allen, Methven, & Gosney, 2014). - A high colour contrast between crockery and food encourages increased food and drink intake in people with AD (Dunne, Neargarder, Cipolloni, & Cronin-Golomb, 2004). - Finger foods presented attractively and with attention to appropriate accompaniment, e.g. sauces or dips, are chosen first and encourage greater consumption (Pouyet, Giboreau, Benattar, & Cuvelier, 2014). - Offering food and drink choices to care home residents across the day is less expensive and more effective than

Intervention	Study and Main Findings
	supplement interventions (Simmons, Zhuo, & Keeler, 2010).
Mealtime Set-up	- Family-style meals increase participation and communication among care home residents with dementia (Altus, Engelman, & Mathews, 2002). - Staff sharing meals with care home residents increased food intake and promoted weight gain while encouraging self-feeding and improving interactions (Charras & Frémontier, 2010). - Reminiscence therapy at meals improves food intake during meals of people with dementia (Cleary, Hopper, & Van Soest, 2012). - Family-style meals maintain quality of life, gross and fine motor function and weight in care home residents with dementia (Nijs, De Graaf, Kok, & Van Staveren, 2006).
Environmental Adaptations	- Improved lighting and table setting contrast encourage increased food intake and functional ability at mealtimes in care home residents (Brush, Meehan, & Calkins, 2002). - Lighting enhancement and noise reduction encourage food and fluid intake in care home settings (McDaniel, Hunt, Hackes, & Pope, 2001). - Mealtime positioning and timely mealtime assistance is associated with greater food intake, while mealtime interruptions do not impact food intake in hospital settings (A. M. Young et al., 2016)
Music at Mealtimes	- Background music at mealtimes reducing physically and verbally aggressive behaviour in care home residents with dementia (F. Y. Chang, Huang, Lin, & Lin, 2010).

Intervention	**Study and Main Findings**
	- Familiar background music encourages greater food intake than an environment with no music (D. W. Thomas & Smith, 2009).
Aquarium Contemplation	- Well-lit aquariums displayed at eye-level during mealtimes encouraged increased oral intake during meals and care home resident weight gain (Edwards & Beck, 2002, 2013)
Mealtime Assistance	- Verbal prompts encourage self-feeding and mealtime skill re-acquirement (Coyne & Hoskins, 1997). - Mealtime assistance and the provision of snacks between meals increases food and fluid intake and promotes weight gain (Simmons et al., 2008). - People with cognitive impairment in mealtime settings benefit from mealtime assistance and meet their nutritional needs at mealtimes. - Direct hand and under hand-feeding encourage greater food intake than overhand feeding. Greater levels of mealtime difficulties were associated with overhand feeding than the other two methods (Batchelor-Murphy et al., 2017)
Resident Training Interventions	- SRT in two skills (eating procedure and behaviour) results in a reduction in mealtime difficulties and improved nutritional status (L. C. Lin et al., 2010). - Montessori intervention reduces mealtime difficulties, increases self-feeding and increases the length of time self-feeding occurs in care home residents with dementia (L. C. Lin, Huang, Watson, Wu, & Lee, 2011). - SRT combined with errorless learning shows improved strategy recall, reduces mealtime difficulties, and increases food intake compared to SRT alone (Wu, Lin, Su, & Wu, 2014).

Intervention	**Study and Main Findings**
	- SRT combined with Montessori-based activities increases food intake and weight gain and reduces mealtime difficulties (Wu, Lin, Wu, Lin, & Liu, 2014). - SRT can reduce hyperphagic behaviour in people with dementia living in nursing homes (Hsu, Lin, & Wu, 2017)

What the direct interventions studies demonstrate is the potential for people with dementia to engage with intervention and relearn mealtime skills (Hsu et al., 2017; L. C. Lin et al., 2010, 2011; Wu, Lin, Su, et al., 2014; Wu, Lin, Wu, et al., 2014). They do this by targeting preserved cognitive channels such as the non-declarative memory system (Wu, Lin, Wu, et al., 2014). While there are issues with the studies' methodological rigour, they raise the possibility of developing more direct approaches to compensation and rehabilitation of dementia-related dysphagia and mealtime difficulties. Nevertheless, it is unclear which strategies healthcare professionals should be recommending and where individual AHPs' roles will overlap.

2.8 Rationale and Aims of the Study

Improvements to the mealtime experience, quality of life, health, and well-being are priorities for all stakeholders involved in supporting people with dementia. However, as has been established, there is a need to determine the best way to achieve this. As this review highlights, there is evidence of distinct profiles of dementia-related mealtime and swallowing changes occurring across different stages and types of dementia. Unfortunately, the research in this area is still developing, and as a result, the available screening tools are not specific or sensitive enough to identify people with dementia when they need support. Furthermore, though the literature attempts to uncover the SLT's role in managing dysphagia, there are clear gaps in understanding SLT practices in dementia-related dysphagia. Another gap that is highlighted is what approaches to managing people with dementia's mealtime difficulties and dysphagia are used in practice. This review reveals that the data is too limited to determine what interventions are appropriate, and there is no clear evidence for interventions. This is exacerbated by the fact that much of the available literature focuses on people with dementia in long-stay or residential settings, yet these are not the only places where people with dementia live. There is a dearth of evidence on how people with dementia are supported across settings and how their needs may differ.

The management of mealtime difficulties and dysphagia associated with dementia is a complex and multifaceted task. It is clear from the literature review that the impact of mealtime difficulties encompasses and goes beyond the SLT's role in dysphagia management. However, there is a complete absence of literature exploring how healthcare professionals outside nursing care manage mealtime difficulties with limited information available to support their decision-making. Likewise, there is no research on their perspectives of supporting people with dementia and their perceptions of their roles. From these considerations and this literature review, the two research questions that underpin this project were developed:

1. What are the experiences and practices of speech and language therapists who support people with dementia-related mealtime difficulties and dysphagia?

2. What influences the practices of allied health professionals who are managing dementia-related mealtime difficulties and dysphagia?

In order to answer the research questions, a multi-phase study was necessary. Given the SLT’s key role in managing one aspect of the mealtime, the swallow, and the researcher’s background, the practices of SLTs were considered a logical starting point before exploring the inputs of other healthcare professionals. The first phase used a survey design to elicit SLTs’ practices and their views on their roles in managing dementia-related dysphagia and mealtime difficulties. The aims of the first phase of the study were:

- To identify current SLT working practices for managing dementia-related dysphagia and mealtime difficulties in the UK and Ireland

- To establish SLTs’ opinions and experiences of the challenges and facilitators to practice they encounter.

This phase's results then acted as the basis to determine the issues of focus for the second phase of the study. The second phase of the study used a qualitative methodology to explore AHPs’ perspectives on their roles in managing mealtime difficulties and the barriers they felt existed. This research's premise is that further exploration in this area will support the development of professional guidance in the management of mealtime difficulties to improve the consistency and quality of support offered to people with dementia. The aims of the second phase of the research were:

- To establish allied health professionals’ perspectives on their roles in managing mealtime difficulties of people with dementia
- To understand what issues and challenges impact on AHPs who support people with dementia and mealtime difficulties.

The next chapter will outline the overarching methodological considerations for both phases of the research. Then, the methods, results, and discussion of the first phase will be presented before describing the second phase's method and outcomes.

3 METHODOLOGY

This chapter outlines the decision-making process and the theoretical and methodological underpinnings of the research. It will address the research paradigm's selection and research methodology common to both phases of this investigation. The first section outlines the research philosophy underpinning this project, followed by the background to the research methodology and design choice. The research methods and techniques unique to each phase will be covered separately in Chapters 4 and 7.

3.1 The Research Paradigm: Philosophical Worldview and Theoretical Lens

Jonker and Pennink (2010, p. 23) use a four-stage pyramid to structure the research design decision-making process. They describe this pyramid as moving from the abstract at the top (research paradigm) to the concrete at the bottom (research techniques). The researcher agrees with the overall pyramid structure and components as a useful model to describe research planning to ensure rigour and transparency. Though, visually this diagram could be interpreted as presenting the research paradigm as a small part of the decision-making process, or the pinnacle of the items below it. However, it should be clear that the research paradigm is the foundation that the research is built on and that influences all other decisions. In figure 3.1, Jonker and Pennink’s original model is displayed on the left. It is juxtaposed with the researcher’s interpretation on the right. The orientation has been maintained to reflect the transition from abstract to concrete decisions, though the weighting has been changed by inverting the pyramid to illustrate that the research paradigm is the element that influences all other decisions.

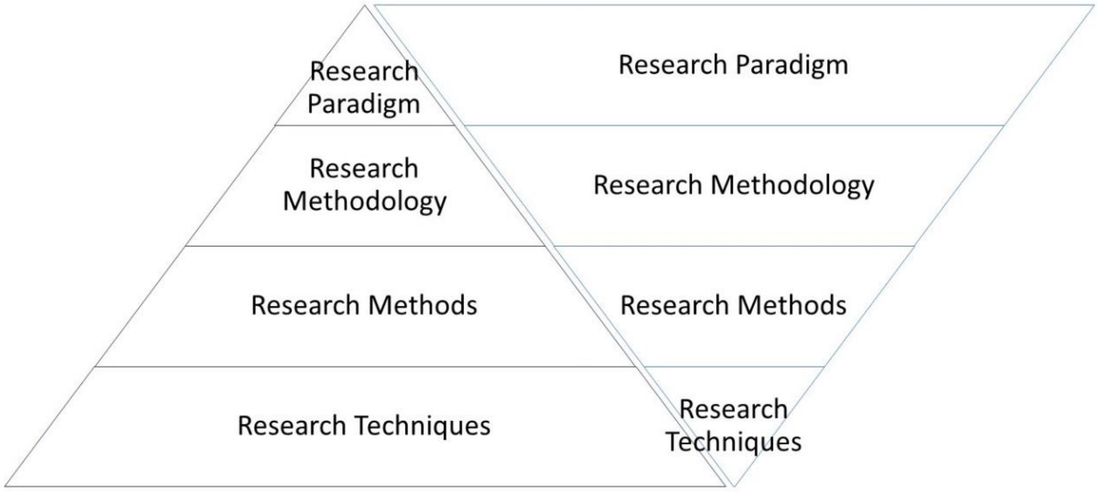


Figure 3.1 Jonker and Pennink’s (2010) research pyramid with the researcher’s inverted interpretation on the right

Typically, when developing a research project, the researcher must decide whether to use a qualitative or quantitative design. The selection and use of one or both of these traditions depend on the researcher’s worldview or paradigm. A paradigm expounds on how the researcher considers knowledge to be created and covers the shared assumptions that guide their approach (Slevitch, 2011). Quantitative and qualitative traditions have different approaches to answering research questions and differing views on the researcher's impact. The quantitative tradition approaches the research question as a provable or disprovable hypothesis. It takes steps to minimise bias and standardise how data is gathered and interpreted to objectively answer the research question (Polgar & Thomas, 2013). The qualitative tradition does not approach research questions in the same way. It seeks to uncover the meaning in people's experiences and describe situations and behaviours from a more subjective perspective (Bryman, 2016). The researcher takes an active role in the process (Mertens, 2005). In other words, quantitative research is the deductive testing of theory, while qualitative research is the inductive generation of theory (Bryman, 2016). Before selecting the design most appropriate for the research question, it is essential to consider the opposing values and components of the research paradigms associated with qualitative and quantitative research. As such, it is necessary to understand what comprises a paradigm.

Denzin and Lincoln (2018a, p. 97) describe a paradigm as an outline of the researcher's *"ethics (axiology), epistemology, ontology, and methodology"*. Axiology considers the researcher's impact; it recognises that the researcher's values and biases impact research and that these need to be acknowledged (Creswell & Poth, 2018). Ontology is the spectrum on which the researcher considers the nature of reality, from one knowable reality to multiple realities influenced by an individual or group's background and culture (Denzin & Lincoln, 2018a). On the other hand, epistemology considers the relationship between the researcher and the questions they aim to answer and how they think knowledge is created. The researcher's epistemological standpoint is their view on the nature of knowledge and the importance they place on objectivity (Mertens, 2005). Methodology, the final component of a research paradigm, is the decision around the most appropriate means to obtain the knowledge or data to increase human understanding (Denzin & Lincoln, 2018a). In practical terms, in order for researchers to determine the paradigm that best aligns to their own world view, it is essential for them to provide an outline of their axiology and background and how that aligns to the ontology and epistemology of the main paradigms, and then outline the methodology that best aligns to these standpoints. Figure 3.2 represents the components of a paradigm visually, with axiology encompassing all areas and methodology nested at the centre, dependent on the components that precede it. The following section will begin by outlining this researcher's axiology and position.

Figure 3.2: A visual representation of components of a paradigm

3.1.1 Axiology: The Impact of the Researcher

Creswell and Poth (2018; p. 21) recommend that researchers *"position themselves"* in the research context to make their assumptions and values explicit. In the quantitative research tradition, there is little emphasis on the researcher's positionality. The approach aims to be completely objective, yielding the same results regardless of the researcher's values and personal biases. However, in qualitative research, the researcher's positionality is central to the research process. Berger (2015, p. 220) describes positionality as including *"personal characteristics, such as gender, race, affiliation, age, sexual orientation, immigration status, personal experiences, linguistic tradition, beliefs, biases, preferences, theoretical, political and ideological stances, and emotional responses to participants*". The researcher's positionality determines the methods and analyses used, and this will, in turn, influence the findings (Braun & Clarke, 2013). In order to demonstrate fidelity with Creswell and Poth's (2018) thesis on positionality, the next section outlines this researcher's position.

At the time of writing, the researcher was a 30-year-old, straight, white woman who immigrated to Scotland in 2016, but was born and raised in rural Ireland in an English-speaking household. Before moving to Scotland, the researcher graduated as an SLT following four years of undergraduate study in Dublin. During this time, approaches to supporting people with dementia, particularly with mealtime difficulties and dysphagia, were not prominent topics on the taught curriculum. Issues including support to continue to communicate with loved ones and enjoy food and drink while maintaining weight, well-being, and quality of life were not well considered. However, undergraduate placement and research project experiences provided eye-opening insights into the idea that people with different conditions could experience barriers to receiving support and treatment. Following graduation in 2012, the researcher moved to Singapore to practice as an SLT. From experiences working in an acute care hospital, it was apparent that people with dementia’s needs were not always addressed equitably, particularly around mealtime difficulties and eating and drinking decision-making. These observations sparked a research interest to develop the evidence base for their management.

As a developing clinician, the researcher was very aware of and focused on delivering evidence-based practice but often skewed the focus to the research evidence base, which was a poor application of evidence-based practice principles. The application of evidence-based practice requires integrating the approaches and expertise of clinicians and specialists who are managing the issues in practice and the individual and their carer’s wishes. Accessing these views is best achieved through qualitative research. Consideration of both perspectives establishes a middle ground which this researcher sees as the intended application of evidence-based practice.

Similarly, in research, the researcher’s view on knowledge creation and reality lies between extremes, believing that the reality of the world is relative to the person experiencing it and that knowledge is generated through the combined influences of their lived experiences and objective facts. The researcher’s background and experiences led to this project's development and are inherently influential on the research questions, design, and analysis. The researcher’s experiences of learning strategies and approaches to care through clinical discussion and peer learning in order to manage the challenges of dementia-related mealtime difficulties and dysphagia in clinical practice have influenced the development of the research design. The aim of this project was to take this learning to a bigger scale to uncover a roadmap to support people with dementia. This aim is achievable by revealing the unheard voices, experiences, and clinical wisdom of AHPs who are doing good work in this area. By uncovering and acknowledging the value of their experience, the ultimate aim of improving care quality and equity for people with dementia could be met. The following section addresses the ontological and epistemological views.

3.1.2 Ontology and Epistemology of Qualitative and Quantitative Paradigms

Quantitative and qualitative research address very different questions and therefore have different perspectives on the nature of reality and knowledge. This section will address the pertinent paradigms and their philosophical underpinnings. The paradigm most associated with quantitative research, and one of the first paradigms described in the literature, is the positivist or post-positivist paradigm (Creswell & Creswell, 2018). This ontological position considers there to be one reality that the researcher must uncover (Petty, Thomson & Stew, 2012). It believes that this reality is determinable by an unbiased observer (Slevitch, 2011). This paradigm aligns with the traditional scientific method. It considers that the social world can be analysed and interpreted in the same way as the natural world, using controlled experiments and driven by hypotheses (Mertens, 2005). Due to its view that reality is knowable, it considers its findings to be generalisable across people and contexts. This paradigm's epistemology considers observable facts to be separable from values, enabling the researcher to achieve the ‘truth’ of the phenomenon (Slevitch, 2011; Mertens, 2005). This paradigm places great value on viewing the researcher as *‘etic’* or an outsider, i.e., unbiased, objective and impartial (Bloomberg & Volpe, 2012).

Interpretivist or constructivist paradigms hold an opposing view based on the idealist outlook (Slevitch, 2011). This ontological standpoint holds that there are multiple realities that are socially and experientially constructed (Lincoln, Lynham & Guba, 2018). Epistemologically, this paradigm views the relationship between the researcher and the research as subjective and the creation of findings is a direct result of this interaction (Blooomberg & Volpe, 2012). This paradigm is generally associated with the collection of qualitative data. This approach is *'emic'* with the researcher considered an insider, as the researcher's values and experiences impact the findings (Bloomberg & Volpe, 2012; Creswell & Creswell, 2018). Interpretivist methodologies aim to understand the meaning of a phenomenon and to jointly construct an understanding of a culture (Lincoln, Lynham & Guba, 2018). An interpretivist paradigm's findings are not generalisable beyond the specific context of the research due to its ontological views (Slevitch, 2011).

These paradigms were considered from the perspective of the researcher's axiology. The researcher's realism did not align with either paradigm as they failed to consider the influence of the clinical environment on the application of research evidence and the nature of knowledge generation in clinical practice. In many paradigms, the researcher's worldview limits the methods that can be used for data collection. Additionally, from this researcher's perspective, the most crucial consideration is what methods are most appropriate to answer the research question. The first phase of the research aimed to determine both the practices and perspectives of SLTs. That is to say; this phase would require the collection and integration of qualitative and quantitative data known as a mixed methods design. There has been considerable debate about the boundaries and limitations of paradigms over the years, particularly with the paradigm wars of the 1980s (see Denzin & Lincoln, 2018b for an overview). This debate is centred on the application of paradigms to mixed methods research, namely how a paradigm can align with both quantitative and qualitative methodologies given the divergence in their views on the nature of reality and knowledge (Creswell & Creswell, 2018). The contrasting views held by positivist and interpretivist paradigms appear to reinforce the view that these paradigms cannot be applied to other research positions. As a result, mixed methods research was once thought to be inherently atheoretical (Creswell & Creswell, 2018).

However, in recent years, the debate has moved away from considering mixed methods as research without philosophical assumptions to considering it to be bounded within the researcher's philosophical worldview and theoretical lenses (Creswell & Plano Clark, 2011). In mixed methods research, the selected paradigm needs to support the integration of qualitative and quantitative data collection and analysis procedures (Mertens, 2005). As such, this study required a paradigm that could balance the subjectivity and objectivity necessary for a mixed methods study (Doyle et al., 2016).

3.1.2.1 The Pragmatic Paradigm

The pragmatic paradigm looks at *what* the purpose of the research is and *how* it can be best achieved (Creswell & Creswell, 2018). This worldview focusses on what works, not what is objectively true (Frey, 2018). Pragmatism is not bound to a defined philosophy as positivism and interpretivism are, allowing more freedom of choice in selection of research design. From an ontological perspective, reality is determined by what is useful to answer the research question (Mertens, 2005), and epistemologically, knowledge is known through the deductive and inductive tools the researcher uses (Creswell & Poth, 2018). The researcher and participants' relationship can vary as appropriate, as axiological beliefs are acknowledged and discussed. The researcher’s axiology aligns with a pragmatic paradigm as one of the researcher’s core values is providing quality care through the integration of evidence-based practice that recognises the importance and value of clinical experience and peer learning. The overarching purpose of this research is to improve care for people with dementia-related mealtime difficulties and dysphagia through practical and achievable means. The pragmatic paradigm was the most appropriate for this study as it allows the paradigm's focus to shift throughout the research process, to respond to the unique needs of the research design stages, and it does not require a single methodological focus. In order to improve practice, it is essential to understand current practice and the barriers and facilitators to providing the most appropriate care. This research examines the optimal ways AHPs, SLTs in particular, can support people with dementia with dysphagia and mealtime difficulties. To meet the aims of the first phase, it is important to gather information on what current practices are (quantitative) and what practitioner views are on these (qualitative). Hearing the voices of those with expertise in the area enhances the validity of quantitative findings. The integration of quantitative and qualitative data to provide a more comprehensive view of an issue is the hallmark of mixed methods research. The following section will provide an overview of the mixed methods research design for this project.

3.2 Research Methodology

Mixed methods research involves the methodical collection and integration of quantitative and qualitative data to provide greater insight than either tradition alone can offer (Meixner & Hathcoat, 2019; Palinkas et al., 2015). However, it is important to note that a mixed methods approach will not produce inherently better research than the use of one or other tradition unless that research is systematic and theory-driven (J. Mason, 2006). Creswell and Plano Clark (2011) propose describing mixed methods research by core characteristics to guide rigorous research design. The first of these key components is the research's positioning within the researcher’s philosophical worldview and theoretical lens. This has been discussed in section 3.1., and in this case, involves the application of a pragmatic paradigm. Another consideration is the research design, including whether the research involves one or multiple phases and whether these phases will run consecutively or concurrently, as discussed in section 3.2.1. Creswell and Plano Clark (2011) also encourage considerations of whether priority will be given to either quantitative or qualitative data and the measures that are taken to ensure rigour; this is discussed in section 3.2.2.1.

3.2.1 Research Design

Unsurprisingly, the selection of the research design is dependent on the goal of mixing methods. In this case, a mixed methods approach was selected for two reasons: i) Complementarity: to understand and evaluate differing perspectives from quantitative and qualitative results in order to develop a more comprehensive understanding of the research problem; and ii) Development: to use the results of one method to inform the other (Creswell & Plano Clark, 2011). Creswell and Plano Clark (2011) identified six major mixed methods designs that researchers can deploy to ensure a rigorous and high-quality design, described in table 3.1. However, there can be multiple permutations and models of mixed methods research, and Creswell and Plano Clark's (2011) major six may not be suitable for all research aims. Doyle, Brady, and Byrne (2016) advocate for a simplified approach by applying Creswell and Plano Clark's (2011) models more widely, with the option of varying them. Given the limited information known about SLTs' roles in supporting people with dementia at mealtimes, it was likely that an exploratory sequential design would be a practical design for generating data on the topic. However, an initial qualitative phase would likely have a small sample size and limited application, and a primarily quantitative focussed second phase would not align with the aims of the research. Using a method that could target a wider sample would allow for increased data to be gathered, which could then be explored in detail within a qualitative phase would be better suited to the research aims.

Table 3.1 Types of Mixed Methods Research Designs (Creswell & Plano Clark, 2011).

Types of Mixed Methods Research Designs
The Convergent Parallel Design - In this design, the quantitative and qualitative strands are run concurrently and independently with equal prioritisation. - The results are analysed independently and then merged during the interpretation of the results.
The Explanatory Sequential Design

- This is a two-phase design that begins with the collection and analysis of quantitative data, the priority for this research design. - The second phase of this design is based on the results of the first and involves the collection and analysis of qualitative data. - This qualitative analysis is used to explain the findings of the quantitative phase.
The Exploratory Sequential Design - This design is also a two-phase sequential design; however, this design begins with and prioritises qualitative data. - The second quantitative phase is used to test or generalise the quantitative phase findings.
The Embedded Design - This design is used when a qualitative or quantitative strand of research is included as part of a traditional quantitative or qualitative research project. - This supplemental strand of qualitative or quantitative research aims to enhance the project.
The Transformative Design - This design is used within a transformative theoretical framework and decisions around the timing of phases, the interaction of results, and prioritisation of quantitative or qualitative data are made based on the theoretical perspective.
The Multiphase Design - This mixed methods design combines sequential and concurrent strands of research to address an overall programme objective. - The research may begin with a qualitative or quantitative phase, followed by a quantitative or qualitative phase, before concluding with a convergent qualitative and quantitative phase. - This design is often used for programme evaluations.

Another consideration in the research design selection was that mixed methods research designs can be fixed or emergent. This refers to whether the design and selection of qualitative and quantitative approaches are predetermined (a fixed design), or when the second phase directions are decided based on the findings of the first one, either quantitative or qualitative (an emergent design) (Creswell & Plano Clark, 2011). The decision was made to adopt an emergent design, i.e., that the first phase's findings would inform the selection of the qualitative approach in the second phase of the study. After weighing up the utility of the designs, and in line with a pragmatic approach, an adapted explanatory sequential design was selected in order to generate as detailed a picture as possible to meet the research aims within the timeframe of the project. Figure 3.3 shows the research design.

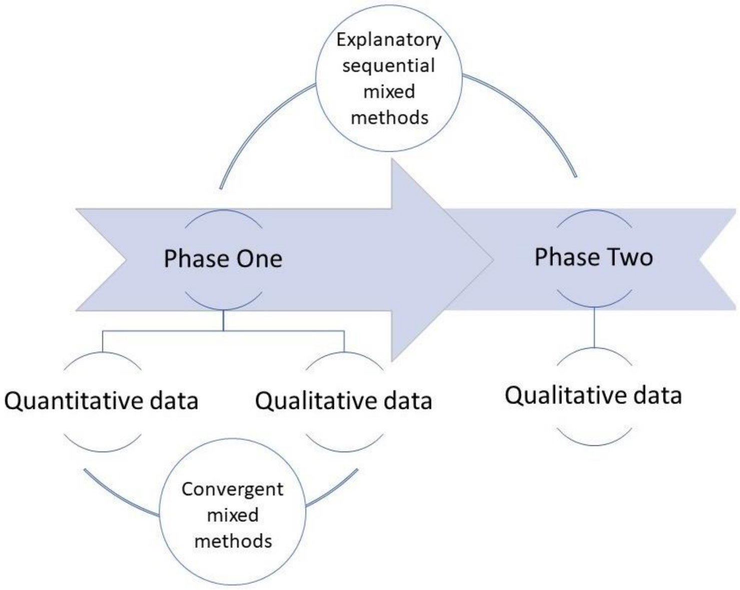


Figure 3.3 Research design

One issue with the explanatory sequential design in its original form is that in their descriptions Creswell and Plano Clark (2011) place emphasis on quantitative data with the qualitative phase taking less importance. However, as noted by Bryman (2016), the elaboration or explanation provided by qualitative data can be of more significance to the research question, thereby requiring greater focus or emphasis. Mason (2006, p. 10) makes the argument for *"qualitative thinking"* as a starting point to mixed methods research to allow the research to reflect the dynamic nature of analysis and the unique contributions of both forms of data. To that end, the design was modified to incorporate both convergent and sequential data collection, as shown in figure 3.3. This adaptation reflected the need for multiple data sources to provide a multifaceted picture in response to the question aims and enabled the capture of more qualitative data across the study. Convergent designs collect qualitative and quantitative data simultaneously and compare their analyses. The first phase of the study used a convergent mixed method design as the survey collected quantitative and qualitative data from SLTs. In sequential designs, one data type is collected first, analysed, and its results inform the next stage of data collection (Creswell & Plano Clark, 2011). As such, the findings of the first phase influenced the development of the second phase. The data collection and analysis methods of phase one are outlined in chapter 4, with chapter 7 outlining the methods used for phase two. The qualitative research design is described further in the following section.

3.2.2 Qualitative Research Methodologies

As described, the study prioritised qualitative data, and both phases of the study included qualitative components, with phase two being solely qualitative. Though the overall approach is mixed methods, it was essential to consider the qualitative design that would best guide data collection and analysis. Being explicit about these considerations makes results more meaningful to the reader (J. Mason, 2006). There are three primary qualitative methodologies, phenomenology, ethnography, and grounded theory (Korstjens & Moser, 2017). Each of these methodologies is associated with different methods of data collection and analysis.

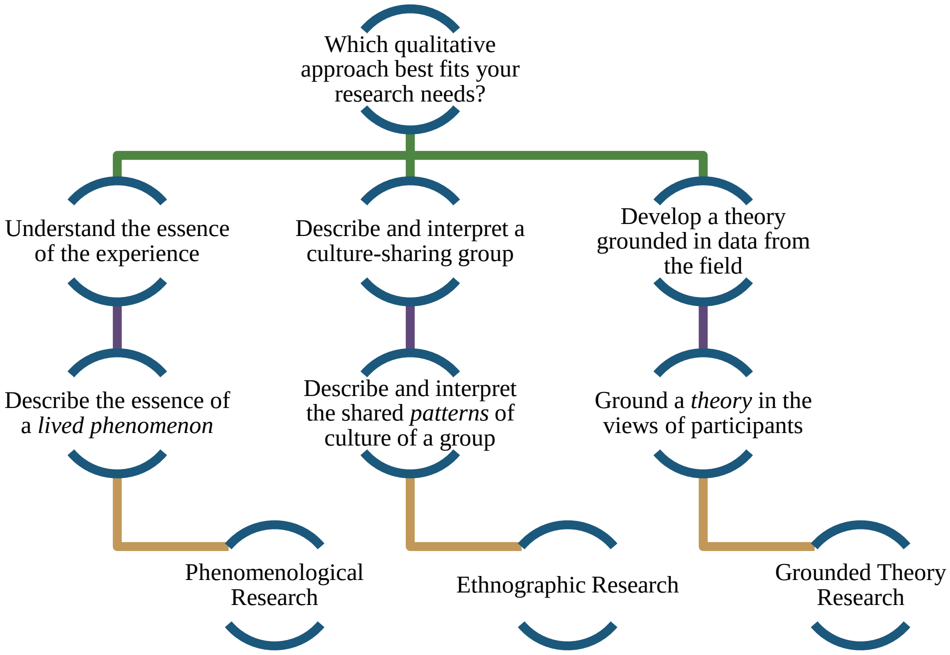


Figure 3.4: Flowchart for evaluating the fit of a qualitative approach with the research needs (adapted from Creswell & Poth, 2018, p. 67)

The flowchart in figure 3.4 (adapted from Creswell & Poth, 2018, p. 67) shows a decision-making aid for determining which methodological approach best fits the research question. This research aimed to understand how mealtime and swallowing difficulties experienced by people with dementia were managed in practice, with the practices and perspectives of SLTs working in the area identified as the starting point of the project. It is clear from this diagram that none of these approaches fit neatly with the research aim. The current study is not seeking to explore individuals' lived experience, as in phenomenology, or attempting to proffer a picture of a culture, as in ethnography. It also does not seek to build a theory and research question from a systematic investigation of the data, as is the aim of grounded theory. The current study sought to understand current practice and uncover the challenges to practice. As such, another methodology was necessary.

Frequently in healthcare research, researchers adopt a *Qualitative Descriptive* approach. Qualitative Description is the term given to qualitative studies that are descriptive in nature (Kim, Sefcik, & Bradway, 2017), meaning that these studies aim to answer *"'what', 'how', and 'why' questions"* (Neergaard, Olesen, Andersen, & Sondergaard, 2009, p .2), as is the case in this research. In her seminal paper on the approach, Sandelowski (2000, p. 337) advocated for Qualitative Description as *"an eclectic but reasonable and well-considered"* approach to data collection and analysis. Neergaard and colleagues (2009) describe Qualitative Description as useful in mixed methods research to generate first-hand understanding of patient or professionals' experiences in health care. It is driven by the participant's clinical experiences and combines the description of responses with interpretation. Table 3.2, taken from Bradshaw, Atkinson & Doody (2017, p. 2), provides the philosophical underpinnings of the approach, which clearly align with this project's needs. This study's multi-phase explanatory design requires an inductive approach that enables the second phase of the study to develop in response to the first phase's findings. Furthermore, the philosophy of subjectivity aligns with the pragmatic paradigm that recognises the influence of the researcher's axiology. Most importantly, the understanding and describing philosophy of a Qualitative Descriptive approach lends itself to considerations of clinical practice and clinical practice development.

Table 3.2 Philosophical underpinnings of a Qualitative Description Approach

Philosophical Underpinnings of a Qualitative Description Approach (Bradshaw, et al., 2017, p. 2).
- An inductive process (describes a picture of the phenomenon that is being studied, and can add to knowledge and develop a conceptual and/or theoretical framework).
- Subjective (each person has their own perspective and each perspective counts). Recognises the subjectivity of the experience of not only the participant but also the researcher
- Designed to develop an understanding and describe phenomenon (not to provide evidence for existing theoretical construction).
- Researcher is active in the research process (researcher becomes part of the phenomenon being studied as they talk directly to participants and/or observe their behaviours).
- An emic stance (an insider view which takes the perspectives and words of research participants as its starting point) but is influenced by the researcher not only because of subjectivity but also when a degree of interpretation occurs.
- Conducted in the natural setting (data collected in the natural setting of the participants who experience the phenomenon).

3.2.2.1 Rigour in Qualitative Research

As the current study is a two-phase study that involved collecting qualitative data by different means in both phases, it was important to ensure a rigorous approach to data collection and analysis. Approaches to achieving rigour in qualitative research vary across traditions, methods, and the researcher’s positionality. For example, in grounded theory, Glaser and Strauss (1967) describe the need to ensure sufficient detail of how and what data was collected and analysed to ensure that the results and findings are plausible. Further to this, Lincoln and Guba's (1985) criteria to ensure the trustworthiness of a study are: credibility, transferability, dependability, and confirmability. However, these criteria are based on the beliefs and positions of the methods that the authors developed. As such, there has been recognition of the need for criteria that can apply more broadly to different methods and traditions (Rheinhardt, Kreiner, Gioia, & Corley, 2018). Following the 'paradigm wars', qualitative researchers described a need for greater uniformity in approaches to qualitative research using the metaphor of a *"bigger tent"* that covers a greater area (Denzin, 2008, p. 321). To that end, Tracy proposed eight "big tent" criteria for excellent qualitative research (Tracy, 2010; Tracy & Hinrichs, 2017), and these were selected for this study to ensure rigour and quality.

These criteria are: (1) a worthy topic, (2) rich rigour, (3) sincerity, (4) credibility, (5) resonance, (6) significant contribution, (7) ethics, and (8) meaningful coherence. A worthy topic refers to a *"relevant, timely, significant, and compelling"* one (Tracy & Hinrichs, 2017, p. 2). The importance and relevance of research into how AHPs support mealtime difficulties and dysphagia in dementia was established in chapter 2, thereby meeting this criterion. The second criterion, rich rigour, denotes the requirement for sufficient, complex, and theoretically driven data collection and analysis. Chapters 4 and 7 describe the methods and analytical approaches used in this study. These are described in detail to meet this criterion. The third criterion, sincerity, refers to acknowledging the researcher's reflexivity and positionality, described in section 3.1, and the need for transparency about the methods and challenges. As mentioned, the methods are outlined thoroughly and clearly in the ensuing chapters, and the study's limitations are discussed in the concluding chapter, thereby meeting this criterion.

The fourth criterion, credibility, requires the researcher to use thick description and crystallisation to justify their interpretations. Crystallisation is the use of multiple perspectives and outlooks in combination with the researcher's views to generate a holistic view of a topic. This is achieved by using multiple phases in the study and the inclusion of multiple expert sources in the second phase of the study. Chapter 5 presents the results of the first phase, which aimed to elicit qualitative and quantitative data to ensure multiple data points and perspectives, and chapter 8 presents the results of the second phase. Both chapters provide rich descriptions and multiple, occasionally opposing, viewpoints of the participants.

Resonance, the fifth criterion, is how the research can be applied to stakeholders' lives or other research. The discussion chapters of this thesis meet this criterion by relating the findings to the impact on the person with their dementia and to the existing research, while also proposing future research directions. The next criterion, significance, is related to the first criterion, a worthy topic. The research's significance is judged by whether it contributes theoretically, heuristically, methodologically, or practically. The current research has heuristic significance in how it may influence policymakers and professionals working with people with dementia to adapt and change services in response to its findings. It also has practical significance in reframing the roles of AHPs in managing mealtime difficulties through explorations of the challenges faced.

The penultimate criterion involves the ethical implications of the research. Steps were taken to ensure that ethical guidelines and practices were adhered to, and ethical approval was granted for the study. The final criterion is meaningful coherence. It requires the research to be logical and rationally designed based on a sound review of the literature, using methods that fit within the research paradigm, and with findings that answer and relate to the research questions. The literature review and the following chapters in this thesis demonstrate adherence to this final criterion.

3.3 Ethical considerations

As the research method involved a two-stage dependent process, it was necessary to prepare and complete two separate ethics applications. The University of Strathclyde’s School of Psychological Sciences and Health ethics committee granted full ethical approval (see appendices 1 and 2). All ethical considerations were taken into account, including confidentiality, anonymity, storage, and data protection. University data protection policies and guidelines were followed throughout, and a data management plan was submitted to the University. Specific issues for each phase are described in chapters 4 and 7.

3.4 Summary

This chapter has outlined the researcher's theoretical standpoint and how that relates to the chosen research design. The design process is shown in Figure 3.5, which shows the adapted Jonker and Pennink (2009) research pyramid. A pragmatic approach was adopted based on the researcher’s axiology and ontological and epistemological beliefs. This approach influenced the methodology, an adapted explanatory sequential mixed methods design. This is a two-phase design that usually has a quantitative first phase; however, this adapted design collected qualitative and quantitative data. The first phase uses survey methods, and the second phase, which is entirely qualitative, uses a qualitative descriptive approach. The next chapter will detail the methods and research techniques used in the first phase of the study, while chapter 7 details the methods of the second phase of the study.

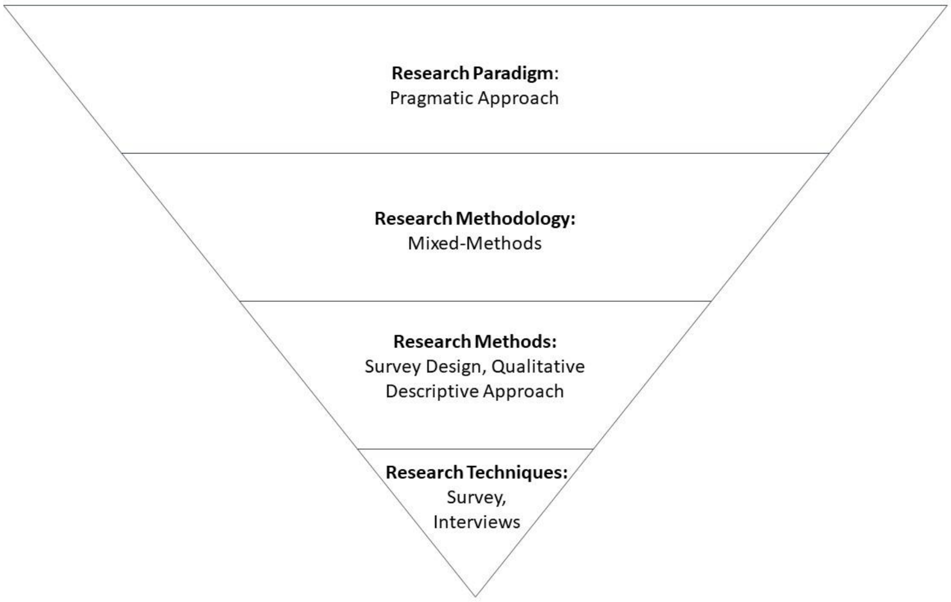


Figure 3.5 Jonker and Pennink’s research pyramid inverted and completed.

4 PHASE 1 – THE QUESTIONNAIRE STUDY: METHOD

This chapter follows the descriptions of the methodology underpinning this research and outlines the method used in the first phase. This phase's aims, described in section 2.8, were (1) to identify current SLT working practices for managing dementia-related dysphagia and mealtime difficulties in the UK and Ireland, and (2) to establish SLTs' opinions and experiences of the challenges and facilitators to practice they encounter. As described in section 3.2, the first phase of the research was a convergent mixed methods design as this phase's aims required the collection of qualitative and quantitative data. Furthermore, a method that allowed the collection of information from a potentially large number of participants was needed. The following section outlines the rationale behind the selection of a survey research design before moving on to describe the development of a questionnaire designed to capture information on the practices and perspectives of SLTs. The subsequent sections then outline the analysis approach and the sampling and recruitment of participants.

4.1 Survey Research

Survey research designs are a means of obtaining data from a large sample of cases by self-administered questionnaire or structured interview (Bryman, 2016). The data collected is *"individuals'* self-reports *of their knowledge, attitudes or behaviours"* (Mertens, 2005, p. 167). Traditionally survey research is considered a quantitative method, whereby participants provide quantitative data in a systematic, standardised manner. Quantitative surveys typically consist of a series of closed questions where the respondents' answers are limited to the available options. However, there is scope for surveys to collect complementary qualitative information. Jansen (2010) describes quantitative surveys as deductive examinations of distribution in a population and qualitative surveys as inductive explorations of the diversity in values or opinions within the population. Further to this, Braun, Clarke, and Gray (2017) describe qualitative surveys as adding value when combined with quantitative questions. They argue for the reclamation of qualitative surveys in order to capture respondents' views *"in their own words"* (p. 251). Qualitative surveys are usually a self-administered series of open-ended questions where participants can write or type their views on various topics (Braun & Clarke, 2013). This qualitative data, described as participant-generated textual data (Braun & Clarke, 2013), allows for the generation of richer data, with qualitative responses having the potential to illuminate the quantitative responses (Bazeley, 2018). It was evident from the research aims that the collection of a combination of qualitative and quantitative data had the greatest potential for generating a full picture of SLTs' management of dysphagia and mealtime difficulties.

Another consideration is the choice of a descriptive, cross-sectional, or longitudinal survey design (Mertens, 2005). The selection of the survey design depends on the data that needs to be collected. Longitudinal research collects data from the same sample at several time points to examine changes and trends over the study period. This design was inappropriate for the current study, which required data from a single time point. Descriptive and cross-sectional surveys both gather data from a single time point. Descriptive designs report on a single sample, while cross-sectional surveys collect data from several groups to compare the data and examine trends in groups (Mertens, 2005). This survey required data collected from one group, SLTs. Therefore, a descriptive design was most appropriate. Following the survey design decision, it was necessary to determine which type of survey research would be most appropriate.

4.1.1 Types of Survey Research

There are two main types of survey research, the standardised interview and the questionnaire. The standardised interview requires the researcher, or interviewer, to verbally administer a standard set of questions to all interviewees and require a fixed range of responses (Bryman, 2016). There is no deviation in question-wording or the order of item presentation, and it is comparable to a questionnaire administered by an interviewer. Survey research commonly uses this format as one of its strengths is the standardisation of both question-asking and answer recording (Gillham, 2005). One issue with using structured interviews is the potential for social desirability bias, where interviewees provide the answer that they view as the more socially preferable or desirable to the researcher (Bryman, 2016). In addition to this, to generate the necessary qualitative data, this method would become a semi-structured or unstructured interview design that would move away from a survey design and add to the process's length and complexity when aiming to gather large amounts of data. The potential impact of this method on participants' openness in responses, as well as this method requiring responses in a fixed format, meant it was not suitable to capture data on SLTs' perspectives. Another issue with structured interviewing is the limited coverage, i.e., the ability to collect data from a broader geographical area and a large number of people (Gilham, 2005). This method was likely to heavily tax the researcher's limited resources to generate sufficient data to answer the research question. Therefore, it was not an appropriate method for this research.

The other survey method is the questionnaire. Questionnaires are similar to structured interviews in that respondents all receive the same questions, in the same format and order, and have the same response options (Bryman, 2016). The primary difference is that the researcher does not need to be present while the participant completes the questionnaire. Therefore, the administration of questionnaires requires less resource than interviews which is a strength of this method. Another advantage of the questionnaire is the potential for collecting anonymous responses. Ensuring participants' anonymity reduces the risk of social desirability bias impacting responses as respondents feel free to provide their honest opinions on a topic (Gillham, 2007). Questionnaires are also convenient for respondents. They can be completed in participants' own time, meaning they can spend as much time on responses as they feel is necessary (Bryman, 2016). However, some disadvantages of questionnaires are that there is a greater risk of missing data as they cannot prompt respondents to answer questions, and if they misinterpret any questions, the researcher is not present to provide clarification (Bryman, 2016, Gillham, 2007). Despite the disadvantages mentioned, a questionnaire survey design was the most appropriate way for this study to gather data from a large number of SLTs in varying geographical locations. In order to integrate questions to generate data successfully, robust questionnaire design and administration planning were vital steps in the process.

4.2 Questionnaire Development

As no previous studies have looked at this area, there was no existing questionnaire suitable for the task. Therefore, it was necessary to develop a tool to capture SLTs' views and practices when managing dementia-related dysphagia and mealtime difficulties. There are several considerations to make when developing surveys. The following sections will outline the decisions made on the method of distribution, how the questionnaire developed, and the piloting of the survey (Bryman, 2016).

4.2.1 Method of Questionnaire Distribution

Questionnaires are typically distributed by post, email, or web (Dilllman, Smyth & Christian, 2009) and each has its advantages and disadvantages. In post and email questionnaires, the questionnaire is sent personally to the targeted sample and responses are returned directly to the researcher. For email questionnaires, the respondents respond directly to questions within an email, and for postal questionnaires, respondents receive a paper document to be completed and returned by post. Postal questionnaires maintain a degree of anonymity by providing respondents with a stamped addressed envelope to return the questionnaire. However, as data collection relies on respondents remembering to return the questionnaire by post, there is a risk of participants forgetting or forms being lost or delayed (Dillman, Smyth & Christian, 2009). Furthermore, accessing the postal addresses of a target sample is often unfeasible. For instance, no governing body or register can provide details of SLTs' specialities or work addresses (discussed further in section 4.3). Additionally, postal questionnaires have cost implications that are not always mitigated by the data collected (Gillham, 2007). As such, it would be unviable to target a postal questionnaire successfully. Similarly, an email survey has access implications as email addresses are not freely available. They also have implications for anonymity as responses are sent directly to the researcher (Bryman, 2016).

It became clear that an online questionnaire was the most suitable means of distribution. With an unquantifiable sample such as this, online questionnaires allow easier and wider scale distribution than paper surveys. For online questionnaires, researchers distribute a weblink to participants, who can then securely access the questionnaire from their browser. Various online sites host questionnaires though these have different levels of functionality. The University of Strathclyde holds a license for Qualtrics software and recommends its use for secure data storage. It also facilitated anonymity as the option to collect IP addresses could be removed. Bryman (2016) also notes that the ability to vary layout in an online questionnaire is an advantage of this method, and Qualtrics offered a range of features and layouts. The following section discusses the importance of variation in layout and question presentation in more detail.

4.2.2 Question Development

Question development is a multi-stage process that begins with topic generation (Gilham, 2007). Gilham (2007) outlined the risk of the researcher's assumptions clouding the creation of questions and missing items or topics outwith their experience. To mitigate potential bias, the researcher approached colleagues from the National Health Service (NHS) informally to discuss their work with people with dementia. Topic headings and preliminary questions were then generated based on these clinical discussions combined with the researcher's own experience working with people with dementia and the available literature on dysphagia and mealtime difficulties in dementia. These steps were taken to ensure content validity, that the questionnaire covered the necessary depth and breadth of the subject (Mertens, 2005). This was also supported by the questionnaire piloting, discussed in section 4.2.3.

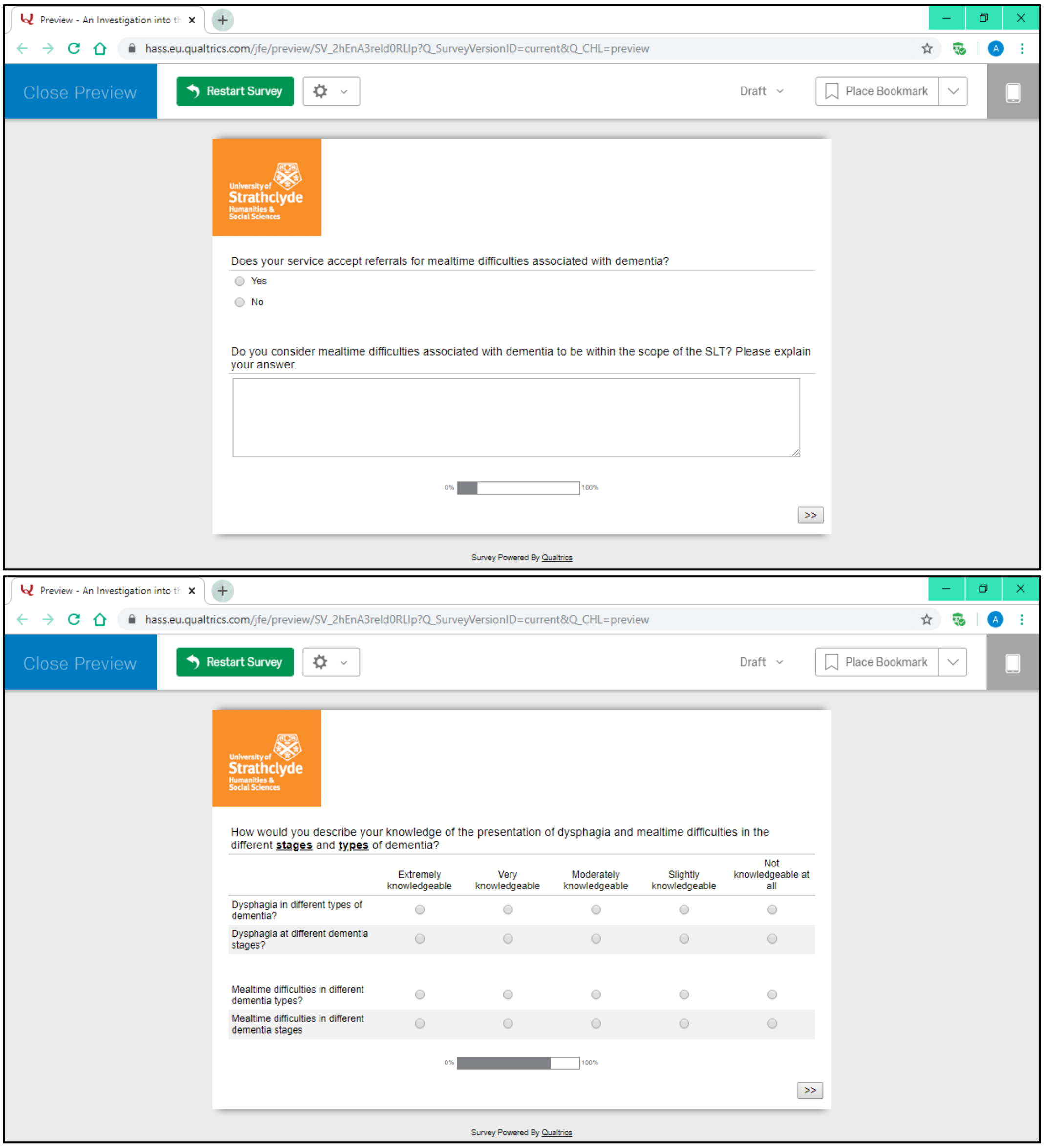
Bryman (2016) recommends taking extreme care at this stage, particularly when deciding whether to ask questions in an open or closed manner. As well as being categorised as open or closed, questionnaire items typically fall into three categories depending on the information they are seeking: 1) facts; 2) opinions, beliefs, and judgements; and 3) behaviours (Gilham, 2007). This questionnaire incorporated all three types through a mix of open and closed questions designed to generate qualitative and quantitative data.

The questionnaire began with an orientation to the research. The first section provided a brief overview of its purpose to allow participants to self-identify if this research was relevant to them. Participants then read the Participant Information Sheet and, as a condition of ethical approval, were required to tick to indicate informed consent for inclusion in the study. Providing their consent was the only compulsory part of the questionnaire. The following section displayed the working definitions of dysphagia and mealtime difficulties used by the project to guide participants' responses. Following the overview, the questionnaire consisted of nine sections covering all aspects of contact with speech and language therapy. Table 4.1 outlines the questionnaire section headings, and the complete questionnaire is in appendix 3.

Table 4.1 Questionnaire Sections

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 Working 9. Final Thoughts

Attention to the layout of the questionnaire was critical. A straightforward presentation ensured that participants could easily follow the structure and flow and understand what the questions asked (Gilham, 2007; Bryman, 2016). As such, the



Does your service accept referrals for mealtime difficulties associated with dementia?

○ Yes
○ No

Do you consider mealtime difficulties associated with dementia to be within the scope of the SLT? Please explain your answer.

How would you describe your knowledge of the presentation of dysphagia and mealtime difficulties in the different **stages** and **types** of dementia?

	Extremely knowledgeable	Very knowledgeable	Moderately knowledgeable	Slightly knowledgeable	Not knowledgeable at all
Dysphagia in different types of dementia?	○	○	○	○	○
Dysphagia at different dementia stages?	○	○	○	○	○
Mealtime difficulties in different dementia types?	○	○	○	○	○
Mealtime difficulties in different dementia stages	○	○	○	○	○

Figure 4.1: Screenshot of questionnaire questions as they appeared to participants.

questionnaire layout minimised the clutter in questions, had large font sizes, and adequate spacing throughout in line with suggested best practice (Dillman, Smyth, & Christian, 2009). Some questions directed participants to different sections depending on their response. For example, participants who indicated they did not conduct training sessions automatically skipped those and moved to the next section. A progress bar indicated to participants how much of the questionnaire remained. Some examples of question presentation are shown in figure 4.1.

4.2.3 Piloting

Piloting questions is essential for design quality (Bryman, 2016). It ensures that the questionnaire has face validity, or that respondents believe it measures what it intends to measure (Jonker & Pennink, 2010). Three SLTs who met the criteria for study inclusion agreed to pilot the questionnaire. They reported the questionnaire was easy to follow but were concerned about the length. Some clarifications to questions were made based on their responses; however, the researcher did not reduce the questionnaire's length as all topics were of equal importance to answering the research question. Once modified, the questionnaire was ready for distribution. In addition to piloting, questionnaire development must take reliability measures into consideration. Reliability is concerned with the consistency of a measurement (Bryman, 2016). This includes whether the measures are stable, i.e., consistent within respondents and over time and (Jonker & Pennink, 2010). Due to survey anonymity, it was not possible to readminister the survey to establish inter-respondent consistency. This was informally evaluated from the responses of the pilot responses. Furthermore, as the survey was designed as a snapshot of SLTs' practice, determining stability of the tool over time was not a priority. Additional questions to determine internal reliability, the extent to which a measure provides stable and consistent results (Taherdoost, 2018), were not included due to the length of the questionnaire. However, the pilot's responses were consistent across items and this was considered to indicate that the tool was reliable. The following section describes the sampling and recruitment decisions made.

4.3 Sampling and Recruitment

Bryman (2016, p. 174) defines a sample as *"the subset of the population that is selected for investigation"* and describes approaches to sampling as probability or non-probability sampling. Research from a positivist tradition requires a probability sample to minimise the risk of coverage errors. In probability or random sampling, every member of a population has an equal chance of being selected for the research, although this is difficult to achieve (Creswell & Creswell, 2018). As described in section 4.2.1, for this research, identifying the total population of SLTs working with people with dementia was not possible. Additionally, as this study was primarily designed for exploratory and descriptive purposes, a probability sample may not have provided a cohort with the desired characteristics to answer the research question.

As this study had a pragmatic approach, it was vital to select a sampling strategy that would enable the collection of the appropriate data to answer the research questions. For that reason, a non-probability sampling strategy, purposive sampling, was selected. A purposive sample is a *"sample selected according to relevance to study"* (Petty, Thomson, & Stew, 2012b; p.380). Namely, the selected sample are the people who can answer the research question. The study also used snowball sampling to ensure that the sample represented was as complete as possible. This sampling is where participants who have taken part in the research suggest others they consider to have experiences or information relevant to the investigation (Bryman, 2016).

The sampling strategy was selected to ensure all eligible SLTs for the survey were made aware of the study, thereby enabling them to self-select. Participants were recruited from the UK and Ireland as the similarities in healthcare provision in these two countries were sufficiently similar to provide comparable responses. Respondents were invited to respond to the survey if they:

1. were qualified SLTs who worked with people with dementia and dysphagia currently or in the last five years; and
2. had worked in the UK or Ireland.

It was necessary to consider and mitigate potential survey errors to ensure the study reached as wide a range of suitable SLTs as possible. Dillman, Smyth, and Christian (2009) described four types of survey error that need to be planned for and considered to maximise the success of the data collection. These errors are measurement, coverage, sampling, and non-response errors. The questionnaire development and recruitment planning processes took steps to minimise these errors. Measurement error occurs when responses to questions are imprecise or inaccurate due to poor design or poor wording. The steps described in section 4.2 aimed to minimise the risk of this error, but they often do not become apparent until analysis.

Coverage, sampling, and non-response errors all relate to the researcher’s success in accessing the desired population. Coverage errors occur when the questionnaire sample does not accurately represent the population as not every member has had equal opportunity for selection (Dillman, Smyth & Christian, 2009). As described, in the absence of a definitive list, it was impossible to ensure all SLTs with relevant experiences were made aware of the study, and it was not possible to calculate a probability sample. As a result, and as is the case for most surveys, sampling error could not be avoided. Sampling errors occur when researchers decide to sample some rather than all of the population of interest (Dillman, Smyth & Christian, 2009). Another consideration was non-response errors, where the respondents sampled who do not respond to the survey have differing or opposing views to the respondents who do respond. In this study, even if it were possible to survey all population members, the entire population could not be identified. The questionnaire was distributed widely through various networks and means to reduce coverage and non-response errors. The following section describes these steps.

4.3.1 Recruitment Measures

The survey was open for three months, from August to October 2016, to allow enough time for data collection. In order to access as much of the population of eligible SLTs as possible, it was essential to advertise the questionnaire widely using multiple and varied means. The researcher anticipated that many eligible SLTs would be members of professional networks (known as Special Interest Groups in Ireland and Clinical Excellence Networks in the UK) as part of their Continuing Professional Development (CPD). The networks’ email addresses were sourced from the two professional bodies' websites, the RCSLT in the UK and the IASLT in Ireland. They assisted in distributing the questionnaire link to their members. The researcher holds full membership of both associations, and these associations also assisted with questionnaire distribution. Both associations shared the details on their social media accounts, and the IASLT also shared the details on their website. One pitfall of distribution across the UK was that, at the time of recruitment, the RCSLT policy was against the blanket advertisement of research opportunities across all members. The RCSLT uses closed online networking groups known as ‘hubs’ to update members in particular regions about practice updates and research activities. They do not share the hub moderators' contact details. Therefore, as the researcher only had access to the Scottish hub, this may have resulted in missed respondents. Efforts were made to distribute the survey to RCSLT members by other means. The RCSLT’s monthly research newsletter published a notice outlining the survey details, and a Letter to the Editor of the RCSLT’s monthly *Bulletin* magazine was also published. The Association for Speech and Language Therapists in Independent Practice (ASLTIP) in the UK also agreed to share the study's details with their members.

The researcher also shared the questionnaire via professional social media accounts, primarily Twitter and speech and language therapy professional groups on Facebook. Participants were also encouraged to share the questionnaire with colleagues who met the criteria, in line with snowball sampling. However, six weeks into the questionnaire’s recruitment window, no respondents had indicated their base was in Northern Ireland or Wales. The researcher contacted the heads of the RCSLT’s Welsh and Northern Irish offices directly to request they distribute the survey to their distribution channels. This contact resulted in the capture of responses from both of these areas. Every measure was taken to distribute the questionnaire to all eligible parties. Nevertheless, given the survey's anonymous and voluntary nature, a non-response error may not have been entirely mitigated.

4.4 Questionnaire Analysis

Once the questionnaire was closed, data were downloaded to Microsoft Excel© and IBM SPSS Statistics for Windows, Version 26.0 for analysis. Qualtrics automatically coded the quantitative data into numerical groups for ease of analysis. The researcher cleaned the data before undertaking the analysis. Some participants entered phrases such as 'as above' or 'see previous answer' in open-ended questions. In these cases, the researcher copied the relevant answers into the cell alongside the original comment. As not all respondents answered all questions, the total number of responses was included in each question's reporting. The Likert scale data were collapsed into groups to meet the assumptions of comparative analysis. The following section describes the various forms of analysis required to deal with open and closed question responses.

4.4.1 Descriptive Analysis of Closed Questions

The data were organised using Microsoft Excel© pivot tables, and descriptive statistics were extracted for all closed questions. Descriptive statistics report averages and percentages to provide a summary and overview of responses to the data (Gillham, 2007). For most questions, univariate analysis, the analysis of one variable at a time (Bryman, 2016), provided the most valuable interpretation of the data. Data can be presented in frequency tables or graphs, but Gillham (2007) recommends caution in graph selection to ensure ease of reading and clarity for readers.

While descriptive statistics provide valuable data for explorative and descriptive studies such as this one, they cannot show associations between any variables. In order to explore relationships between variables, statistical tests of association are necessary.

4.4.2 Tests of Association of Closed Questions

Tests of association tease out whether there is a relationship between two or more categorical variables (Field, 2009). However, before conducting these tests, it is necessary to generate hypotheses of expected relationships. For each potential variable pair, a null (H_0) and an alternative hypothesis (H_1) was documented. An example of H_0 and H_1 hypotheses are:

- H_0: No relationship exists between knowledge of mealtime difficulties in dementia types and the perceived importance of tailoring management to dementia type in the population.
- H_1: There is a relationship between knowledge of mealtime difficulties in dementia types and the perceived importance of tailoring management to dementia type in the population.

IBM SPSS Statistics for Windows, Version 26.0 was then used to create clustered bar charts to visualise these variables. For example, in the graph shown in figure 4.2, the *x*-axis shows the respondents' self-rated knowledge of mealtime difficulties in different types of dementia as it relates to their view of the importance of tailoring their management to the dementia type. The *y*-axis shows the number of SLTs who shared this view. If there was a visual relationship between the variables, a test of association was carried out in SPSS. For example, 14 SLTs who rated themselves as ‘very or extremely knowledgeable’ considered it ‘very or extremely’ important to tailor their management to the type of dementia. There was clustering between the SLTs who rated themselves as having ‘moderate’ or ‘low’ knowledge with their views on the importance of tailoring to dementia type.

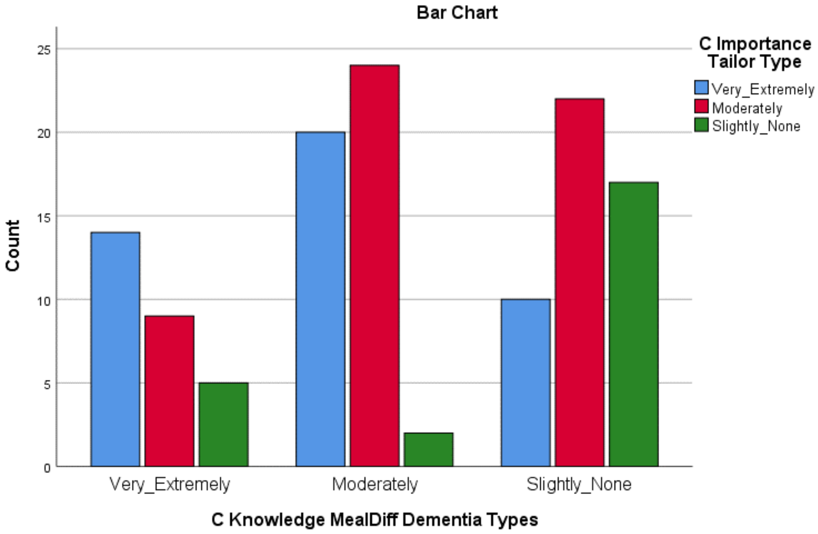
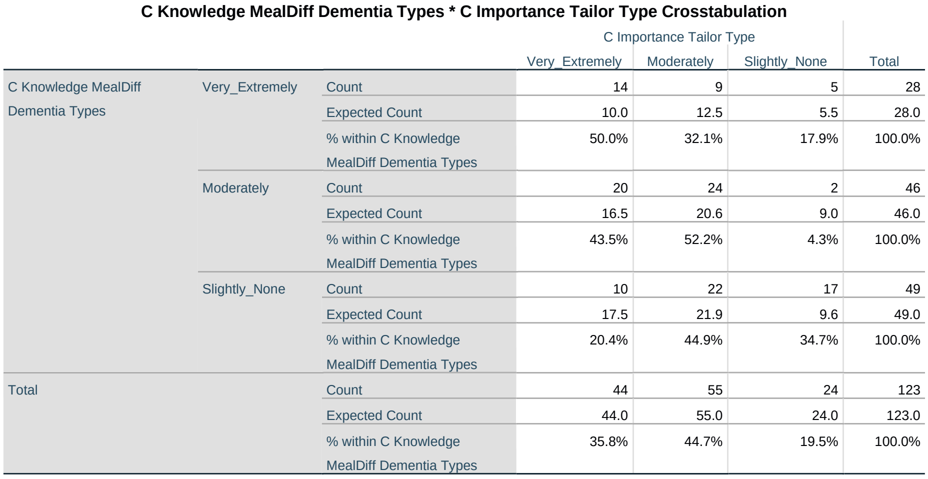


Figure 4.2 Example clustered bar chart

As a result, a contingency table was created to look for a pattern of association between the variables and hypothesise a direction. In contingency tables, the factor influencing the other variable is typically shown in the rows (Bryman, 2016). Figure 4.3 shows a sample contingency table with expected frequencies, where the influencing variable was hypothesised to be the respondents’ knowledge of mealtime difficulties in different dementia types.



C Knowledge MealDiff Dementia Types * C Importance Tailor Type Crosstabulation

			C Importance Tailor Type			
			Very_Extremely	Moderately	Slightly_None	Total
C Knowledge MealDiff Dementia Types	Very_Extremely	Count	14	9	5	28
		Expected Count	10.0	12.5	5.5	28.0
		% within C Knowledge MealDiff Dementia Types	50.0%	32.1%	17.9%	100.0%
	Moderately	Count	20	24	2	46
		Expected Count	16.5	20.6	9.0	46.0
		% within C Knowledge MealDiff Dementia Types	43.5%	52.2%	4.3%	100.0%
	Slightly_None	Count	10	22	17	49
		Expected Count	17.5	21.9	9.6	49.0
		% within C Knowledge MealDiff Dementia Types	20.4%	44.9%	34.7%	100.0%
Total		Count	44	55	24	123
		Expected Count	44.0	55.0	24.0	123.0
		% within C Knowledge MealDiff Dementia Types	35.8%	44.7%	19.5%	100.0%

Figure 4.3 Sample contingency table with expected frequencies

The chi-square (χ^2) is a statistical test applied to contingency tables to establish the likelihood of a relationship between the variables (Bryman, 2016). It calculates the difference between the expected frequency counts of the cells in the contingency table and the actual or observed values to provide the chi-square statistic (Berman & Wang, 2017). It also produces a *p*-value which indicates if the difference is significant (Field, 2009). Cramer's V (ϕc) determines the strength of the relationship (Bryman, 2016). A figure between .10 to .30 indicates a small effect, between .30 to .50 is a medium effect, and .50 and above is a large effect size. It is important to note that the chi-square and *p*-value do not indicate the direction of the relationship. The direction is established by examining the values in the contingency table.

For the chi-square test to be reliable, it needs to meet two assumptions. The first is that each respondent only contributes data to one cell in the table. The current data met this assumption. The second assumption is that no cell of the table has an expected frequency of less than five (Field, 2009). Given the relatively small nature of the sample, this was not always the case. For this reason, the Likert scales were collapsed from five items to three: a positive, neutral, and negative. However, for some items, this assumption was still violated. For these items, a Fisher’s exact test was used. This test was developed to calculate the chi-square's exact probability for smaller samples and does not require the same assumptions as the chi-square test. The Fisher’s exact provides a *p*-value for statistical significance, but again this does not indicate the direction of the association, which can be determined by examining the contingency table.

4.4.3 Content Analysis of Open Questions

Though Gillham (2007) acknowledges the invaluable depth of information provided by open-ended questions, he cautions against their use because of the time it takes to complete analysis. Nevertheless, the questionnaire included open-ended questions because of the vital complement they offer to quantitative data, as described in section 4.1. A robust analysis method was needed to interpret the data and provide insight into the SLTs’ perspectives. Content analysis was chosen as it is an approach to coding text that allows its categorisation into meaningful units that provide a descriptive overview of the data's results (Bryman, 2016).

There are three approaches to content analysis: conventional, directed, and summative (Hsieh & Shannon, 2005). Conventional content analysis is inductive, and codes are developed directly from the data. In contrast, in directed content analysis, the coding is directed by theory, and codes are pre-generated before viewing the data. Summative content analysis is a more quantitative approach to analysis. It involves counting keywords or phrases and reporting their frequency of use (Leung & Chung, 2019). For this study, a conventional content analysis approach was most appropriate, given the limited theoretical data available. Furthermore, as the aim was to understand under-researched SLTs' perspectives on dysphagia and mealtime difficulties associated with dementia, conventional content analysis allowed a more iterative and generative approach.

The steps of conventional content analysis are coding, categorisation and theme generation (Erlingsson & Brysiewicz, 2017). Coding data describes the development of a label for a section of data that captures the data's meaning (Hsieh & Shannon, 2005). All textual data is read, reread, and coded, sometimes receiving more than one code. All of the generated codes are then grouped and categorised before being developed into themes (Erlingsson & Brysiewicz, 2017). In content analysis, themes are descriptive and provide an insight into the issue for the reader. A simplified example of the process from raw data to theme is shown below in figure 4.4.

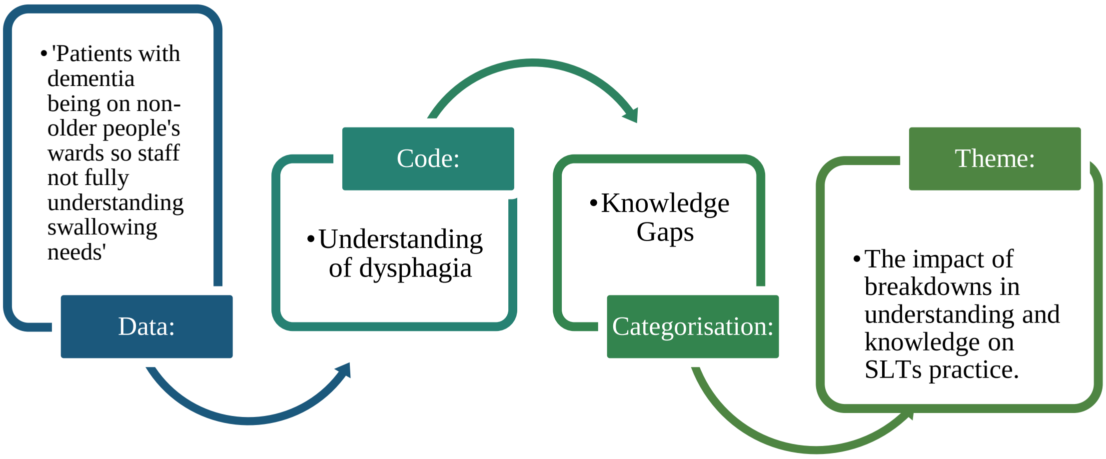


Figure 4.4. Example of coding and theme generation process.

4.5 Ethical Considerations: Anonymity and Confidentiality

An ethical issue for this questionnaire was the anonymity and confidentiality of participants. While the questionnaire did not seek to collect any personal data from respondents, there was still potential for respondents to disclose personal or identifying information in their responses. Additionally, as the field of speech and language therapy is relatively small, if SLTs provided details of their work, there was a risk of anonymity breaches. This was a particular concern as the selection of SLTs who support people with dementia further refines this small pool. To combat this, the questionnaire only asked participants to identify the country they worked in and the type of setting and did not attempt to drill down geographical areas beyond rural, suburban, or urban labelling. The questionnaire was also set up not to collect identifiable information such as IP addresses. The questionnaire's final question asked people to directly contact the researcher if they would like updates on the research or would like to be involved in future research. Contacting the researcher directly, rather than give their details as part of the questionnaire, prevented any attribution of names or details to responses.

4.6 Summary

This section outlined the questionnaire design and development, as well as recruitment and analysis procedures. The following section outlines the results of this questionnaire study.

5 PHASE 1 – THE QUESTIONNAIRE STUDY: RESULTS

This chapter outlines the results of the questionnaire study. This study explored SLTs practices when managing mealtime and swallowing difficulties associated with dementia and their views of these services. Each section will outline the participants' responses to the various segments of the questionnaire. Not all participants responded to all questions; therefore, the number of respondents per item is reported, and percentages were calculated using these figures.

5.1 Respondent Demographics and Caseload Details

The questionnaire was completed by 125 SLTs who primarily worked in the UK (81.6%, *n* = 102). Respondents' years working as an SLT and number of years' experience managing dysphagia were evenly spread. Table 5.1 shows a breakdown of respondents' demographic information. Some notable findings were that for the majority of respondents (71.2%, *n* = 89), dysphagia cases accounted for at least 50% of their workload, though over half of the respondents indicated that dysphagia cases accounted for 80% of their caseload (52.0%, *n* = 65). However, dementia-related dysphagia accounted for 50% or less of their overall dysphagia caseloads (84.8%, *n* =

106). Notably, most respondents (87.2%, *n* = 109) usually saw people with dysphagia across multiple workplaces, with just 12.8% (*n* = 16) working exclusively in one workplace. Respondents typically worked in two (29.6%, *n* = 37), three (21.6%, *n* = 27), or more settings (36.0%, *n* = 45). To make their interpretation more meaningful, given the wide range of settings, the workplaces where respondents identified they worked '*most*' or '*all of the time'* were collapsed into three categories. These categories are acute inpatients (25.6%, *n* = 32), non-acute settings (54.4%, *n* = 68), and mixed acute and non-acute settings (20%, *n* = 25). The collapsing of categories also facilitated the analysis process.

Table 5.1: Respondents' Demographic Information (*N* = 125)

Demographics	**Percentage**	**Response Count**
Country of Work		
England	40.8	51
Scotland	31.2	39
Wales	8.0	10
Northern Ireland	1.6	2
Republic of Ireland	18.4	23
Geographical Area of Work		
Urban Area	51.2	64
Rural Area	18.4	23
Suburban Area	8.8	11
Mixed Locations	21.6	27
Employer Type		
Public Sector (e.g. NHS/HSE)	87.2	109

Demographics	**Percentage**	**Response Count**
Public Sector & Private Practice	4.8	6
Private Practice	3.2	4
Charity/Voluntary Sector	3.2	4
Private Practice & Charity/Voluntary Sector	0.8	1
Private Practice & Higher/Further Education	0.8	1
Years working as an SLT		
Less than one year	4.8	6
1 -5 years	28.0	35
6-10 years	20.0	25
11-15 years	18.4	23
16 years +	28.8	36
Years Managing Dysphagia		
Less than one year	5.6	7
1-5 years	28.8	36
6-10 years	26.4	33
11-15 years	15.2	19
16 years +	23.2	29
Workplace Setting		
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

Demographics	**Percentage**	**Response Count**
Non-acute Outpatient Clinic	11.2	14

5.2 Scope of Speech and Language Therapy Practice

The majority of speech and language therapy services accepted referrals for mealtime difficulties associated with dementia (93%, *n* = 116). Most respondents (*n* = 118) provided their opinion on whether mealtime difficulties associated with dementia were within the scope of speech and language therapy practice. The majority (78.0%, *n* = 92) felt that SLTs should manage mealtime difficulties. They listed reasons such as their training which ensured they were uniquely skilled in supporting the issues (12.7%, *n* = 15), and the impact of communication on the mealtime, which the SLT can support (12.7%, *n* = 15). Some SLTs stressed the importance of their involvement as mealtime difficulties could contribute to an unsafe swallow (14.4%, *n* = 17), and that SLT intervention was essential for quality of life (10.2%, *n* = 12). One respondent summed it up as:

> *Definitely. Obviously oro-pharyngeal dysphagia as a result of dementia is a clear SALT [Speech and Language Therapist] role, but also support around effective communication at mealtimes is clearly a SALT role. I also feel that we have expertise to share around oral phase difficulties e.g. hyposensitivity (looking at taste, temperature) and also around behaviours such as rushing and overfilling- these factors can increase the risk of aspiration and choking, so we have a role in helping to reduce these risks and promote safe and enjoyable mealtimes.*

Around a fifth of respondents felt that in order to provide the most appropriate management for the person with dementia, they should manage mealtime difficulties as part of an MDT (20.3%, *n* = 24). The respondents described their role in managing mealtime difficulties as providing training and education to families and staff (18.6%, *n* = 22), advising compensatory strategies for mealtimes (17.8%, *n* = 21), and recommending environmental changes at meals such as reducing distractions and noise levels (14.4%, *n* = 17). Some SLTs also described offering general advice around feeding and mealtimes (14.4%, *n* = 17), with a few SLTs suggesting they may offer this advice without assessing the person with dementia (7.6%, *n*=9).

Notably, not all SLTs felt that they could manage dementia-related mealtime difficulties (22.0%, *n* = 26). Most of these SLTs' reservations related to service capacity, as they did not have the resource to extend their service to manage mealtime difficulties as well as dysphagia. Some of these respondents considered the presence of dysphagia to be central to the SLT's input (7.6%, *n* = 9). For example, *"[the person] would need to have a dysphagia component to continue SLT involvement"*, and "*I think it is within the role of the SLT to educate and advise re: feeding techniques and strategies, however clinically we only accept referrals where there are reports of dysphagia"*.

5.3 Referrals

Respondents (*N* = 125) indicated that the most frequent source of referrals, across settings, were nurses (76.0%, *n* = 95), with the second most common referrer being care home staff (48.0%, *n* = 60). Respondents also received referrals from specialist doctors (23.2%, *n* = 29), junior doctors (22.4%, *n* = 28), and GPs (16.0%, *n* = 20). The SLTs (*N* = 125) received referrals for dementia-related mealtime or swallowing difficulties in a variety of ways. The most common means of receiving referrals were by post (57.6%, *n* = 72), by phone (55.2%, *n* = 69), or by electronic referral systems (47.2%, *n* = 59). Interestingly, just 23.2% (*n* = 29) had only one means of referrals with most SLTs using a combination. The most common combination was phone-calls, emails, and by post (6.4%, *n* = 8).

The respondents (*n* = 123) were then asked about the types of referral forms or screening tools that services needed to complete to access an SLT. The majority indicated that they used multiple means (52.0%, *n* = 64), though 13.8% (*n* = 17) reported that they used no tool or form. The most commonly used form was a generic SLT form developed by their service (48.0%, *n* = 59) or a dysphagia screening tool (35.8%, *n* = 44), with 29.3% (*n* = 36) reporting that this was developed by their own service. Around 10% (9.8%, *n* = 12) of respondents used a dementia-specific screening tool or referral form. The same number of respondents reported using a commercially available tool. The named commercial screens included screens developed for people post-stroke (*n* = 5). Respondents (*n* = 68) indicated that swallow screens were usually conducted by nursing staff (57.4%, *n* = 39), or a therapy assistant (23.5%, *n* = 16). Responses that referred to acute stroke screening (*n* = 4) were excluded. Not all respondents trained referral agents in swallow screening. Of the respondents (*n* = 49) who provided training to those completing swallow screens, 22.4% (*n* = 11) felt that this training was unnecessary.

Reasons for a referral to be considered inappropriate varied for respondents (*n* = 112). Most commonly, SLTs would reject a referral if the referral was not within the SLTs' scope of practice, for example, oesophageal issues, difficulty swallowing medication, issues with dentition, or weight loss not linked to dysphagia (28.6%, *n* = 32). Other referrals were rejected if they did not indicate the presence of dysphagia (19.6%, *n* = 22) or mealtime difficulties (4.5%, *n* = 5). Several respondents would reject a referral if a patient was not fit for assessment, for example, due to being at the end of life (12.5%, *n* = 14), if they had reduced alertness (12.5%, *n* = 14), or if behavioural issues such as food refusal were present (18.8%, *n* = 21). Other reasons a referral would be considered inappropriate were if a management plan was already in place, for example, if the patient was known to be feeding with accepted risk (8.9%, *n* = 10), if there had been no change in clinical presentation since they had last had SLT input (15.2%, *n* = 17), or if an SLT's recommendations were in place, but they were not being followed (9.8%, *n* = 11).

Protocols for the length of time between receiving a referral and the assessment appointment varied across service settings and respondents (*n* = 123). As stated previously, the majority of respondents worked across multiple settings, and it was not always clear which setting they referred to when providing waiting times. The wait times in acute inpatient settings were the shortest at two days (26.8%, *n* = 33). On the other hand, wait-times in non-acute inpatient and outpatient settings ranged from two days to over 12 weeks, though two weeks was the most common (18.7%, *n* = 23). Just over a third of respondents (35.8%, *n* = 44) indicated that they used prioritisation to stream referrals. Where a prioritisation policy was in place, respondents in acute inpatient settings indicated that patients would be seen within 24 hours if they were judged to be an urgent case, for example, if they were being kept nil by mouth. The community setting results indicated that they saw most urgent referrals within two weeks, with cases the respondents described as *"routine"* taking up to 12 weeks. Overall, 87.0% (*n* = 107) of respondents indicated that they could meet their service's waiting list criteria. Some further comments on referrals and referral systems were provided by 33 of the respondents. The main issue to arise from these comments was that referrals often lacked details, and the processes were inefficient, which was costly to the SLT's time. One SLT's lengthy response reflected frustration at these commonly described issues:

> *Our referral process is terrible for SLT. A generic form used to capture all health and social care referrals therefore no helpful dysphagia information. Referrals are taken by non-health and untrained staff therefore the person processing the referral can never ask beneficial questions and makes things up when they have misheard e.g.: expressive diabetes, receptive dysphagia, and usually each referral just says 'problems swallowing' often with no diagnosis attached so we then must explore if the person has dementia, LD [learning disability], CVA [cerebrovascular accident], MND, cancer etc... There is no knowledge to consider referring oesophageal DG [dysphagia] back to GP so often SLT will need to call GP to discuss barium swallow etc without ever having*

> *met the patient. This results in each referral needing about 20 mins of SLT time to actually figure out what is needed (e.g. DG assessment for person with early stage dementia).*

Some respondents described ways they had tried to mitigate these issues, for example tailoring referral forms or opening referrals to allow care homes to refer directly to the SLT. Several respondents (*n* = 7) described triaging referrals over the phone to screen out inappropriate cases by redirecting or providing advice. However, two respondents reported that they had moved away from phone triage because of concerns about its appropriateness: *"I do not feel this is adequate as so many of the mealtime difficulties are associated with the environment and the communication skills of the carers, so we have abandoned this"*.

5.4 Assessment

Figure 5.1 presents the items typically included in assessment. This figure presents the items in five categories: History, Cognition and Communication, Client Factors, The Mealtime Environment, and the Mechanics of the Swallow. No item was universally included by all respondents (*N* = 125), but the most frequently reported items were medical history (97.6%, *n* = 122), the history of the complaint (94.4%, *n* = 118), alertness (96.8%, *n* = 121), dentition (92.8%, *n* = 116), and the client's positioning (92.0%, *n* = 115).

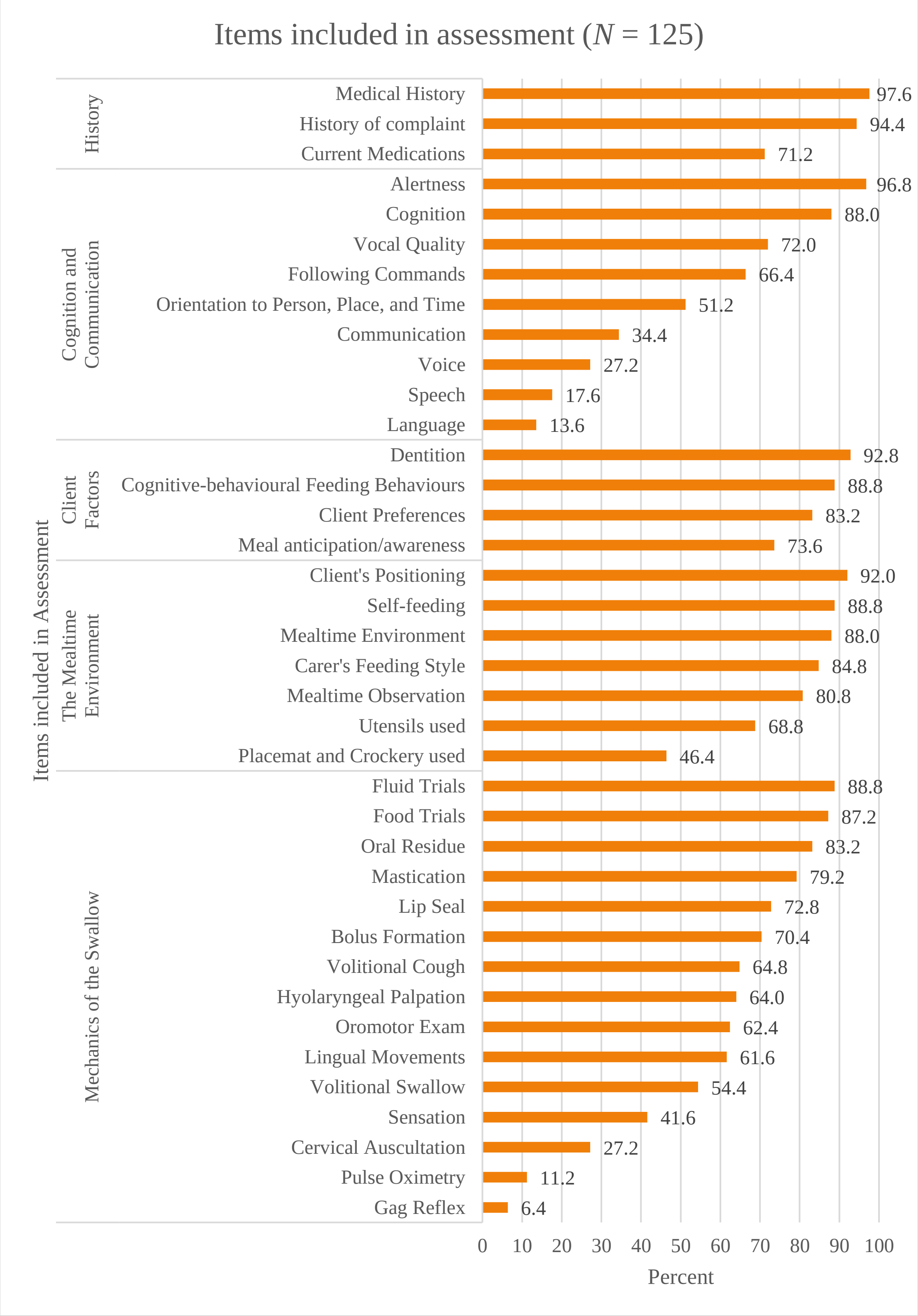


Figure 5.1 Items SLTs typically included in their assessments

From a list of seven factors (including a free text option), 121 respondents ranked the factors that influenced their decision to include items in their assessment procedures. The SLTs' clinical experience was the dominant influence (53.7%, *n* = 65), followed by client factors (e.g., their presentation, cognition, history, etc.; 26.4%, *n* = 32), and then the evidence base (10.7%, *n* = 13). Almost half of the respondents (47.1%, *n* = 57) ranked these three factors (in any order) as the top primary influences on their assessment decisions. Out of the remaining respondents, a fifth ranked clinical experience, client factors, and the SLT scope of practice as the most common influencing factors (21.5%, *n* = 26). Service requirements and the availability of effective interventions were not identified as strong influences on the SLTs' decisions to include items in assessment.

A small number of SLTs (*n* = 19) provided some more general comments on assessment. They reported that their assessments of people with dementia were often based on observations of meals than a direct assessment of the swallow (36.8%, *n* = 7). Usual dysphagia assessment tasks were referred to as tools in the toolbox (21.1%, *n* = 4), which may not always be used: "*they are tools that I have to hand which I can use if necessary, although most of the time I find observational assessment most informative*". These SLTs thought it was important to consider how people's presentation may vary across settings and with different people supporting them at meals (26.3%, *n* = 5).

The majority of SLTs (*N* = 125) had on- or off-site access to at least one form of objective assessment (92.0%, *n* = 115). Access to VFSS (total: 92.0%, *n* = 115, on-site access: 44.8%, *n* = 56, off-site access: 47.2%, *n* = 59) was more common than access to FEES (total: 40.8%, *n* = 51, on-site access: 20.8%, *n* = 26, off-site access: 20.0%, *n* = 25). No respondent indicated that they used any other forms of objective assessment. Most respondents (*n* = 124) identified the factors that influenced their decision to recommend an objective assessment for a person with dementia. These were the person with dementia's ability to follow assessment procedures (87.9%, *n* = 109), the relevance of an objective assessment to the person's clinical presentation (59.7%, *n* = 74), and the person with dementia's ability to follow recommendations (54.0%, *n*=67). Some respondents had concerns that an objective assessment might not be appropriate for a person with dementia (85.5%, *n* = 106), or that it was unlikely to change the management plan (43.5%, *n* = 54). Availability of appointments impacted SLTs' decisions, regardless of whether they had on-site (19.4%, *n* = 24) or off-site (12.9%, *n* = 16) access. SLTs with off-site access also considered the distance (16.9%, *n* = 21) and the travelling time (12.9%, *n* = 16) to attend appointments.

Some SLTs provided further detail on their thoughts on using objective assessment with people with dementia (*n* = 105). Respondents mainly referred to the VFSS in their comments, although three SLTs who mentioned FEES viewed it as inappropriate for people with dementia as it *is "intrusive and does not yield the same information as VFU [sic: VFSS]"*. A prominent view was that objective assessment was worthwhile if it would inform or change the management plan, but for people with dementia, constraints meant that it often would not (38.1%, *n* = 40). As one respondent noted: *“I would generally not request a VF as it is not likely to change management, difficult to show functional ability re out of context”*.

SLTs also felt that the decision should be made on a case-by-case basis, as they would for all objective assessment decisions (36.2%, *n* = 38): *“As with any other client group based on the individual”, and “depend on the patient as to whether this might be appropriate*”. However, SLTs felt that they needed to balance whether the value of assessment findings with the impact the experience could have on the individual with dementia (17.1%, *n* = 18). For example, several respondents (17.1%, *n* = 18) described an objective assessment as potentially distressing, frightening, or even harmful to the well-being of the person with dementia. These comments demonstrate the interaction of the clinicians’ clinical experience and a client-centred approach to supporting people with dementia. For example, “*I use it very rarely for people with dementia because of the potential distress to them*”, “*I will refer for VF if I feel the client will not be too distressed with the procedure and I want further evidence as to what might be happening in the swallow process*”, and “*Often the management plan would be unlikely to change even with objective assessment findings and the risk and distress of the procedure outweighs any potential benefits*”.

However, some SLTs (14.3%, *n* = 15) felt that a diagnosis of dementia or cognitive impairment should not automatically preclude someone from consideration for objective assessments: “*I feel that there is often an assumption made unfairly that all patients with dementia will be non-compliant and patients are missing out on a more thorough assessment this way*”. Nevertheless, the decontextualised nature of an objective assessment also influenced the respondents' decision to recommend them. Respondents cited the need to consider the person with dementia in a broader context than an objective assessment allowed, for example, "*Rarely used because of the disruption to their normal routine which can cause distress and make the assessment unrepresentative of their usual functional leve*l" (15.2%, *n*=16).

5.5 Management

Respondents (*n* = 124) then described their usual practice in following up with people with dementia presenting with dysphagia only (54.8%, *n* = 68), presenting with mealtime difficulties only (47.6%, *n* = 59), and people presenting with both dysphagia and mealtime difficulties (89.5%, *n* = 111). Unsurprisingly, several respondents indicated that their choice of follow-up would vary as they selected a range of responses (dysphagia only: 16.1%, *n* = 20; mealtime difficulties only: 12.9%, *n* = 16: both mealtime difficulties and dysphagia: 28.2%, *n* = 35). The most common practice was an initial assessment with an in-person review for dysphagia only (33.1%, *n* = 41), mealtime difficulties only (12.1%, *n* = 15), and both dysphagia and mealtime difficulties (55.6%, *n* = 69). However, for mealtime difficulties only, respondents were more likely to provide a telephone consultation with no assessment or other follow-up (12.1%, *n* = 15) or an initial assessment with no follow-up (5.6%, *n* = 7). Respondents were equally likely to follow up an initial assessment with a phone review for all issues (dysphagia only and mealtime difficulties only, both 4.8%, *n* = 6; mealtime difficulties and dysphagia 4.0%, *n* = 5). Figure 5.2 outlines all the management strategies recommended by respondents.

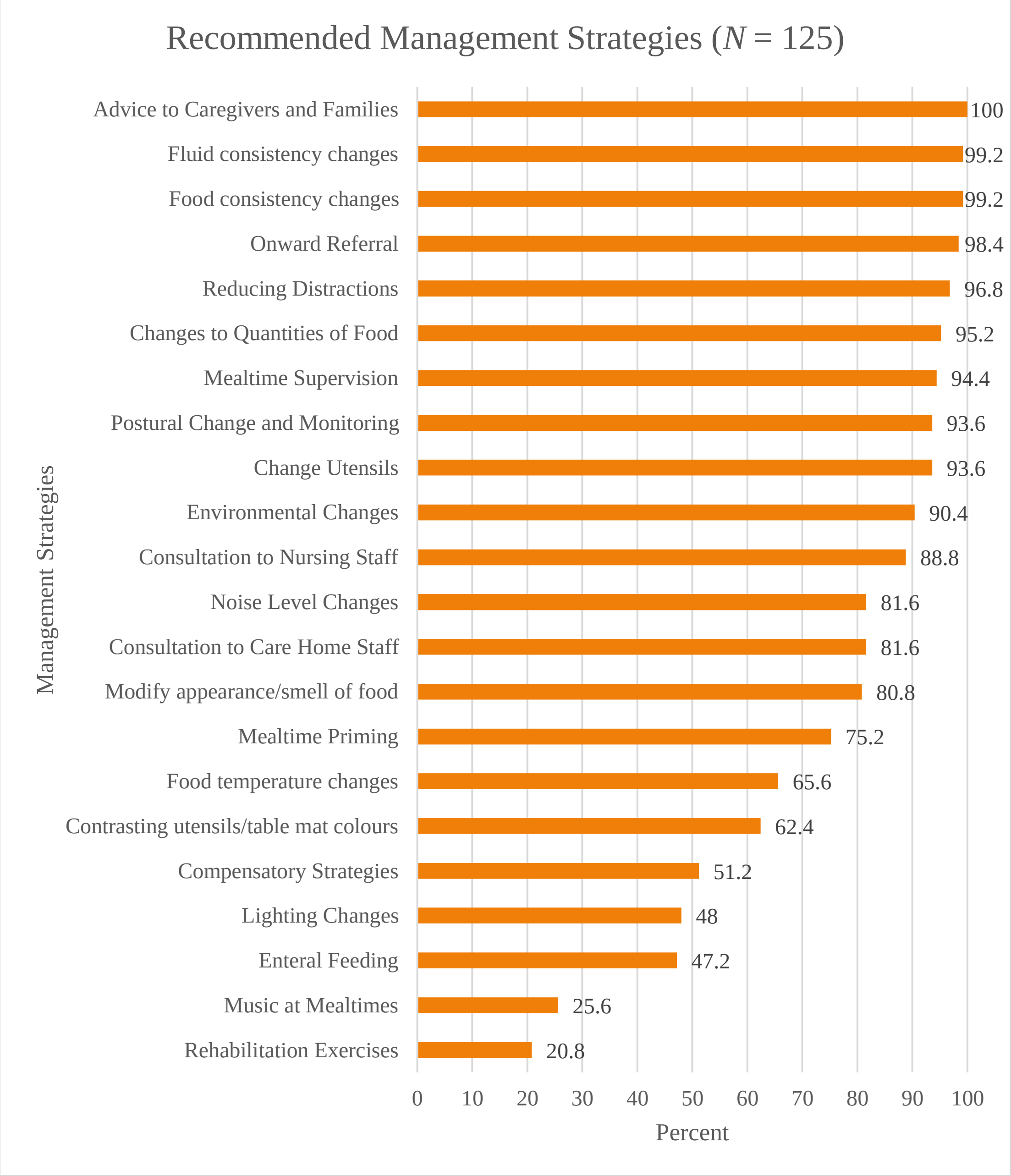


Figure 5.2 Recommended Management Strategies

The most common management strategies used were indirect compensatory strategies, including giving advice to caregivers and family (100%, *N* = 125), recommending changes to food and fluid consistency (both 99.2%, *n* = 124), onward referral to other medical or allied health professionals (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 changes (93.6%, *n* = 117), and recommending changes to the mealtime environment (90.4%, *n* = 113). Some respondents (*n* = 11) indicated that recommendations for changes to utensils or recommending colour contrast of crockery (used by 62.4%, *n* = 78) would be made by, or in liaison with, other allied health colleagues.

The available evidence and the SLTs' clinical experience were the primary drivers of clinical decision-making for management strategy decisions. The respondents were also able to provide comments on these strategies individually, though the amount and level of detail provided varied widely. As such, no themes could be generated. Instead, a selection of comments are reported to provide a flavour of the views expressed. The least recommended strategy was rehabilitation exercises (20.8%, *n* = 26). These SLTs reported that they rarely recommended rehabilitation due to concerns about people with dementia's cognition and ability to follow directions. The SLTs who reported not using rehabilitation exercises gave similar reasons, although some suggested that "*this is not a 100% blanket ban. It depends on the client*". Similarly, for compensatory strategies such as head turns and chin tucks, the respondents had concerns about the person with dementia's ability to recall and correctly carry out the strategy. One respondent considered it on a case-by-case basis: *"depends on patient, but unlikely to retain and effectively use compensatory strategies*". Another SLT had not had past success with the strategies: "*have tried in* *the past but results have been too variable to guarantee patient safety"*. In relation to enteral feeding, SLTs were more split on those who recommended (47.2%, *n* = 59), and those who didn't (48.8%, *n* = 61). In comments, both those who reported they did recommend enteral feeding and those who did not describe its use as an exception, with two SLTs citing the Royal College of Physicians (RCP) guidance to *"use 'wise reluctance'"*. The SLTs also referred to available evidence: *"Evidence doesn't generally support in advanced dementia, however this is considered on a case-by-case basis*".

The next section of the questionnaire asked whether, in their opinion, other staff such as nursing and care home staff should be able to make food texture and fluid consistency changes without an SLT's input (*n* = 124). Around half of respondents (49.2%, *n* = 61) thought that other staff should be able to make changes to food (no: 39.5%, *n* = 49; unsure: 11.3%, *n* = 14). However, when asked about fluid modifications, just over a quarter (26.6%, *n* = 33) believed that care home or nursing staff should be able to make changes without SLT input, while 60.5% (*n* = 75) said they should not, or were unsure (12.1%, *n* = 15). Correspondingly, most respondents stated that nursing or care home staff in their services could not modify food (55.6%, *n* = 69) or fluids (60.5%, *n* = 75) without SLT input. When asked who could make changes to food and fluid recommendations, respondents (*n* = 51) indicated that this was primarily a nursing (64.7%, *n* = 33) or medical staff responsibility (37.3%, *n* = 19). In comments, SLTs (*n* = 97) viewed it as appropriate for staff to make changes to ensure patient safety while they were waiting on an SLT assessment (43.3%, *n* = 42) and that staff should be able to use "*common-sense*" and their own judgement to modify diets for patient comfort, for example choosing softer diets for people with dentition issues (27.8%, *n* = 27).

However, SLTs noted a risk of unnecessary and inappropriate changes to diet and fluid consistencies without SLTs' input (19.6%, *n* = 19), and that there could be implications for the person with dementia's health and quality of life as a result (11.3%, *n* = 11). Some SLTs felt that changes could be made appropriately by trained staff (18.6%, *n* = 18), but there was a limit to what care and nursing staff training enabled them to do (9.3%, *n* = 9). As such, respondents felt there should be a cap to what changes can be made without an SLT's input (11.3%, *n* = 11). Where staff could make changes without consulting speech and language therapy, it was felt that a follow-up and review mechanism was needed to ensure that recommendations did not remain in place inappropriately (10.3%, *n* = 10). A subsection of SLTs had particular concerns about staff other than SLTs making fluid texture changes (12.4%, *n* = 12). They had concerns about the appropriateness and efficacy of thickener and felt that the recommendation of thickening fluids required more nuance and consideration than care and nursing staff training in dysphagia allowed. Their view was that only appropriately trained SLTs (11.3%, *n* = 11) had the knowledge and experience to balance all factors when making recommendations.

5.6 Training and Education

This section of the questionnaire was designed to redirect respondents who did not have experience providing training on dysphagia and mealtime difficulties related to dementia. All respondents were asked a question on the importance of providing training and if this was a service that they offered. Participants then expanded on this question in an open comment box. All respondents (*N* = 125) indicated that it was important that all types of caregivers, such as care home staff, nursing staff, and family carers, had a basic knowledge of dementia-related mealtime difficulties and dysphagia. However, only around a fifth of respondents provided this training (21.6%, *n* = 27). Figure 5.3 illustrates the spread of training delivery.

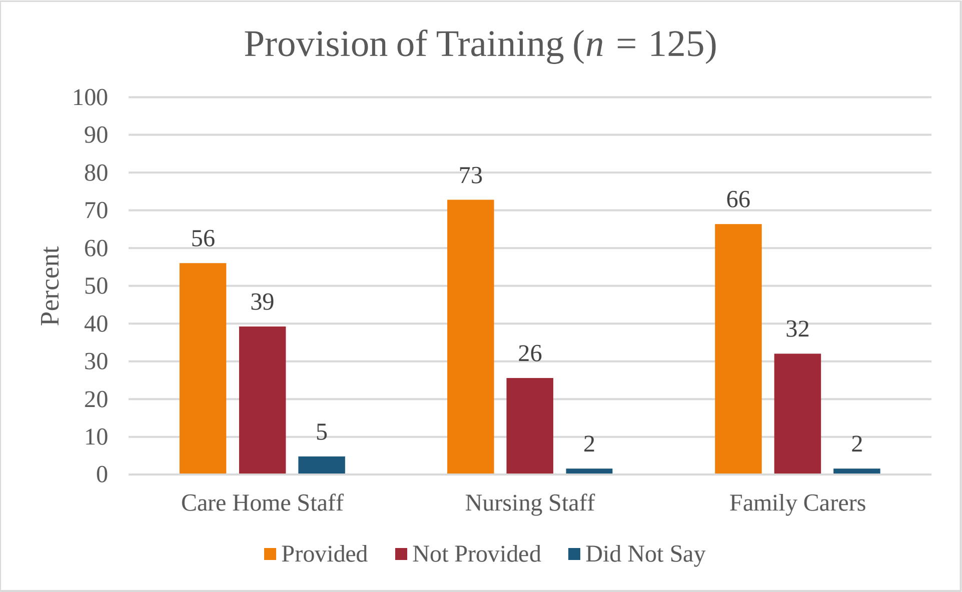


Figure 5.3 Provision of training to carers and nursing staff

Respondents who commented on their answer (*n* = 69) reported that they generally offered training *"as needed*" (89.9%, *n* = 62), for example, offering training to family carers on an individual, case-by-case basis (39%, *n* = 27), or an ad hoc basis to nursing and care staff (30%, *n* = 21). Several respondents (26.1%, *n* = 18) identified care home-related issues for this, such as limited uptake of provided training, staff not released by management to attend, and care homes declining training if it had an associated cost. One respondent described, "*Difficulties with staff being released from duty to attend a more formal training session have repeatedly limited the effectiveness of our attempts to provide this.*" The SLTs described their resources as limited, which made training provision a challenge (42.0%, *n* = 29). Some SLTs referenced issues with service commissioning and funding: *"We are able to provide training to carers/family/nurses but this usually has to be tailored around an individual patient so that it is recorded as patient contact (and therefore funded/commissioned)"*, and *"I think we are patchy on what formal training we provide because commissioners often forget to include training in what they ask services to provide"*. Respondents felt that training had benefits (30.4%, *n* = 21), such as improving the person with dementia's experience.

Participants were then asked if they provided training related to dementia, dysphagia and mealtime difficulties. Those who did were directed to a series of questions about this training's specifics (78%, *n* = 98). Around two-thirds of respondents offered training to care home staff (67.3%, *n* = 66) and family carers (66.3%, *n* = 65). Around half provided training to hospital nurses (49%, *n* = 48) and in-home paid carers (48%, *n* = 47). Information and training courses were provided to hospital doctors by 16.3% (*n* = 16) and to GPs by just 2% (*n* = 2) of respondents, and to members of the MDT by 7.1% (*n* = 7). 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%, *n* = 48), as well as supportive ward or nursing managers (48%, *n* = 47), were considered facilitators to training. Free text ‘other’ facilitators highlighted the onus on the SLT to pursue training provision (*n* = 23). For example, “*Good SLT management-level support and a lot of hard graft by the SLT team to get into the nursing homes to provide the training*” and “*establishing a good relationship and presence on the ward*”. This responsibility was associated by some with the SLT’s demeanour, as they described “*Enthusiastic speech therapists!”* and *“proactive SLTs!”* as drivers to building relationships. On the other hand, identified barriers included staff availability (88.8%, *n* = 87) and high staff turnover (81.6%, *n* = 80). SLTs’ selection of suggested barriers echoed their responses to the previous open-ended question. 51% of respondents (*n* = 50) felt that their workloads and high caseloads presented a barrier to conducting training. Almost half felt that training was not a priority for care home management (46.9%, *n* = 46) and staff (44.9%, *n* = 44), with just 35.7% (*n* = 35) reporting that dysphagia training was mandatory for staff. A further 14 ‘other’ responses outlined a variety of additional barriers, with comments including: “*huge SLT staffing issues”, “lack of understanding about SLT role/dysphagia*”, and *“if management do not drive outcomes of tra[i]ning (eg better feeding etc) then it seems to fall flat”*.

The respondents went on to provide details on how they carried out training and what information was included. Respondents (*n* = 78) reported a wide range of training volume, from less than one hour (7.7%, *n* = 6), to one day (7.7%, *n* = 6), with the most common length being between one and two hours (52.6%, *n* = 41). Most respondents (*n* = 98) included general explanations of dysphagia (93.9%, *n* = 92), signs and symptoms of aspiration (94.9%, *n* = 93), the normal swallow (90.8%, *n* =

89), and indications of when to refer to speech and language therapy (90.8%, *n* = 90) in their training sessions. Respondents also reported providing information on general strategies to manage dysphagia (91.8%, *n* = 90), how to modify diets (93.9%, *n* = 92) and fluids (88.8%, *n* = 87), and how to make environmental (88.8%, *n* = 87) and behavioural modifications (70.4%, *n* = 69). Relatively fewer respondents offered practical demonstrations and opportunities to practice techniques: thickened fluid preparation demonstration (74.5%, *n* = 73), hands-on thickened fluid preparation (61.2%, *n* = 60), and peer practice of strategies and feeding techniques (63.3%, *n* = 62). Positively, mealtime difficulties were explained by 75.5% (*n* = 74), with mealtime difficulties specific to dementia included by 73.5% (*n* = 72). Contrastingly, just 42.8% (*n* = 41) included explanations of dysphagia characteristics associated with dementia.

Training group sizes varied with groups of six or more (80.6%, *n* = 79), smaller groups of five or less (68.4%, *n* = 67) or one-to-one training sessions (43.9%, *n* = 43). It was not common for the respondents to provide self-study materials, for example paper (9.2%, *n* = 9) or electronic materials (3.1%, *n* = 3). The main methods respondents used for training were verbal explanation (95.9%, *n* = 94), PowerPoint presentations (84.7%, *n* = 83), diagrams (81.6%, *n* = 80), and video clips (61.2%, *n* = 60). Around 40% of respondents (38.8%, *n* = 38) did not provide any training follow-up, though 32.7% (*n* = 32) reported carrying out pre- and post-training assessments or mealtime audits of staff performance (20.4%, *n* = 20).

In open-ended comments (*n* = 42), respondents reiterated the issues they faced in getting buy-in and recognition of training's value from care home managers and staff (31.0%, n = 13). Again, respondents identified issues such as access to staff, persuading managers of the importance of training, and finding it difficult to motivate staff to engage. Some typical comments were: "*Motivation for staff and getting them to care is the biggest issue*", "*In my experience, many Staff and Family Carers would not realise/recognise the need for information and training related to FEDS in dementia*", and

> *[it is] currently difficult to persuade home managers of the importance of training in this area. Would like to link with CQC [Care Quality Commission] and give this type of training mandatory status, but our service does not hour [sic] the resources at present to pursue this. Needs to be raised at commissioning level.*

Resource issues were a common theme, with respondents (19.0%, n = 8) citing a lack of staff time to access training, as well as their own time and capacity to deliver it.

Other respondents described their training as 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*". They also discussed a need to adapt and innovate care staff training to account for their limited availability (28.6%, n = 12). Respondents described some success with delivering training in bite-size blocks and carrying out pre-training visits to staff to identify specific needs and tailor training accordingly. However, this was not without its issues. For example, one SLT described following a successful pilot: “*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*”.

The SLTs (*n* = 64) also provided some background on the types of CPD or specialised training they received specific to dementia and dysphagia and mealtime difficulties. No SLT reported attending a training specific to this, although some had attended general dementia training (e.g., Dementia Champion Training or other general courses, both 4.7%, *n* = 3). The most commonly reported CPD was attendance at professional study days relevant to the topic (29.7%, *n* = 19) or in-service talks from colleagues (9.4%, *n* = *6*).

The SLTs then described the resources that they found useful in their clinical practice (*n* = 58). Respondents listed resources in a variety of formats such as videos, books, and mobile applications. Though they identified 45 individual resources, only those recommended by at least two SLTs are included in table 5.2. This table presents the resources grouped by use, i.e., resources for SLTs’ learning and practice, resources that can support carers, and resources that can be used with people with dementia.

Table 5.2 Clinical Resources (*n* = 58)

Name of Resource	**Percentage**	**Response Count**
Resources used by SLTs		
Book: Kindell, J., (2002). *Feeding and Swallowing Disorders in Dementia.* Speechmark Publishing Ltd.	32.8	19
Information Guide: National Patient Safety Agency (NPSA) Dysphagia Care Plans.	10.3	6

Name of Resource	**Percentage**	**Response Count**
CPD: Accessing journal articles and evidence-based practice information	5.2	3
Resources used with People with Dementia		
Toolkit: Talking Mats. Information available at https://www.talkingmats.com/	3.4	2
Resources for Carers		
Information Guide: NHS Dumfries and Galloway: The Communication and Mealtimes Toolkit. Available from: http://www.nhsdg.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., & Hare, P. (2010). *Supporting people with learning disabilities and dementia training pack: A training pack for support staff* (based on the Supporting Derek film and guide). Available from: 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: ‘Eating well: Supporting older people and older people with dementia’. Available from: https://www.cwt.org.uk/wp-	5.2	3

Name of Resource	**Percentage**	**Response Count**
content/uploads/2014/07/EW-Old-Dementia-Practical-Resource.pdf		
CPD: E-learning modules	5.2	3
Information Guide: Dementia Care - Support with eating and drinking. Available from: http://www.dementiacarers.co.uk/documents/dementia-eatinganddrinking.pdf	3.4	2
App: Dysphagia Apps	3.4	2

5.7 Dementia Type and Stage

Access to information on dementia type and stage was variable across respondents (*N* = 125). Some reported having access to details of type and stage (36.8%, *n* = 46), while others only had information on dementia type (26.4%, *n* = 33) or stage (7.2%, *n* = 9). However, almost 30% of the respondents had no or sporadic access to details on dementia type and stage (29.6%, *n* = 37). The SLTs' (*n* = 124) views on the importance of tailoring their management to dementia type and stage varied, as shown in figure 5.4. More respondents considered it very or extremely important to tailor their management to the stage of dementia (79.0%, *n* = 98), compared to dementia type (36.3%, *n* = 45).

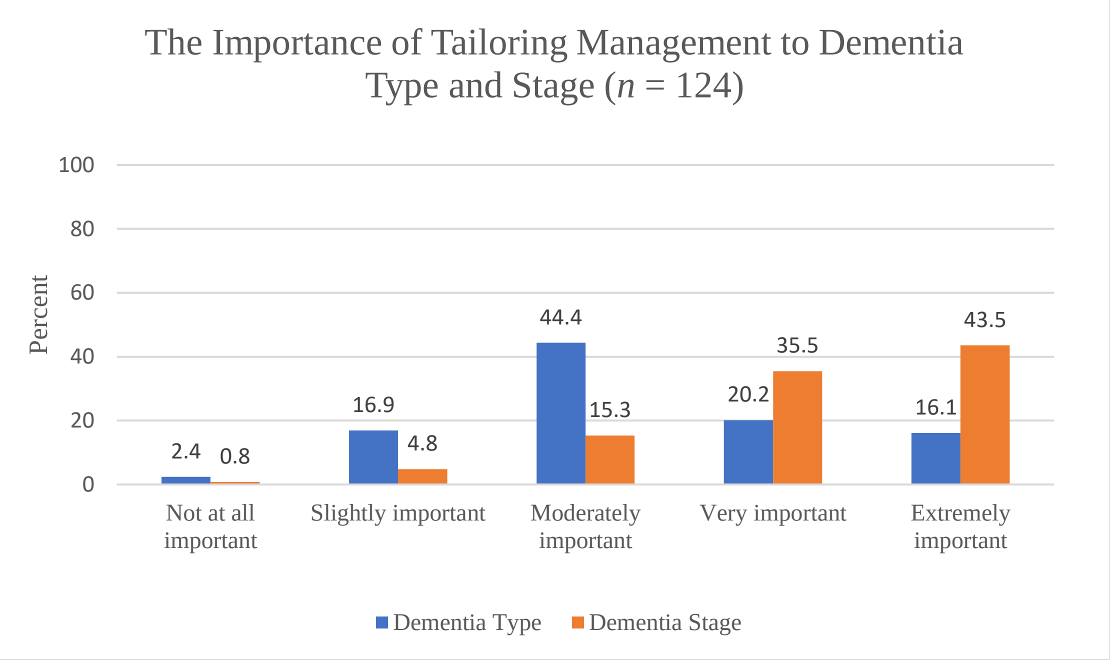


Figure 5.4 The importance of tailoring management to dementia type and stage

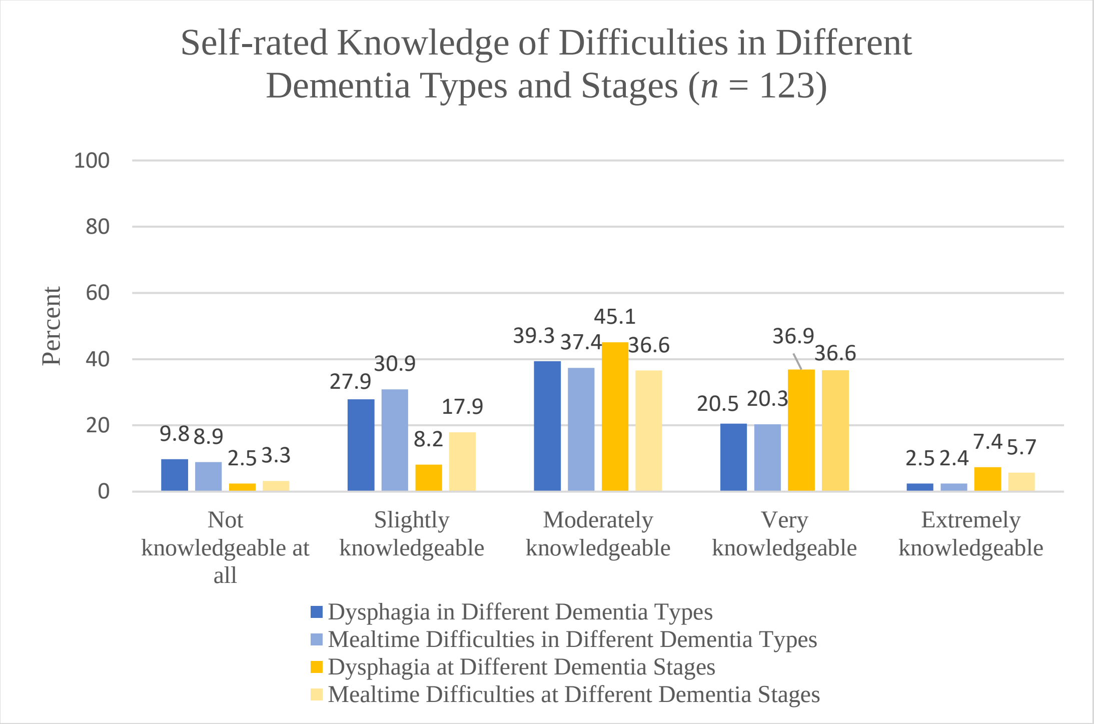


Figure 5.5 Participants' self-rated knowledge of difficulties in different dementia types and stages

How respondents (*n* = 123) rated their knowledge of the presentation of dysphagia and mealtime difficulties in different stages and types of dementia reflected their views on its importance, as shown in figure 5.5. SLTs considered themselves more knowledgeable on variations in the presentation in different dementia stages than in dementia types. However, respondents viewed themselves as more knowledgeable about dysphagia presentation than mealtime difficulties presentation overall and rated themselves relatively equally knowledgeable about both presentations in different dementia types.

It had been hypothesised that there was a relationship between the respondents' knowledge of presentations in stages and types, their views on the importance of that information, and demographic factors. A series of null and alternative hypotheses were developed, and these are presented in appendix 4. An example of these hypotheses is:

- H_0: No relationship exists between knowledge of dysphagia in dementia types and the perceived importance of tailoring management to dementia type in the population
- H_1: There is a relationship between knowledge of dysphagia in dementia types and the perceived importance of tailoring management to dementia type in the population

Table 5.3 presents the findings of the tests of association for comparisons between knowledge of mealtime difficulties and dysphagia and the respondents' views on the importance of tailoring management to dementia types and stages.

Table 5.3 Tests of Association Results

Factor 1	**Factor 2**	**χ^2 or Fisher's Exact**	**Φc**	**Significance (two-tailed)**
Knowledge of dysphagia in dementia types	Importance of tailoring management to dementia type	$\chi^2(4) = 21.34$	$\Phi c = .30$	***p* = < .001**
Knowledge of mealtime difficulties in dementia types	Importance of tailoring management to dementia type	$\chi^2(4) = 18.39$	$\phi c = .27$	***p = .001***
Knowledge of dysphagia in dementia stages	Importance of tailoring management to dementia stage	Fisher's Exact		***p = .006***
Knowledge of mealtime difficulties in dementia stages	Importance of tailoring management to dementia stage	Fisher's Exact		*p* = .281
Knowledge of dysphagia in dementia types	Knowledge of mealtime difficulties in dementia types	$\chi 2(4) = 150.20$	Φc = .78	***p = .000***
Knowledge of dysphagia in dementia stages	Knowledge of mealtime difficulties in dementia stages	Fisher's Exact		***p = .000***

Factor 1	**Factor 2**	**χ^2 or Fisher's Exact**	**Φc**	**Significance (two-tailed)**
Knowledge of dysphagia in dementia stages	Knowledge of dysphagia in dementia types	Fisher's Exact		***p = .000***
Knowledge of mealtime difficulties in dementia stages	Knowledge of mealtime difficulties in dementia types	$\chi^2(4) = 55.52$	$\phi c = .55$	***p = .000***

A chi-square test of association revealed that knowledge of dysphagia in dementia types was significantly associated with the perceived importance of tailoring management to dementia type, with a small effect size. Analysis of the contingency table indicated that SLTs who considered themselves very or extremely knowledgeable were more likely to think it very or extremely important to tailor to dementia type, SLTs with moderate knowledge were more likely to think tailoring to type was moderately important, and SLTs who rated themselves as slightly or not knowledgeable were less likely to tailor to dementia type. Similarly, there was a relationship between the respondents' knowledge of mealtime difficulties in dementia types and their perception of the importance of tailoring to dementia type. Contingency table analysis revealed that SLTs who considered themselves very or extremely knowledgeable were more likely to think it important to tailor to dementia type, SLTs with moderate knowledge were more likely to think tailoring to type was moderately important, and SLTs who rated themselves as slightly or not knowledgeable were less likely to tailor to dementia type.

The relationship between knowledge of presentations in dementia stages and the perception of importance were then examined. These variables violated the assumptions of the chi-square test. As such, Fisher's Exact tests were used. This test indicated a significant association between knowledge of dysphagia at different stages of dementia and the importance of tailoring management to the dementia stage. An examination of the contingency table indicated that respondents who considered themselves very or extremely knowledgeable considered it more important to tailor management to the dementia stage. However, another Fisher's Exact test indicated a non-significant association between knowledge of mealtime difficulties at different stages of dementia and the importance of tailoring management to dysphagia type.

The next series of comparisons questioned if a relationship existed between the respondents self-rated knowledge of mealtime difficulties and their knowledge of dysphagia in different dementia types and stages. Knowledge of dysphagia in dementia types was significantly associated with knowledge of mealtime difficulties in dementia types, with a large effect size. It showed that SLTs with very or extremely good knowledge of dysphagia in dementia types were more likely to have very or extremely good knowledge of mealtime difficulties in dementia types. Knowledge of dysphagia in dementia stages was also significantly associated with knowledge of mealtime difficulties in dementia stages, with a large effect size.

A Fisher's Exact test indicated that knowledge of dysphagia in dementia stages was significantly associated with knowledge of dysphagia in dementia types, with a medium effect size. There was also a significant association between the respondents' knowledge of mealtime difficulties in dementia stages and their knowledge of mealtime difficulties in dementia types. For these four comparisons, contingency table analysis demonstrated that SLTs' rating of their knowledge of the first variable reflected their rating on the second variable.

A series of other comparisons were made, and the null and alternative hypotheses for these are also shown in appendix 4. The results are shown in appendix 5. Many of these comparisons did not show a significant association between the variables. For example, there was no relationship between respondents' workplace (acute, non-acute, and mixed acute and non-acute settings) and their knowledge of dysphagia or mealtime difficulties in different types of dementia in different stages. However, there was an association between their place of work and their perception of the importance of tailoring management to dementia type ($\chi^2(4) = 14.73$, $p = .005$ (two-tailed), $\phi c = .25$), as SLTs in acute settings did not view tailoring management to type as important. There was also an association between respondents' knowledge of mealtime difficulties in different types of dementia and the country they worked ($\chi^2(2) = 7.88$, $p = .019$ (two-tailed), $\phi c = .25$). SLTs in Ireland were more likely to rate themselves as moderately knowledgeable, while SLTs in the UK were more likely to rate themselves as slightly or not knowledgeable. The SLTs' years of experience were associated with their self-rated knowledge of dysphagia in different dementia types as SLTs with less experience were more likely to rate their knowledge lower than SLTs with more experience who were more likely to rate their knowledge higher.

5.8 Stakeholder Liaison and Adherence to Recommendations

Most SLTs (*n* = 122) reported providing feedback to all the major stakeholders involved in supporting people with dementia, for example, medical colleagues, family members, and nursing or care staff, shown in figure 5.6. The respondents identified challenges to liaising with them. The majority described issues liaising with the person with dementia (83.6%, *n* = 102), such as their cognitive ability (42.2%, *n* = 43), their ability to comprehend the feedback (40.2%, *n* = 41), and their ability to retain and act on this information (19.6%, *n* = 20).

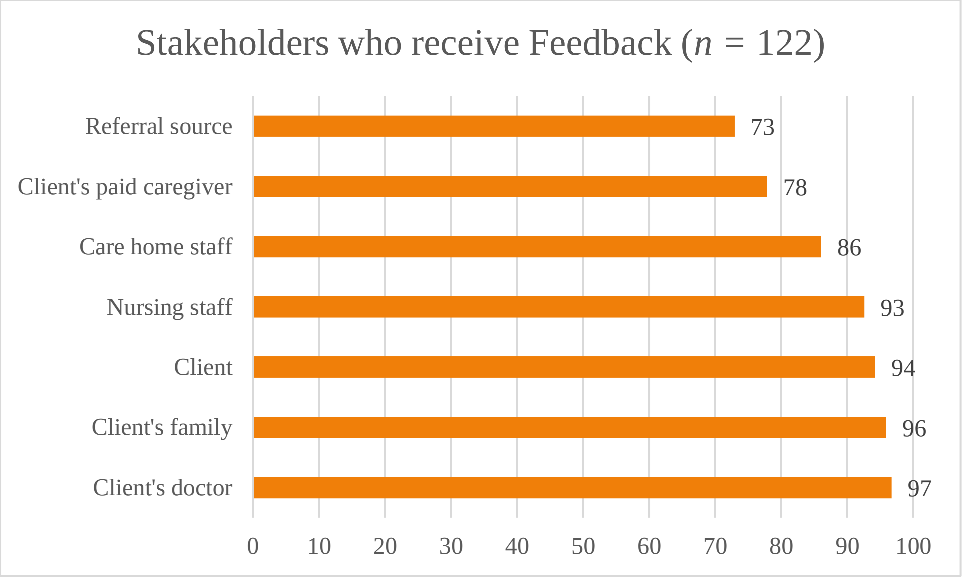


Figure 5.6 Stakeholders who receive feedback from the SLTs

Providing feedback to the person with dementia's family was challenging for 57.4% (*n* = 70), with their availability for discussion cited as a common issue (34.3%, *n* = 24). Respondents also identified issues when liaising with care home staff (45.9%, *n* = 56), with staff turnover and availability being the primary challenges reported (32.1%, *n* = 18). How care home staff disseminated information amongst themselves was an additional concern for SLTs (23.2%, *n* = 13). The SLTs made comments such as: "*not always sure that feedback is interpreted and/or passed on the way I intend it to be*" and *"Staff changes and difficulty with information being disseminated to all care home staff who need it".* Similarly, liaison challenges were faced with doctors by 36.1% (*n* = 44). While some respondents reported an established system of feedback that was working well (4.9%, *n* = 6), around half of these SLTs (50.0%, *n* = 22) reported that their main issues were accessing the doctor and the doctor's availability. There was also a concern that doctors were not engaged with supporting the person with dementia (22.7%, *n* = 10), as one respondent commented: *"Communication with GPs is often all one way, but some do engage very well".*

In addition to liaison challenges, many of the SLTs faced issues with client or caregivers not following recommendations (93.6%, *n* = 117). A number of the respondents (*n* = 103) provided further details on the adherence issues they faced, with close to half (43.7%, *n* = 45) identifying issues related to diet and fluid modification recommendations. Some of the SLTs associated this with a lack of understanding of these recommendations' rationale (46.6%, *n* = 48). They also felt that there were issues understanding the recommendations' scope, for example, that modifications applied across all food and drink, and that there could be negative consequences for the person with dementia if they were not followed. They also reported that people with dementia (20.4%, *n* = 21) and their carers (9.7%, *n* = 10) tended to dislike modified textures.

The majority of these SLTs viewed training and education (52.4%, *n* = 54) as the best strategy to increase adherence to recommendations. Some also felt that being available for discussion and involving stakeholders in discussions supported the understanding and implementation of recommendations (31.1%, *n* = 32). Tailoring recommendations to individuals' and carers' preferences through compromises was also viewed as an important strategy (13.6%, *n* = 14). As one SLT 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".* In order to facilitate care home staff adherence to SLT recommendations, some SLTs reinforced the ethical and legal consequences for care home and nursing staff and management who caused harm by not abiding by recommendations appropriately (14.6%, *n* = 15). For example, these SLTs reminded care home staff of their obligations to residents under their regulators' care standards.

5.9 Multidisciplinary Team Working

Most SLTs (81.6%, *n* = 102) indicated that they do work as part of an MDT. Of those who described their team (*n* = 95), the most common team members were OTs (89.5%, *n* = 85), physiotherapists (78.9%, *n* = 75), nursing staff (78.9%, *n* = 75), and dietitians (75.8%, *n* = 72). The respondents (*n* = 92) reported working most closely with dietetics (62.0%, *n* = 57) and nursing colleagues (62.0%, *n* = 57). The majority of respondents (*n* = 119) considered being part of the MDT as extremely important (65.5%, *n* = 78) or very important (24.4%, *n* = 29).

5.10 Speech and Language Therapists' Final Thoughts

The questionnaire's final section was a series of open-ended questions on practice facilitators, barriers, resources, training, and general comments. Many of the themes generated here reflected and echoed the issues described throughout the chapter. These themes related to family and carer knowledge, carer availability and consistency, referral challenges, and MDT relationships.

Respondents ($n = 81$) identified several facilitators to effective practice. One of these facilitators was the knowledge levels of families, carers, and staff achieved through SLT education on mealtime difficulties and dysphagia associated with dementia (45.7%, $n = 37$). It was typical for respondents to indicate that their practice was enhanced when this understanding was present. A robust referral system (42.0%, $n = 34$) was also a facilitator, and they linked this to the knowledge and education of referrers. SLTs described a robust referral system as one where the team recognised the need for SLT input, referred in a timely manner, and included sufficient information for the SLT to triage the case. SLTs (24.7%, $n = 20$) felt that a collaborative approach to management with carers, the MDT, and the family was central to supporting the person with dementia to achieve the best outcomes. As one SLT described: "*listening to clients and carers - SLT advice is only one aspect, client/carer choice and eating and drinking wishes are the ultimate concern, to enhance quality of life*". They also viewed access to an MDT (22.2%, $n = 18$) and good relationships (19.8%, $n = 16$) as facilitators of effective practice.

The SLTs also described barriers to effective practice (n = 87). The most-reported barrier was carer issues (52.9%, *n* = 46), with responses related to concerns about the carers' ability to understand and implement recommendations (13.8%, *n* = 12), high staff turnover (11.5%, *n* = 10), and unmotivated or disinterested staff (10.3%, *n* = 9) being typical. Gaps in carer knowledge were also identified as a concern (39.1%, *n* = 34), particularly around their knowledge of dysphagia (17.2%, *n* = 15) and the SLT role (11.5%, *n* = 10). Another barrier was the SLT services' capacity (essentially their available time and resource) to provide an effective service, for example: "*lack of staff ability to see clients in a timely manner e.g. only 8 adult SLTs working across a wide geographical area pushing up waiting times".* A lack of trained carers was also a barrier (27.6%, *n* = 24), with some SLTs linking this to their lack of service capacity: "*Due to SLT caseload pressures we are unable to provide the training needed*". A further barrier was when there were issues following SLT recommendations (26.4%, *n* = 23). These included when supports such as mealtime assistance were not provided, carers did not follow advice (11.5%, *n* = 10), and when inflexible environments, such as hospital wards, did not allow for recommendations to be implemented (9.2%, *n* = 8). While a robust referral system was considered a facilitator to good practice, unsound referral practices created barriers for SLTs (20.7%, *n* = 18).

5.11 Summary

This chapter presented the results of a survey of SLTs' practices and perspectives when supporting people with dementia-related dysphagia and mealtime difficulties. The survey was completed by 125 SLTs, and they shared details and provided their opinions across nine topics. The data presented here provides the first comprehensive documentation of SLT referral, assessment, management, and training practices. It allows an insight into the barriers faced in practice by therapists across the UK and Ireland and shines a light on areas of good practice and innovation. This study offers previously unknown details on how SLTs view their knowledge of mealtime difficulties and dysphagia, what this self-rated knowledge influences, and what influences it. The following chapter will explore these results in more detail and relate the findings to the relevant literature. As this study was the first phase of an adapted explanatory sequential mixed methods design, the following chapter will also expand on how it influenced the second phase's development.

6 PHASE 1 – THE QUESTIONNAIRE STUDY: DISCUSSION

This study is the first comprehensive survey of SLT practices encompassing all aspects of the assessment and management of dementia-related dysphagia and mealtime difficulties in the UK and Ireland. It ascertains the SLTs' views on the challenges that they face when managing these difficulties. It was evident from the range of responses that procedures vary between SLTs and services. The issues raised in the survey are discussed here in light of the available literature. This chapter concludes by outlining how the survey's outcomes informed the next phase of the research.

6.1 About the Respondents

In the first section of the questionnaire, the respondents provided their demographic information and an insight into their caseloads. Though the RCSLT (2019) report approximately 17,000 SLTs are working in the UK and the IASLT (2018) suggest 1098 SLTs are working in the public health service in Ireland, neither body provides information on where these SLTs work. As such, it was not possible to determine a representative sample, though the responses had similarities to previously published studies. For example, dysphagia accounted for at least 50% of SLTs' caseloads, similar to studies in the UK, Ireland, Australia, and the USA (Bateman et al., 2007; Mathers-Schmidt & Kurlinski, 2003; Pettigrew & O'Toole, 2007; Vogels et al., 2015). However, it is the first to consider the percentage of dementia-related dysphagia in SLTs' caseloads.

Table 5.1 showed the range of settings where SLTs support people with dementia, such as acute hospitals, community clinics, and home or home-like settings. One particularly compelling finding is that the majority of respondents work in three or more settings. The nature of the clinical setting and the reason for attendance would suggest a different profile of need. From the researcher's clinical experience, the stability of a person's health influences decision-making around a condition's management. For example, a person with dementia requiring speech and language therapy services in an acute hospital setting is likely to have an acute medical issue or a change or decline in their health status that may require more conservative management in the short-term. A person with dementia attending an out-patient clinic, on the other hand, is likely to have a more stable medical presentation so management can focus on maximising comfort, safety and quality of life in the longer term. Therefore, the fact that the majority of respondents work in three or more settings was surprising, as these SLTs will need to consider the impact of factors such as the environment, the person's health, and their mealtime environment, differently in each setting, and their practice is likely to vary across settings. A supposition from these findings is that SLTs may face complexities in adapting their roles across settings. SLTs' practices and needs across different settings are as yet unexplored.

Unfortunately, comparing which factors and practices are more relevant and likely in different settings was not possible given the respondents' variations in setting combinations. As such, the results are primarily presented as a single group. Future research should explore the SLT's role in different settings and the implications for SLT education and working practices. The following section considers the SLTs' perceptions of their role in managing dementia-related mealtime difficulties.

6.2 Scope of the Speech and Language Therapist's Role Managing Mealtime Difficulties

This survey is the first to look at the SLTs' perception of their role in managing mealtime difficulties. This section of the questionnaire also considered barriers to this role. The current respondents agreed that dysphagia treatment is an integral part of their role in supporting people with dementia, although their views on their role in mealtime difficulties were not as clear cut. Most respondents reported their services accepted referrals for mealtime difficulties, and they generally agreed that these issues were within their scope. This view aligns with findings from Australia that indicate that SLTs perceive this aspect of their role as one of value to older adults (Bennett, Cartwright, & Young, 2019). However, some of the sentiments expressed in the current study indicated that this did not always translate into practice. For instance, around a fifth of the respondents (*n* = 26 of 118 responses) reported that they did not have the resource to offer support for mealtime difficulties without concomitant dysphagia and other respondents reported that they could only provide over-the-phone advice to people with mealtime difficulties. A number of these respondents (*n* = 9) indicated that they did not consider mealtime difficulties without dysphagia to be within the SLT’s remit, despite research described in section 1.2 highlighting that factors beyond a functional swallow can be as significant as the impacts of dysphagia on health and well-being. The Australian survey’s respondents felt that resource limitations hindered their service delivery for this client group (Bennett et al., 2019). That finding is reflected here; however, this survey adds more details to how resource limitations impact practice and suggests that they result in variability in practice and service delivery. This variability risks inequitable access to speech and language therapy services for people with dementia. Given the significant risks associated with unmanaged mealtime difficulties and dysphagia, these findings are concerning. They underscore the need to resource services sufficiently to enable them to support individuals with dementia-related mealtime difficulties, as well as dysphagia.

However, gaps at policy level do not support services to commission and resource SLTs to manage these issues. An example of where this is relevant is in the current NICE (2018) dementia guidelines. Despite these guidelines covering the period from dementia diagnosis to palliation, they only recognise the SLT’s role in end of life care as they advise health professionals to “*consider involving a speech and language therapist if there are concerns about a person’s safety when eating and drinking*” (NICE, 2018, p. 30). NICE’s omission of the SLT in the earlier stages of dementia indicates that commissioners do not recognise the SLT’s role in managing dysphagia and mealtime difficulties across the course of dementia. Furthermore, it does not take account of research evidence such as Humbert et al.’s (2010), which demonstrates early-stage swallowing changes.

Based on the gaps in service for people with dementia revealed in this study and the lack of policy clarifying the SLT’s role, there is a clear need to develop consensus on the management of mealtime difficulties and dysphagia across dementia types and stages both within the profession and at a policy level. This limited awareness and understanding of the SLT’s role also led to issues with referrals, as outlined in the next section.

6.3 Challenges in Case-finding and Referral of Dementia-related Mealtime Difficulties and Dysphagia

The next part of the questionnaire focused on how cases of mealtime difficulties and dysphagia are referred to SLTs and the tools they use to support this. This section will discuss the issues with inappropriate referrals highlighted by the respondents, the link between the referral tools used and over and under-referral, and the impact on waiting times for people with dementia accessing speech and language therapy services.

The respondents frequently highlighted issues with the quality and quantity of the referrals they received. The SLTs described referrals for cases outwith the SLT’s scope, referrals of people who were not fit for assessment, referrals for people with dementia who had recommendations already in place, and referrals that lacked relevant information. These issues indicate that referral agents are not aware of why and when referrals should be made and are over-referring cases to speech and language therapy services. However, this over-referral does not discount the possibility that appropriate referrals are missed. As such, it is important to consider how referrals are made and who is making them.

Results of this study (discussed in section 6.6), as well as Niezgoda et al. (2014), suggest that many care home staff are ill-equipped to recognise the signs of dysphagia. A recent Dutch study further backs this up, reporting that nurses suspected dysphagia in just three out of 63 cases of dysphagia on their wards (Spronk et al., 2020). This finding is concerning given that Park et al. (2015) concluded that nurses are in a prime position for screening and identifying cases due to their presence in care home settings. This view is reflected in the survey finding that nursing staff were primarily responsible for completing dysphagia and mealtime screens. Interestingly, the SLTs reported that they did not always train nurses to do so, despite frequently identifying knowledge issues with their referral agents. The lack of training is surprising, given that the RCSLT recommend that healthcare professionals who complete swallow screening should be trained in the process (RCSLT, 2014a). One explanation could be that the respondents to this survey identified challenges to providing training, a view also held by respondents to an Irish study (Walshe et al., 2017). However, it is not clear if those challenges fully explain the limited use of screening or if other factors are at play. For example, this study’s respondents reported that where training was delivered, learning was not being acted upon or disseminated by recipients across their services, leading to ongoing issues identifying cases and SLT referrals.

Furthermore, in addition to issues with the referral agents’ knowledge, the lack of suitable case-finding tools may compound them. Niezgoda and colleagues state that the evidence base does “*not clearly define the elements and processes needed for valid and reliable case-finding during mealtime[s]*” (Niezgoda et al., 2014, p. 296), and section 2.5 established that there are no suitable tools available for identifying dysphagia and mealtime difficulties. This nebulosity impacts clinical practice, and, consequently, it is unsurprising that the respondents primarily used self-developed forms to receive referrals and screen for issues. Furthermore, this issue is broader than dementia services, as findings from Australia and Ireland indicate that 50-80% of SLTs use personally developed dysphagia screens in their services (Rumbach et al., 2017; Walshe et al., 2017). The number of SLTs who use self-developed referral and screening tools is concerning as these tools are not standardised or comparable, and there is no documentation of their effectiveness or suitability for the unique needs of people with dementia.

As a result, in the absence of standardised referral and screening tools for people with dementia, there is an increased likelihood of inappropriate referrals, negatively impacting SLT time and resource. However, more worryingly, there is an increased risk of services missing people with dementia in need of treatment. Research is needed to identify what other factors are needed to support referral agents to identify cases and refer them to the appropriate professional. Inefficient referral processes that lead to over-referral of inappropriate cases create backlogs, waste SLTs’ time, and delay or prohibit people with dementia and their carers from accessing necessary supports.

Further to referral issues, a disquieting finding were the routine waiting times for people with dementia. In community settings, it was standard to wait at least ten days before being seen by an SLT. The over-referral of inappropriate cases and the time-consuming process of vetting these cases may be causing these long, unacceptable waiting times. 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 swallow deterioration. Waiting lists of ten 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 (for example, prior knowledge of the individual) or whether 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.

Unfortunately, referral pathway issues relate to more than the tools used, and the issues described reflect referral processes that are not fit for purpose. There is an urgent need for research that holistically examines SLT referral processes for people with dementia and identifies how these can become joined-up, coherent pathways. Homogenising the information provided by referrers and standardising how information is requested would be a step towards improving their referral quality and quantity. The use of standardised referral forms or screening tools means that SLTs can guide referral agents to include relevant and necessary information. The referral agents can then identify if they are referring to the correct service and ensure that they have sought all necessary information before creating a referral. Furthermore, there is a training need as referral agents should know the signs and symptoms of dysphagia and mealtime difficulties and their responsibilities to manage these issues. Future research should seek to clarify and develop referral processes to ensure prompt identification of cases and referral for evaluation, as well as seeking to quantify the impact of over and under-referral on speech and language therapy services.

6.4 Variation in Assessment and the Appropriateness of Objective Assessments for People with Dementia

In this section of the questionnaire, the SLTs described the items they included in their assessments and the factors that influenced their decision-making processes. Interestingly, no item was universally included by all SLTs surveyed, reflecting previous studies into SLTs' practices that found significant variability in dysphagia assessment (Bateman et al., 2007; Martino et al., 2004; Mathers-Schmidt & Kurlinski, 2003; McCullough et al., 1999; Pettigrew & O'Toole, 2007; Rumbach et al., 2017; Vogels et al., 2015). However, as previously discussed, these surveys did not look at the assessment and management of one particular condition, and it is reasonable to expect that practices vary in different conditions and stages of a disease, as well as age groups. As the available literature does not provide a breakdown of this, it is difficult to extricate whether the hypothesis holds that practice naturally varies across different conditions or if this study truly reflects the items that SLTs value when assessing people with dementia.

Further to this, this is the first study to look at SLTs' practices when managing mealtime difficulties. It is interesting to note that most respondents do consider factors such as the mealtime environment, anticipation and awareness of meals, and feeding behaviours influenced by cognitive and behavioural changes in their evaluations. However, there are no established protocols or rating scales to determine the impact of difficulties on other mealtime activities and food or fluid intake. There are also limited evidence-based management strategies that target specific skill issues. This survey provides a vital new insight into the work that SLTs are doing in managing mealtime issues. Future research is needed to determine which factors have the most impact on mealtime success and how they can be ameliorated. Furthermore, there was no consensus among the SLTs around what items to include in assessing mealtime issues. For example, 89% evaluated cognitive-behavioural feeding issues, but just 46% considered the placemats and crockery that individuals were using. It was also surprising to note that SLTs did not unanimously collect information on medication use, considering their impact on the swallow (Groher, 2015; Miarons et al., 2018). As these items have the potential to impact the success of a meal (Whear et al., 2014), it is necessary to consider what other healthcare professionals consider their roles in the management of mealtime difficulties or if these are issues that are falling between the gaps of what services can offer. These important considerations guided the development of the second phase of the study. Further research is necessary to determine if the items the SLTs value in assessment differ across stages and types of dementia and what factors influence their decision-making across different time points of the disease and in different settings. The following subsection discusses SLTs' decision-making when conducting assessments.

6.4.1 The Factors influencing SLTs' Assessment Decisions

In this study, the SLTs' clinical experience had the most significant influence on their decision-making of what to include in assessments, followed by the client's presentation, and then the available evidence. Though this preference is in line with Vogels et al.'s (2015) findings that SLTs based their clinical decisions on a combination of their knowledge of the evidence base and their judgement of whether an assessment practice provided useful information in previous experiences, it is a thought-provoking ranking of these influencing factors. The definitions of evidence-based practice suggest that the clinician's clinical expertise, the client's values, and the evidence base should be factored equally into the decision-making process (Dollaghan, 2007). Interestingly, the clinician's experience had the greatest influence, while the evidence for assessment practices came third. The SLTs clinical experience is likely the most variable and subjective factor, dependent on exposure, training, workplace culture, and personal views and experiences. The SLTs' under-reliance on the evidence likely reflects its limitations, but the prioritisation of their own experience is worrying when it is the most difficult to standardise. Furthermore, in this ranking, the client's values were not a factor. Instead, the challenges and merits of their presentations had the second most substantial influence on how the SLTs completed assessments. This finding may reflect McCurtin and Clifford's (2015) conclusion that SLTs with more specialism are less influenced by client factors. However, given the limitations of the evidence and the variability of the SLTs' experience, it could be argued that client values should be the factor with the greatest influence on the assessment. Specifically, assessment items should evaluate the issues of most concern to the person with dementia to tailor intervention and management to what is important to the individual.

Moreover, the variability in the items that the SLTs reported including in their assessments reflects the respondent's comment that assessment items "*are tools that I have to hand which I can use if necessary"*. This comment appears to align with the studies discussed in section 2.6, which describe assessment as a non-linear process impacted by clinician experience (McAllister et al., 2016) and that strict adherence to assessment protocols impedes the SLT's decision-making process (McAllister et al., 2020). However, while these studies mark the beginning of research exploring SLT decision-making practices, they have implications for SLTs and AHPs working in healthcare. Further research is necessary to determine what factors SLTs and other healthcare workers consider in their management of people with dementia and the factors and challenges that influence the assessment of dementia-related mealtime difficulties and dysphagia.

6.4.2 Instrumental Assessment

The SLTs in this study typically had access to objective assessments, primarily VFSS and FEES, though their use was not without issues. The respondents had concerns about the impact of cognition on the assessment process and the trialling and recommendation of rehabilitation and compensatory strategies. Many respondents did not consider an objective assessment to be a valuable tool as they did not consider it a true reflection of the eating challenges faced by people with dementia. They felt that an objective assessment could not provide relevant information about behaviour in a meal setting, self-feeding abilities, and other mealtime challenges. This belief aligns with research from an Australian context that found SLTs preferred a clinical bedside exam to an objective assessment due to ease of access and the immediacy and applicability of results (Rumbach et al., 2017). Around a fifth of respondents indicated that accessibility impacted their decisions to use objective assessment, which contrasts with a study that found availability had no impact on the decision (Pettigrew & O'Toole, 2007).

To date, no research has examined SLTs decision-making around objective assessments in dementia and, as such, what benefits there are for their inclusion in an assessment process. The purpose of recommending a VFSS, for example, is *"to determine the effect of various behavioural and sensory interventions on the physiologic function of the swallowing mechanism*" (Martin-Harris & Jones, 2008, p. 775). However, as the focus of the literature has been on the use of objective assessments to describe the nature of dysphagia in dementia (Feinberg, Ekberg, Segall, & Tully, 1992; Humbert, McLaren, Malandraki, Johnson, & Robbins, 2011; Miarons et al., 2018; Suh et al., 2009), there is no available literature that can advise the compensatory or rehabilitation strategy most suitable for people with dementia which can be identified through an objective assessment. Typically, in practice, objective assessments are a tool to guide management decisions, though, as noted by Smith and Leslie (2012, p. 234), "*the type of information that is most useful in the development of a supportive care plan [in dementia] is rarely found through instrumental assessment*". However, studies have shown a higher prevalence of silent aspiration with thicker fluids than thin ones (Miles, Mcfarlane, Scott, & Hunting, 2018). Therefore, the exclusion of objective assessments as the only means of detecting silent aspiration from assessment protocols risks negative consequences for people with dementia who are advised thickened fluids.

Whilst previous studies have used instrumental assessments to investigate the structures and functions involved in swallowing in different conditions, this study provides new insights into clinicians' perceptions of their use. The clinicians viewed instrumental assessments as distressing, upsetting, and harmful to the well-being of people with dementia. This insight is based entirely on the SLTs' perceptions of the procedure and their experiences carrying them out. There is no evidence to show that objective assessment is harmful to people with dementia, but there is also no evidence to the contrary. SLTs have a duty of care to their clients to not engage in activities that could harm them, physically or emotionally. Given this concern about the impact of objective assessments on people with dementia, further research is needed. This research should determine the frequency with which people with dementia undergo objective assessments and evaluate differences in outcomes where objective assessments have or have not been used. This evidence would resolve when objective assessments are appropriate for people with dementia.

6.5 Decision-making and the Management of Mealtime Difficulties and Dysphagia

To generate a supportive care plan for people with dementia, clinicians consider their assessment findings and rationalise a management approach that will optimise swallow safety, quality of life, and health and well-being. This plan should also align with the person with dementia and their caregivers' concerns and values and reflect the evidence base (P. A. Smith & Leslie, 2012). In dementia care, this is not a straightforward process. In this section of the survey, the respondents provided insight into their management practices, the strategies they use and do not use, and their rationale for doing so.

As determined by Carnaby & Harenberg (2013, p. 567), there is no such thing as usual care in dysphagia rehabilitation, so it stands to reason that there is no "*usual care*" in the management of mealtime difficulties. As such, it is not a surprise that the respondents to this survey reported that their involvement and follow-up with people with dementia varied depending on whether dysphagia or mealtime difficulties were under consideration. For the most part, respondents indicated that they would follow-up in-person for dysphagia referrals after an initial assessment. However, for people referred with mealtime difficulties but no suspected dysphagia, some SLTs provided no means of follow-up. Moreover, in some cases, no face-to-face assessment for mealtime difficulties was offered, replaced instead by a phone consultation. These practices may stem from the resource issues identified by the SLTs, but they have significant implications for the care of people with dementia and the development of services. A more hands-off approach to managing mealtime difficulties may suggest to stakeholders that SLTs are not as invested in its management as they are in dysphagia and that the consequences of mealtime difficulties are not as significant, perpetuating issues in commissioning services. Alternatively, it could indicate that SLTs do not value the management of mealtime difficulties as a core aspect of their role. As a result, stakeholders may not refer suspected mealtime difficulties to SLTs, resulting in people with dementia becoming malnourished or unwell and reducing their quality of life. The responses to this questionnaire illustrate the necessity of clarifying the SLTs' roles in managing mealtime difficulties. This role clarification is imperative to establish their management as a core part of speech and language therapy services and support their commissioning. The RCSLT's (2014b, p. 2) statement that "*pathways of care for persons with dysphagia should integrate speech and language therapy and take account of the changing needs and focus of interventions as the condition alters or declines*" does not go far enough in advocating the SLTs' role. Furthermore, the limited guidance for SLTs on managing dementia-related dysphagia and mealtime difficulties complicates the situation.

As the available evidence base is relatively limited, it is not unexpected that, as with assessment decision-making, the SLTs prioritised clinical expertise, or "*knowing how*" (McCurtin and Clifford, 2015, p. 1183) in decision-making over the research evidence. However, this assurance in the strength of their clinical expertise could result in inconsistent or even inappropriate practice, particularly in the absence of clear protocols. The SLTs decision-making reflects findings that speech and language therapy treatment decisions primarily hinge on their view of patient suitability and the SLTs' knowledge (McCurtin & Healy, 2017). As such, they anchor their decision-making in practice-based evidence (McCurtin & Carter, 2015). For example, rehabilitation exercises were ruled out by respondents due to the cognitive demands of the tasks, while around half of the respondents did not recommend compensatory strategies for similar reasons. Additionally, none of the SLTs indicated that they used alternative, potentially promising approaches such as spaced retrieval training to support the implementation of rehabilitation or compensatory strategies (Benigas & Bourgeois, 2016; Wu, Lin, Wu, et al., 2014). It is unclear whether the respondents were aware of these approaches or whether service pressures, understaffing, and lack of resource impacted their ability to implement effective yet time-consuming interventions.

Furthermore, strategies targeting the mealtime environment, such as recommending background music at mealtimes, ensuring contrasting colours between crockery and food, or recommending lighting changes, were the least recommended interventions. Given that the SLTs frequently highlighted resource constraints throughout the questionnaire, the intensiveness of their interventions may have been limited in the interests of serving a wider number of referrals. Likewise, the respondents' limited resources hampered their management plans. A lack of readily available evidence-based resources hinders the SLTs ability to provide management, and their development should be a priority to standardise and drive practice development.

A disconnect between evidence and practice has implications for people with dementia. For the most part, the research base provides no consensus on management practices in dementia (Alagiakrishnan et al., 2013; Herke et al., 2018; Liu et al., 2014). However, as discussed in section 2.7.2, greater care needs to be taken when recommending modified diets and thickened fluids to people with dementia due to the risks of compromising health and well-being (Flynn et al., 2018; O'Keeffe, 2018; Painter et al., 2017; Vucea, Keller, Morrison, Duizer, et al., 2018; Vucea, Keller, Morrison, Duncan, et al., 2018). These modification practices were the most commonly recommended management strategies from this survey, reflecting similar findings from Australia (Rumbach et al., 2017).

A comparable disconnect between the evidence and practice has been demonstrated in other areas of SLT practice. For example, there is a debate in the literature about the appropriateness of recommending non-speech oromotor exercises when managing dysarthria (a motor speech disorder). Despite the evidence indicating that they provide no additional benefit (Mackenzie, Muir, Allen, & Jensen, 2014), they continue to form part of SLTs' therapy repertoires (Conway & Walshe, 2015; Gracia, Rumbach, & Finch, 2020; N. Miller & Bloch, 2017). Garcia et al. (2020) link the continuing use of this questionable practice to a lack of clinician engagement with the literature, as well as an assimilation to the culture of service settings. These factors may also have influenced the SLTs in the current study. However, though some SLTs highlighted concerns about recommending thickened fluids, their almost unanimous use, alongside modifying diets, may indicate that SLTs felt it is the only strategy they could effectively use with people with dementia. Further exploration of modified food and fluids' longer-term effects is necessary if SLTs wish to continue using them with this population. Future research should also consider how SLTs access and act upon research evidence.

One area where there appears to be a relative consensus between the literature and clinician perspectives is the use of enteral feeding with people with dementia. The literature does not endorse the use of enteral feeding in moderate to advanced dementia as it does not reduce mortality risk (Ticinesi et al., 2016). The SLTs in this study initially appeared split on a binary question asking whether or not they would recommend enteral feeding for people with dementia. However, an analysis of their comments showed that both those who do and do not recommend it consider it a case-by-case decision. Two SLTs cited the Royal College of Physicians advice to use "*wise reluctance*". The full quote advises that: "*the wise reluctance to use artificial nutrition and hydration in dementia cannot be translated into a blanket ban*" (Royal College of Physicians, 2010, p.31), thereby indicating that enteral feeding may still have a role to play in management. Unfortunately, as the current study did not request further details, these results do not provide an insight into the situations where SLTs view the recommendation of enteral feeding to people with dementia to be appropriate.

Like many areas of SLT practice, there is a lack of clear evidence to support evidence-based decision-making in the management of dementia-related mealtime and swallowing difficulties. The above considerations recognise an urgent need to widen the evidence base for effective interventions, establish more insight into how and why SLTs make their choices when managing dementia-related dysphagia and mealtime difficulties, and disseminate this information among the profession. Dobinson and Wren (2019) propose extending the evidence base by developing SLTs' practice-based evidence into research evidence. This need for practice development highlights the necessity of additional investigation of the SLT and MDT roles in dysphagia and mealtime support for people with dementia to effectively steer future policy development of guiding the management of dementia-related dysphagia and mealtime difficulties.

6.6 The Provision of Training to Family Carers and Care and Medical Staff

Training is an established part of the SLT’s role in supporting people with dementia (IASLT, 2016b; RCSLT, 2014c). In line with this, the respondents in this study unanimously agreed that all paid, unpaid, and family carers of people with dementia should have training around dementia-related dysphagia and mealtime difficulties. However, the available literature and the variability in practice uncovered by this survey do not clearly demonstrate training’s potential benefits. The surveyed SLTs evidently viewed training as essential to supporting the SLT role and as a means of ensuring appropriate referrals and management implementation. They viewed themselves as playing a part in delivering it; however, only a fifth of respondents indicated that they provide this training, with many reporting that training occurred “*as needed*” or on an “*ad hoc*” basis. Several systemic issues prevented the SLTs from providing this training and education. One issue identified by the SLTs was a lack of resource. The SLTs described high caseloads impacting their ability to organise and provide training, and some reported that their management did not commission their services to provide it. This may indicate that higher management in health services cannot afford to support their SLT staff to provide training or that they do not see or value the impacts of training.

Although not yet directly demonstrated in a research study, the wider literature and current survey responses suggest that successful training programmes could result in changes to referral patterns, improvements in well-being and quality of life, or reductions in adverse events such as hospitalisations, the development of aspiration pneumonia or malnutrition. Demonstrating such benefits could encourage commissioners to provide an SLT staffing resource for training and follow-up. As discussed in section 2.7.1, many dementia-specific training programmes do not provide information on the longer-term outcomes of their training but focus on short-term outcomes such as pre- and post-training knowledge and increases in food intake (Batchelor-Murphy et al., 2015; C. C. Chang, Wykle, & Madigan, 2006). Similarly, many of the respondents in this study indicated that they did not follow-up on training, though some assessed knowledge. This inconsistency in follow-up combined with the respondents' variation in training styles and approaches supports findings that there is no clear guidance on what an effective training programme should look like and what it should include (Burger, Hay, Comabella, Poots, & Perris, 2018). Without longer-term follow-up of training, it is impossible to see how effective or ineffective training is.

Similarly, without clear evidence and guidance on what knowledge and skills change practice, clinicians cannot adapt their programmes to meet these aims. Furthermore, no research to date has looked at how SLTs are managing training in practice. For example, as noted in section 2.7.1, just two studies examined how SLTs provide training in the management of mealtime difficulties and dysphagia to nursing and care home staff (Davis & Copeland, 2005; O'Loughlin & Shanley, 1998). Moreover, no study has examined how they provide dysphagia or mealtime difficulties training to in-home carers and family members of people with dementia. The omission of the SLT perspective in the training research base is striking and highlights a gap in the evidence. SLTs are clearly providing this training, and research is needed to uncover its goals, anticipated outcomes, and effective delivery methods. Future research needs to consider if there are differences in SLT or other healthcare professional developed training, and this research needs to consider mid- to long-term follow-up.

However, even if there were greater guidance on evidence-based training and SLTs were adequately resourced to provide it, training could only be effective if it is accessible to those who need it and if the systems surrounding people with dementia can initiate change. In particular, many of the SLTs referred to paid care staff in their responses. They highlighted that when paid carers did not understand the rationale for SLT recommendations, they did not follow them. They also remarked on breakdowns in how their recommendations are shared between care staff and frequently linked these referral issues to a lack of knowledge. Some of these concerns were associated with systemic problems such as high care home staff turnover, care staff management not valuing SLTs' input, and nursing and care home staff's limited understanding of the SLT's role and recommendations due to a lack of training. Such systemic barriers to change directly impact the care of people with dementia and negatively affect the SLTs' workload, which further compounds the resource limitations they are already facing. Issues with changing care staff practices are not just a speech and language therapy issue; they are pervasive in the healthcare sector. There is a documented need to combine training with structural and organisational change (Moyle, Borbasi, Wallis, Olorenshaw, & Gracia, 2011). Training cannot change practice if the structures in the workplace are not developed to support care staff to implement their new knowledge, and mechanisms should be in place to support the sustainment of practice change

(Caspar, Cooke, Phinney, & Ratner, 2016; Nolan et al., 2008). Thus, these issues demonstrate a need for further research into paid carer and medical staff training, structural factors that impede change in practice, training outcome measurement, and consolidation of training recommendations and policies for the care sector.

6.7 The Implications of Dementia Type and Stage on Speech and Language Therapists' Approach to Management

Accessing a diagnosis of dementia can be a challenging and lengthy process for people with dementia and their caregivers (Innes, Szymczynska, & Stark, 2014). Furthermore, delays in diagnosis and under-documentation of the condition are internationally recognised issues (Bradford, Kunik, Schulz, Williams, & Singh, 2009; Cappetta, Lago, Potter, & Phillipson, 2020; Crowther, Bennett, & Holmes, 2017). As such, it was interesting to note the differences the SLTs experienced in accessing information and details of the dementia diagnoses of the people they were seeing. Around 30% of this study's respondents had no or inconsistent access to information on the type and stage of dementia which reflects the findings of a notes review of a UK hospital which reported that 26% of people with a confirmed diagnosis did not have it entered into their documentation (Crowther et al., 2017). The Crowther study also found that while dementia subtype was reported in 35% of cases, it only matched the psychiatric notes in 25%, and, while it was recorded less frequently (14% of cases), dementia severity was more accurately recorded. This study's findings are similar, as the respondents had mixed access to information on the type and stage of dementia.

This study is the first to reveal how SLTs self-rated knowledge of mealtime difficulties and dysphagia in different dementia types and stages influenced their management approach. The results showed relationships between the degree of self-rated knowledge of both impairments and the importance of tailoring their management to dementia type. There was also an association between knowledge and dementia stage, but not with dementia type. This finding was interesting, as, broadly speaking, more SLTs considered it important to tailor their management to the dementia stage than to the dementia type. This is despite the evidence for the impact of dementia type on the swallow presentation of people with dementia discussed in section 2.4. Further to this, the SLTs rated themselves more knowledgeable about dysphagia in dementia stages than types. This is interesting because, as shown in section 2.4, a lot of the available dysphagia literature is inconsistent in its reporting of dementia stages; therefore, this finding likely represents the application of the SLTs' clinical knowledge. The SLTs' limited, inconsistent, and potentially inaccurate access to information on dementia type may explain why they did not value this information as much as information on dementia stage when tailoring management plans.

A further explanation for why SLTs do not value diagnostic information could be the lack of dementia-specific training available to them. While the SLTs did not provide details of their pre-registration training, it was interesting to note that no SLT reported receiving additional instruction in managing dementia-related dysphagia and mealtime difficulties. Furthermore, the SLTs also rated their dysphagia knowledge higher than that of their mealtime difficulties knowledge overall. They also rated themselves less knowledgeable of dysphagia in different types of dementia than its stages, and this related to their view that tailoring management to dementia type is of less relevance. The tests of association also demonstrated relationships across the SLTs' knowledge; for example, SLTs who considered themselves knowledgeable of dysphagia presentation in dementia types also considered themselves knowledgeable of dysphagia in dementia stages. The limited evidence base and the apparent absence of training may limit the SLTs' awareness and understanding of the implications of dementia type on the presentation of dysphagia and mealtime difficulties.

Interestingly, self-rated knowledge was not related to years of experience as an SLT, with the exception of knowledge of dysphagia in different types of dementia. This finding may indicate that the SLTs become more aware of the impact of dementia type on dysphagia as their exposure to working with people with dementia increases. Additionally, SLTs working in Ireland were more likely to rate their knowledge of mealtime difficulties in dementia types higher than their UK-based colleagues. This difference may indicate a disparity in either formal pre- or post-registration education or on-the-job learning opportunities.

Whilst SLTs should tailor their intervention to the unique needs of each individual, the research evidence highlights the need to consider type and stage in management decisions (Alagiakrishnan et al., 2013; Flynn et al., 2018). The respondents' lower self-rating of their knowledge of mealtime difficulties may indicate a gap in training and education. As most SLTs considered mealtime difficulties to be within their scope of practice, it seems unlikely that limited exposure to such a caseload explains this difference in knowledge. As such, further pre- and post-registration training in dementia-related dysphagia and mealtime difficulties are necessary to empower SLTs with the knowledge to manage these disorders.

6.8 Challenges to Care Partnerships and the Implementation of Recommendations

This section discusses communication and liaison challenges between the SLTs, people with dementia, and other stakeholders involved in their care, such as their family members and the medical team. Additionally, almost half of the respondents identified specific issues with adherence to their food and fluid modification recommendations. Adherence to speech and language therapy dysphagia recommendations has mainly been studied in relation to prophylactic treatments for people with head and neck cancers, and it is a rarely reported consideration in intervention studies (Krekeler, Broadfoot, Johnson, Connor, & Rogus-Pulia, 2017). For people with dementia, their cognitive ability to comprehend the recommendations, and their rationale complicates their adherence to recommendations. This is further complicated by their family and paid carers' inability to understand and implement the recommendations. Other issues include the SLTs' ability to liaise with other key stakeholders such as GPs and stakeholders' personal perceptions of some SLT recommendations. The following section will examine each of these considerations in turn, beginning with the person with dementia.

6.8.1 Communicating and Decision-making with People with Dementia

RCSLT's mission statement is "*enabling better lives for people with communication and swallowing needs*" (RCSLT, 2019). This statement implies that all

SLT actions should be for the greater good of the people they work with, but what is encouraged from definitions of evidence-based practice is that clinicians should also understand the values and goals of an informed individual (Dollaghan, 2007). As such, SLTs need to communicate their assessment findings and diagnoses, co-develop intervention goals with relevant persons, and communicate the recommended management approach to the appropriate sources. Therefore, to fulfil this mission and align with evidence-based practice, the SLTs should communicate and liaise closely with the person with dementia to ensure the management of their dysphagia and mealtime difficulties aligns with their values and wishes. Nevertheless, this is not without its challenges, as the majority of respondents described encountering complex predicaments when attempting to have their recommendations implemented and integrated into the lives of people with dementia.

Rogus-Pulia and Hind (2015) use the metaphor of driving for discussions around treatment decision-making. They describe the patient as being in the driving seat of decisions and the SLT as the knowledgeable navigator who lays out the roadmap for care and describes the terrain challenges associated with different decisions. As such, a patient may decide not to follow their SLT’s recommendations, but they are aware of and understand the potential implications of their decision. However, this model does not consider how people with cognitive challenges are involved in decision-making around their care. Furthermore, one study has found that regardless of cognition, individuals resident in long-term care are chiefly unable to self-report swallowing issues (Namasivayam-MacDonald, Steele, & Keller, 2019). From their sample, 80% (*n* = 142) of residents who failed a swallowing screening did not report any issues with swallowing. Additionally, a study of adherence to dysphagia recommendations described one reason for non-adherence (termed compliance in the study) as the participants' perception that there was no swallowing issue (Colodny, 2005). While there are methodological and bias issues in the study as the same SLT made the recommendations, determined the participant was not adhering, conducted the interviews, and completed the analysis, it is one of only a few studies that look at reasons for non-adherence to recommendations. This finding has implications for SLTs as individuals may not share the same views of their swallowing challenges. It is particularly relevant as the primary challenges the SLTs identified when communicating feedback to the person with dementia were related to cognitive and communication issues.

Cognitive communication challenges are an inherent part of living with dementia, and they impact all aspects of daily living (Dooley & Walshe, 2019). As a result, these communication issues are also likely to inhibit the person with dementia's ability to engage with the speech and language therapy process. The respondents' concerns about people with dementia's ability to understand and recall their recommendations have implications for service delivery to people with dementia. It implies that service delivery needs a different approach than in other conditions where clients are likely to be more active partners in the process. This raises questions about how SLTs and other healthcare professionals adapt their involvement with people with dementia across the course of the disease and whether plans are put in place in the early stages. This consideration influenced the planning of the second phase of the research study.

The SLTs described the need to tailor recommendations and compromise with individuals' and carers' preferences to ensure management decisions are acceptable and implementable by them. Given the limited research that has looked at adherence to dysphagia recommendations, there are apparent gaps. Furthermore, for people with moderate or advanced dementia, the role of "*drive*r" may not be appropriate and a carer or loved one may act as a decision-maker. Further research is needed to explore this decision-making dyad or triad and determine what factors influence decision-making from all sides. If the SLT is involved early in the process, it is likely to be a dyad of the SLT and the person with dementia making decisions and future care plans. However, suppose the person with dementia accesses speech and language therapy services later in the disease process when they do not have the capacity to advocate for themselves. In that case, the decision-making process is likely to involve the family carers to a greater extent, where the carer will advocate for their perception of the person with dementia's wishes (Sellars et al., 2019). However, from the survey responses, it is clear that the SLTs also faced challenges in how family members adhered to recommendations which will be discussed in the next section.

6.8.2 Family Carers and Decision-making

One of the issues the SLTs reported is the availability of family members for discussion, though this is a challenge that is likely to vary across settings. It is also likely to impact how people with dementia who remain at home implement recommendations. The SLTs felt that carers did not understand the scope of recommendations and the negative consequences of non-adherence. Interestingly, a qualitative study of carer adherence to recommendations when supporting people with intellectual disabilities found that knowledge and understanding of recommendations did not translate to adherence (Chadwick, Jolliffe, & Goldbart, 2002). They felt that providing context-specific and contingency information was more relevant to carers and would facilitate adherence. However, a further report on the study identified that additional training and monitoring of carers' roles and responsibilities was necessary to facilitate adherence to strategies and safer mealtimes (Chadwick, Jolliffe, Goldbart, & Burton, 2006). This finding aligns with the views of the SLTs in the study that additional training and education was the best strategy to increase adherence to recommendations.

Furthermore, as people with dementia may experience dysphagia and mealtime difficulties, it is important to note that Chadwick et al. (2006) found that carers had more difficulty implementing environmental changes and the use of prompts and priming. Though their study focused on carers of people with intellectual disabilities, the management strategies are similar in dementia. As such, further research needs to explore adherence challenges from the perspectives of people with dementia and their carers. Little is known about how SLTs facilitate this practice. Therefore, research is needed to discern SLTs and AHPs approach to working with family carers and people with dementia to plan and implement their recommendations. Research by Chadwick and colleagues (2002, 2006) that included samples of family carers and paid caregivers found that challenges to adherence exist in both groups, which aligns with the reports of the SLTs. The following section will address paid carers.

6.8.3 Challenges to Liaison with Paid Carers

The SLTs surveyed described their concerns around how care home staff interpreted and disseminated their recommendations. The procedures for sharing information in care homes are understudied (Orellana et al., 2019), but a scoping review provides some insights and identifies several issues with handovers. This review uncovered issues such as consistency in handover implementation, variability in who should attend, and issues around paying staff for their time in attending handovers (Moriarty, Lipman, Norrie, Elaswarapu, & Manthorpe, 2019). There are also issues around staff knowledge and how this impacts mealtimes (Beattie, O'Reilly, Strange, Franklin, & Isenring, 2014; Bernoth, Dietsch, & Davies, 2014). Information dissemination and staff turnover were concerns for the SLTs in the current study, and unstable staffing is one of the most significant issues facing care homes in the UK (Cousins, Burrows, Cousins, Dunlop, & Mitchell, 2016). As discussed in section 6.6, respondents identified staff turnover as a factor impacting training take-up and its ability to change care homes' practices. Other studies have shown that care home staff are not always aware of existing recommendations and that this mealtime support does not reflect person-centred care (Bennett, Ward, & Scarinci, 2015). These overlapping issues have significant implications for how people with dementia receive mealtime support in care homes and how SLTs can implement changes.

Furthermore, a paper aptly titled "*Everyone's problem but nobody's job*" that explored the issues around the management and implementation of nutritional recommendations found that these challenges related to a lack of shared responsibility or ownership for managing nutritional care and limited knowledge (Ross, Mudge, Young, & Banks, 2011). Though this study looked at nutritional care and not mealtime or dysphagia management, the same challenges are likely to apply. The SLTs described reinforcing care home and nursing staff's ethical and legal responsibilities to prompt stricter adherence to SLTs' recommendations. The need for this reinforcement may indicate that care staff do not automatically view the implementation of these recommendations as within the remit of their responsibilities.

Responsibility and ownership issues have also been linked to SLTs' presence and availability (Smith-Tamaray, Wilson, & McAllister, 2011). This study interviewed a small number of SLTs about their views on dysphagia services post-stroke in a non-metropolitan area of Australia. The responsibility and ownership of recommendations centred around the impact of SLTs' limited time to provide input due to the nature and extent of their services. The SLTs felt that these limited opportunities to engage with care teams meant that their services were undervalued, misunderstood, and occasionally under-mined (Smith-Tamaray et al., 2011). They viewed education and training as a means of demonstrating the value of SLT input and engaging nursing and care colleagues with their decisions, but they reported similar challenges in completing training as the SLTs in the current study described. Though respondents did not indicate it, the SLTs in this study may also face the same issues of presence on the ward given the vast number of settings they work across, as discussed in section 6.1. Further research is needed to explore SLTs' views on their practices and how they collaborate on the management of mealtime and swallowing issues within teams.

As well as communication issues with care home staff, the respondents described challenges to their communications and interactions with GPs, discussed in the next section.

6.8.4 GP communication

The challenges experienced centred around accessing GPs and issues with engaging GPs in managing mealtime difficulties and dysphagia. For example, one SLT described communication with their GP colleagues as "*all one way*". This comment and the respondents' issues may reflect findings that GPs consider some aspects of dementia care, primarily behavioural challenges, to be difficult to manage and outwith their knowledge (Jennings et al., 2018). This is also interesting when we consider that very few SLTs provided training to GPs on mealtime difficulties or dysphagia, and it is unknown to what extent their medical training covers them. A lack of knowledge of dysphagia and mealtime difficulties amongst GPs may make them less likely to engage with their management. The SLTs' comments also reflect the documented issues experienced by people with dementia and their carers of having their needs met in primary care services. A systematic review revealed that people with dementia and their carers believe that GPs do not have sufficient knowledge of dementia and its presentations to support them to manage its symptoms (Prorok, Horgan, & Seitz, 2013).

There are also recognised issues amongst UK-based GPs in record-keeping for people with dementia, particularly around documenting management approaches (Wilcock et al., 2009). The SLTs in this study identified concerns about whether GPs read their reports, which poses challenges to coordinated dysphagia and mealtime difficulties care provision. If all parties involved in managing these issues are not on the same page, it could lead to discrepancies in care and missed opportunities. Consistency of care is essential for ensuring the benefits of an SLT's interventions. Future research of GPs' interpretations of their role in managing mealtime difficulties and dysphagia may indicate whether there is a training need. Alternatively, in the absence of case management guidelines, the SLT may perhaps need to adapt their services to support the access of people with dementia.

A further issue with implementing and adhering to recommendations discussed in the next section is their acceptability to people with dementia and their paid and family carers.

6.8.5 Dislike of recommendations

The respondents identified that the main adherence issue they faced was the implementation and acceptance of food and fluid modification. Studies have also identified a dislike of food and fluid modifications as a reason for non-adherence (King & Ligman, 2011; Krekeler et al., 2017). The limited evidence for food and fluid modifications has been discussed, and the reported "*unpleasant experience*" of drinking thickened drinks is a concern (McCurtin et al., 2018, p. 35). In their study, McCurtin and colleagues (2018, p. 34) reported that people post-stroke recognised a "*trade-off*" between the unpleasantness of the thickened fluids and the potential they offered to maintain their health and well-being and, as such, they accepted the need to use thickening agents. People with dementia, on the other hand, may not have the cognitive capacity to understand the implications of non-adherence to speech and language therapy recommendations and thereby make an informed decision on their care choices. This has implications for how SLTs support decision-making and research must consider whether the value of these recommendations outweighs their impact on quality of life and well-being.

6.8.6 Summary

Overall, the SLTs faced significant issues liaising with the key stakeholders supporting people with dementia. These issues can be linked to access and knowledge, and further exploration is needed.

6.9 Working in a Multidisciplinary Team

Earlier in the questionnaire, around a fifth of respondents indicated their view that they should only manage mealtime difficulties within an MDT. The MDT members with the scope and ability to make recommendations for managing mealtimes are AHPs. The respondents reported working closely with dietetics to ensure that their recommendations would not interfere with the person with dementia's nutrition and hydrate intake and with nursing staff who assisted with implementing and monitoring the SLTs' recommendations. They also worked closely with the OT and described their role in managing equipment and other aspects of the meal, and on occasion, with the physiotherapist. While they saw working within a team as extremely important, the interaction and working relationships between SLTs and other team members remains unclear.

The research to date has not explored how other team members, particularly AHPs, support the management of mealtime difficulties and dementia. How these roles overlap and intertwine in clinical practice is also not clear. Clarifying these aspects is essential to establishing the SLT’s role and changing practice. As described in section 2.7, most mealtime interventions focus on increasing food and fluid intake, and the majority of training focuses on supporting other healthcare staff to increase food and fluid intake. Few of these interventions and training programmes have been developed with SLTs or other AHPs. As such, from the literature base, the SLT’s role in the MDT managing mealtime difficulties, first among their AHP colleagues, and secondly in the wider MDT including nursing, care staff, and medical teams, has not been established. Without exploring AHP roles in managing mealtime difficulties in dementia, the speech and language therapy profession cannot advocate and develop theirs.

6.10 Summary

The results of this survey of SLTs working with people with dementia-related mealtime difficulties and dysphagia revealed several factors that influenced speech and language therapy practice. Some themes developed across the sections, and the SLTs reiterated these in the final section of the questionnaire. The SLTs outlined their views on practice facilitators and what hampered their management. They highlighted that:

- the knowledge of others and referral systems both impacted positively and negatively on the SLTs’ practice.
- resource issues impacted their ability to complete their interventions in a timely manner and carry out carer training.
- access to a multidisciplinary team is essential to carrying out their role in managing mealtime difficulties and dysphagia, and,

- the inflexibility of work environments made implementing their recommendations challenging.

The findings of this survey study determine that, in tandem with an insubstantial evidence base to guide effective assessment and management, there is a need to clarify and establish guidance around the SLT's role in managing dysphagia and mealtime difficulties in dementia. Research that fully explores the impact of different aspects of mealtime difficulties on well-being in order to guide the development of interventions is needed. Furthermore, research needs to consider the timing of intervention. As variation and delays in service delivery can negatively impact people with dementia's health and well-being, there is a need to establish guidelines that clarify the SLT's role across dementia stages. Research also needs to consider what impact SLTs' understaffing and limited availability have on waitlists and the health of people with dementia. Policy development should establish guidelines on optimal waiting times.

The SLTs viewed themselves as under-resourced in their attempts to provide necessary assessments, interventions, and training. The responses highlighted the particular impact that gaps in carer's knowledge and training had on management as a direct consequence of limited access to training. However, the absence of consensus on training and follow-up makes it impossible to ascertain the necessary components of such training. More collaboration with the care sector is needed to develop materials and ensure adequate training in dysphagia and mealtime difficulties for all carers. These measures will support the effective management of people with dementia from all perspectives and enhance their quality of life.

Furthermore, the variations in service delivery across the UK and Ireland indicate that there is insufficient guidance to govern the extent and nature of the SLTs' roles, particularly in the management of mealtime difficulties. The development of this guidance should be a priority given the consequences of inappropriate or no management for people with dementia. Guidelines also need to consider the diverse needs of the various settings where SLTs see people with dementia and the factors that will impact the SLT's role in different settings. There is also a clear need for increased CPD for SLTs supporting people with dementia-related mealtime and swallowing difficulties, particularly in understanding how these issues present across different dementia types and stages. Understanding SLTs' clinical decision-making is a developing area of research. The next stage of development for speech and language therapy should look at the factors that influence their assessment and management decisions in more detail. Variation in values can lead to variation in care, and research to understand these processes will support equitable care provision.

6.11 Rationale for Phase 2

While the SLT is the primary professional who diagnoses and manages dysphagia, the pervasive and extensive nature of mealtime difficulties means that the SLT is unlikely to be the only professional with a vested interest in their management. These issues have particular relevance when the progressive nature of dementia is considered as well as the impact it has on the implementation of and adherence to recommendations. Person-centred care and the importance of personhood (Kitwood, 1997) for people with dementia means that SLT support must recognise the individual’s unique circumstances and wishes. However, the pervasive nature of cognitive impairment means that people with dementia cannot make decisions about their care as the disease progresses, and their carers are primarily responsible for decision-making and implementation. Further to this, as discussed briefly in chapter two and section 6.9, the SLT may share some capacity with other AHP colleagues in the management of mealtime difficulties. As stated in section 6.9, without further clarification of AHP roles, the SLTs cannot clarify their own role and plan and develop services that address the issues that this survey research has uncovered to ensure that services for people with dementia align with their values and maximise their well-being.

The roles of these AHPs, the OT, physiotherapist, and the dietitian, may overlap, though the nature and extent of these roles is uncertain. It is also unclear if other AHPs consider themselves to have ownership of the management of mealtime difficulties in dementia. The reason for this uncertainty is because this is an under-researched area. There may also be scope for greater collaboration among AHPs and for more investigation into how the MDT functions when managing mealtime difficulties.

Accordingly, further research is needed to establish the scope and boundaries of AHPs’ management of mealtime difficulties and to determine how these AHPs work. Therefore, the second phase of this adapted explanatory sequential design will seek to determine how AHPs view their roles in managing mealtime difficulties and what challenges they face.

6.11.1 Aims of Phase 2

- To establish AHPs' perspectives on their roles in managing mealtimes of people with dementia
- To understand the issues AHPs face in supporting people with dementia and mealtime difficulties.

This chapter has compared and contrasted the survey's findings with the literature and sought to explore the implications of these findings on SLTs' practice. The Conclusion chapter considers recommendations for future research in more depth. The final section of this chapter has outlined the rationale for the second phase of the study, and the following chapters will describe the methods and results of the second phase of the study.

7 PHASE 2 – THE INTERVIEW STUDY: METHOD

Following the analysis of the questionnaire data results, it was clear that a greater understanding of the complementary but potentially overlapping roles of AHPs involved in managing dementia-related mealtime difficulties was needed. In line with an explanatory sequential mixed methods design, a qualitative approach was essential to expand on and explain the first phase's findings. This chapter presents the rationale behind the selected design. It begins with an overview of qualitative data collection methods that justify selecting a qualitative interview study and then describes the development of the interview schedule and its administration. The following section describes the selected analysis approach before detailing the sampling and recruitment of the study participants. The chapter closes with an overview of specific ethical issues for this study.

7.1 Qualitative Data Collection Methods

Section 3.2.2 outlined the qualitative research methodology underlying the research, Qualitative Description. The chosen approach supports the research's aims of understanding how AHPs manage dementia-related mealtime difficulties and what their perspectives of this management were and what challenges they faced. For phase 2, it was essential to select a data collection method that could generate data to meet these aims and complement the information provided by the survey in phase 1.

The most commonly used data collection methods in qualitative research are focus groups, interviews, and observation (Moser & Korstjens, 2018). In observation studies, the researcher observes and records the actions of their participants to generate information about their behaviour in various situations as an alternative to self-completed survey reports of their behaviour (Bryman, 2016). These observations aim to provide an unbiased perspective of the participants' reality; however, this is not without issues. One such issue is the observer's paradox, the notion that participants will act differently as a result of being observed, thereby influencing the research findings (Hazel, 2016). On the other hand, some have argued that the observer effect can be beneficial to research. For example, Monahan and Fisher (2010) maintained that participants' behaviour for the benefit of the recorder added valuable depth to the research and that the recording of questionable behaviour by participants in research studies acts as evidence for the negligible effects of the observer. Nevertheless, the nature of observational studies would not produce the data necessary to answer this study's research aims, as this research is seeking to understand AHPs views on issues faced as well as their perspectives on management. Therefore, another approach was needed.

The other commonly used methods are focus groups and interviews. Focus groups generate qualitative data by facilitating group discussions on a series of topics by participants who share similar characteristics (Silverman, 2017). In this case, these would be AHPs with a specialist interest in dementia who offer mealtime support. One of the benefits of focus groups is the opportunity to gain additional depth of understanding from the group's interactions (Mertens, 2005), as well as insight into the *“sub-culture”* of the group and the range of its priorities and concerns (Gillham, 2005, p. 67). However, there are limitations to the approach, one being the emergence of *“groupthink”*, where participants do not dissent from a particular idea or worldview that does not consider all facets of the issue (Bloomberg & Volpe, 2012, p. 123). The data collected can also be incomplete and patchy, requiring a different follow-up method to elicit the desired level of detail (Gillham, 2005). Due to concerns about the method's capacity to generate in-depth data on AHPs’ views needed to answer the research question, focus groups were not an appropriate method of data collection. The issue of groupthink was also a concern, and it was clear that a method that allowed for the individual collection of data would be more suitable, such as the third commonly used method, the interview.

As described in chapter 4, the standardised interview is a form of survey research used to collect data using standardised question asking and recording (Bryman, 2016). This form of interview generates quantitative data in a narrow field, not suitable for a qualitative study. To illustrate the difference, Braun and Clarke (2013, p. 77) define qualitative interviewing as *“a ‘professional conversation’, with the goal of encouraging participants to talk about their experiences and perspectives, and to capture their language and concepts, concerning a topic that you have determined*”. Qualitative researchers frequently use unstructured or semi-structured interviews to achieve this (Silverman, 2017).

In its freest sense, Gillham (2005) describes the unstructured interview as led by the interviewee rather than the researcher and as useful for the initial stages of developing a research agenda. It typically begins with an open topic prompt from the researcher with occasional prompts to encourage more sharing. However, it can be challenging to generate rich data from an unstructured interview in the absence of an interview schedule, topic guide, or list of suggested questions to steer the interview (Gillham, 2005). In semi-structured interviews, the researcher has a list of topics and questions, but there is scope for the interviewee to speak beyond this list (Braun & Clarke, 2013). As a result, some qualitative researchers advocate for considering the structure of interviews as a continuum rather than an absolute (Braun & Clarke, 2013; J. Mason, 2002), as all interviews must have some form of inherent structure to allow for flexibility within the interview process. By that logic, unstructured and semi-structured interviews are not opposing methods, but related ones, and the researcher must decide where they sit on the continuum.

Given that the first phase of data collection had provided rich insights into SLTs' perspectives, a wholly unstructured interview for topic generation was not appropriate here. Instead, building on this data in a more focused way was a more salient aim. Gillham's (2005, p.70) argument for the semi-structured interview to be considered the most useful and important type of qualitative interview *"because of its flexibility balanced by structure, and the quality of the data obtained"* influenced the decision to adopt this method. Mason (2002) also prompts that the form of qualitative data collection selected must align with the researcher's positionality. The semi-structured interview's flexibility allowed the adaption of the method to align with this researcher's views on knowledge creation, the nature of reality, as well as the view of the researcher's impact on data collection. The next section outlines the development of the interview schedule and the interview administration and relates this to the researcher’s positionality.

7.2 Interview Development and Administration

7.2.1 Interview Development

The widely accepted keys to successful qualitative interviewing are preparation and planning (Braun & Clarke, 2013; Gillham, 2005; J. Mason, 2002). One of the main priorities of preparation was developing the interview guide. The starting point for this was the findings of the first phase of the study, the questionnaire. Preparation began by separating the issues that arose from the questionnaire into broad topic areas. Each topic area then became a starting point for brainstorming relevant questions before refining these questions down to a list of accepted questions (Braun & Clarke, 2013). Bryman (2016, referencing Kvale, 1996) describes nine different types of questions: introducing, following-up, probing, specifying, direct, indirect, structuring, silence, and interpreting. The interview guide should include sample and suggested questions of each of these types. Braun and Clarke (2013) also suggest determining the opening and closing questions to be used in the interview. The opening question should be broad and open and designed to ease the participants into opening up. The closing question should signal to the participants that the interviews were wrapping up, and allow them to share any other thoughts or opinions they felt were not captured throughout the interview. During the interview, structuring questions and redirects establish topic changes and navigation through the interview questions.

Piloting the interview schedule was then necessary to refine the questions, test the probes, and clarify if participants felt there was repetition or a lack of clarity (Bryman, 2016). It was completed in two phases, as recommended by Gillham (2005). Two SLTs working with people with dementia outwith Scotland agreed to pilot the interview questions for both phases. However, it was not possible to pilot with other AHPs at the time. Furthermore, given the different work locations and the pilot nature of these interviews, these pilots did not form part of the analysis. The first phase of piloting, the pre-pilot, involved asking for critical feedback on the topic areas and questions. In contrast, the pilot itself was a trial run of the interview administration. The feedback received from the pilot allowed the refining and reordering of the questions and topics. It is important to note that the schedule was to act as a guide to the interview. The researcher did not intend to follow the schedule formulaically, but rather the intent was for the schedule to allow flexible movement between topic areas. The interviewees' responses determined the order of the topics and questions, and as such, not all questions were presented. Table 7.1 provides an overview of the interviews' main topics and areas of focus, and a copy of the interview schedule with sample questions and prompts is in appendix 6.

Table 7.1 Overview of topics in the interview schedule

1. Rapport building (completed during interview set-up)
2. Background Information and Perception of Own Role
    a. Type of professional and length of time in that career?
    b. Clinical caseload/main scope of current work?
    c. *Your profession's* priority role (or roles) is in management or care of the elderly?
    d. Experience working with people with dementia?

   e. *Your profession's role* in managing mealtime or swallowing difficulties with people with dementia?

3. Roles of the MDT
   a. Who should be involved in a team supporting people with dementia?
   b. What do you consider the roles of these team members to be?
   c. Where do you think these roles overlap?
   d. Are there any things that you work on that you think should be *your profession's* sole role?
4. Provision of training
   a. Types of training provided and to who?
   b. Any dementia-specific training?
   c. Any training relevant to mealtimes or swallowing problems?
   d. Any barriers in providing training?
   e. Any supports to providing training?
5. Receipt of Training or Education
   a. Any dementia-specific training received?
6. Working practices or policies around referrals and liaison with care staff or nursing homes
   a. Usual practice when working with care homes?
   b. Any issues with follow-up of recommendations?
7. Policy and Implementing new Evidence and/or Guidance.
   a. Impact of new policies or changes to legislation on services?
   b. How are policy changes implemented?
8. Partnerships with external bodies
9. Questions specifically for speech and language therapists
   a. Views of the scope of SLT involvement in the management of mealtime difficulties?
   b. Any gaps in the management of mealtime difficulties?
   c. Any problems or issues in implementing recommendations?
   d. The role of the SLT in decisions around tube feeding and comfort feeding?
   e. Any comfort feeding protocol?

f. Managing situations where a person with dementia refuses recommendations?
g. What direction for growth of the SLT role in dementia management?

10. Wrap-up
    a. The biggest need or gap in service for mealtime care?
    b. Any policy or services that have made a difference in mealtime support?
    c. Anything else to add?

7.2.2 Interview Administration

Gillham (2005) describes five stages of interview administration: The preparation phase, the initial contact phase, the orientation phase, the substantive phase, and the closure phase. The preparation phase occurred from the point of recruitment. It involved providing information to the participants about the research’s purpose and an opportunity to indicate whether they agree to participate (Gillham, 2005). The participation information sheet and consent form are available in appendix 7. This phase also involved organising the logistics of where the interviews were to occur, with a quiet, comfortable, safe location being necessary (Braun & Clarke, 2013). Participants could suggest a neutral location of their choice or attend the University for the interviews. The preparation phase also involved the preparation of the recording equipment, such as testing and ensuring spare batteries. Interviews were recorded using a Dictaphone, and this was tested before each interview. The initial contact phase was at the point of first contact with the participant and was primarily social (Gillham, 2005); this was the rapport building part of the interview schedule. An effort was made to put participants at ease and ensure they were comfortable before beginning the interviews.

The orientation phase then involved ensuring that participants could discuss the information sheet provided face to face and have any questions answered. It was also an opportunity to orientate the participants to the interview process, such as familiarising them with the recording equipment and the interview's schedule (Gillham, 2005). The substantive phase of the interview was the conduction of the interview itself. Bryman (2016) outlined ten skills a successful interviewer should demonstrate, summarised below.

1. The interviewer should be knowledgeable about the interview focus.
2. They should use clear structuring during the interview.
3. The interviewer should ask short, clear questions.
4. They should be gentle to the interviewee, i.e., allowing pauses and time to finish.
5. They should be attentive to the participant and empathetic where necessary.
6. The interviewer should be open to discussing what is important to the interviewee.
7. They should steer the interview to find out what is needed to meet the interview's aims.
8. The interviewer should challenge what the interviewee has said if necessary.
9. They should remember what has previously been said.
10. The interviewer should interpret, but not impose meaning, on the interviewees' statements.

The researcher's training as an SLT was transferable to conducting interviews, and they applied these skills during the interviews. The closure phase then allowed the participant to expand on any points they wished or to raise new points they felt had not been sufficiently covered before the end of the interview (Gillham, 2005).

7.2.3 The Impact of the Researcher’s Positionality on the Interview Development and Administration

The ability to flexibly deliver a responsive interview schedule to participants aligns with the researcher’s view that the reality is relative to the person experiencing it. As a result, it was likely that AHPs would jump off various topics of the schedule from the opening question, and a flexibly applied schedule would allow the participants to direct the interview. Allowing the participants to direct the interview aligns with the researcher’s position that an individual’s lived experience influences how knowledge is created and that allowing the participant to guide the interview would ensure that the data generated was richer and more in-depth. The researcher anticipated that allowing flexibility during the interview would generate unexpected topics and information beyond the schedule. As described in section 3.1.1, this researcher believes their background and experiences are fundamentally influential on the research and, as such, can potentially blinker issues or topics beyond the scope of their experience. A flexibly delivered interview schedule is a step to mitigating this and getting closer to the heart of the issues faced in practice by the AHPs. The next section describes the approach to analysis.

7.3 Analysis Approach

A conventional content analysis approach was used to interpret the qualitative data extracted from the questionnaire. This analysis approach is traditionally associated with a qualitative descriptive approach, as it is useful for *“summarising the* *informational contents of that data"* (Sandelowski, 2000, p. 338). However, for this phase of the study, a summary of the information was not sufficient; an analysis approach that allowed for an open and flexible interpretation, not merely a summary, of the interview data was essential. It was expected that the interviews would generate a large amount of data that would need to be collated and condensed for interpretation. Therefore, other forms of qualitative analysis were explored. Content analysis is closely related to, and sometimes incorrectly conflated with, thematic analysis, though thematic analysis allows for a more nuanced interpretation of data. Clarke and Braun (2017, p. 297) define thematic analysis as *"a method for identifying, analysing, and interpreting patterns of meaning ('themes') within qualitative data"*. It is an umbrella term for a group of diverse analysis approaches that seek to identify and extract patterns and themes from data sets (Braun, Clarke, Hayfield, & Gareth, 2019). Two common approaches to thematic analysis in healthcare research are the framework method, or the framework approach, and reflexive thematic analysis. Both of these approaches were examined for their suitability for the current study.

The framework method is not aligned with one particular paradigm (Gale, Heath, Cameron, Rashid, & Redwood, 2013) and could, therefore, sit under the selected research paradigm, a pragmatic approach. The approach is structured and deductive; the researcher builds a coding framework from existing models, such as the mealtime models discussed in section 2.2.1, issues and questions derived from the research questions, and an initial familiarisation with the raw data (Pope, Ziebalnd, & Mays, 2000). Under the umbrella of thematic analysis approaches, the framework method can be classified as belonging to the codebook school of thematic analysis

(Braun et al., 2019). A codebook contains a list of the study's codes, code definitions, whether this definition relates to the literature or ideas arising from the data, and the origin of the code, i.e. whether the code was determined *a priori* analysis or from the data (K. Roberts, Dowell, & Nie, 2019). A disadvantage of deductive approaches is that it constrains data interpretation from the outset and does not allow fluid and reflexive engagement with the data (K. Roberts et al., 2019). The analysis of the data through the structured lens of an existing thematic frame can be useful for time-constrained healthcare research (J. Smith & Firth, 2011), but for this phase of the research, examining the under-researched perspectives of AHPs supporting people with dementia at mealtimes and understanding the issues faced in their care, an inductive approach that allowed flexibility in interpretation and that would not impede the identification of themes beyond the scope of the thematic frame was needed.

Another form of thematic analysis that is a viable alternative to the framework approach was *reflexive* thematic analysis (Braun & Clarke, 2019a). This method was first delineated by Braun and Clarke in their seminal 2006 paper and has become increasingly common in psychology and health research. It is an approach that can provide "*robust and even sophisticated analyses of qualitative data*" for those in the health and well-being field (Braun & Clarke, 2014, p. 2). Reflexive thematic analysis is theoretically flexible (V. Clarke & Braun, 2017), meaning it can be used within a qualitative descriptive approach under a pragmatic paradigm, as is the case for this research. This flexibility is a strength of the approach as it allows researchers to demarcate their use of reflexive thematic analysis within their own theoretical positions (Braun & Clarke, 2006), and the description of this theoretical position is critical to quality research (Terry, Hayfield, Clarke, & Braun, 2017).

Reflexive thematic analysis was considered a suitable approach for this phase of the research due to its theoretical flexibility, its inductive approach to analysis, as well as having researcher reflexivity at the core of its approach (Terry et al., 2017). However, before the publication of their paper in 2006, thematic analysis was not a well-defined analysis approach in the literature, and publications were often unclear about the steps followed in analysis (Braun & Clarke, 2006). As such, it is critical for researchers to identify which approach to thematic analysis they are following, particularly as the reflexive thematic analysis approach has been refined by the authors since their inaugural publication (Braun & Clarke, 2019a). The next section will describe how the analysis was conducted.

7.3.1 Reflexive Thematic Analysis

The reflexive thematic analysis approach has become ubiquitous in qualitative research due to the clarity of its analysis process, namely its six-steps. However, in response to what the authors viewed as misconceptions of the application of their approach, they have updated their thesis on the topic in a paper entitled '*Reflecting on reflexive thematic analysis'* (Braun & Clarke, 2019a). Their analysis process's six-stages remains the same, but some modifications to their terminology will be addressed.

Braun & Clarke (2019a, p. 5) define themes as *"patterns of shared meaning underpinned or united by a core concept (we later conceptualised this as a 'central organising concept')"*. This central organising concept is "*a clear core idea that* *underpins a theme, the essence of what the theme is about"* (Braun, Clarke, & Rance, 2015, p. 192). Essentially, in reflexive thematic analysis, themes are not simply "*domain summaries"*, i.e., a mere summary of the responses to the questions asked. Domain summary themes surround a shared topic but do not share meaning and are considered under-developed in reflexive thematic analysis (Braun & Clarke, 2019a). Instead, themes should offer insight and depth to the meanings in the data and be structured around the central organising concept. In this approach, data items refer to individual interviews, and the data items combine to form the dataset (Braun et al., 2015). The six phases of the data analysis are outlined next.

Phase 1: Familiarisation: This phase involves data transcription and reading and re-reading the data. Once the interviews were completed, they were transcribed verbatim by the researcher using Express Scribe transcription software. Interviews were then read back once while simultaneously listening to the audio and a second time without audio. Notes on initial thoughts and ideas were made in a separate notebook, but no codes or themes were generated at this point.

Phase 2: Coding: In this second phase of analysis, meaningful labels were created and applied to segments of the dataset. These labels aimed to capture important data features and were applied by systematically working through the dataset. Coders are advised to generate codes or labels that work independently of the data, i.e., would the meaning of the code still be clear if the data was removed (Terry et al., 2017). Codes can be described as semantic or latent. Semantic codes label overt features of the data, while latent codes specify the data's conceptual or analytic features (Braun et al., 2015). Table 7.2 illustrates an example of text coded with latent and semantic codes.

Data was coded by hand, as recommended for novice users of the method (Braun & Clarke, 2013); a sample of this is shown in appendix 8. Related codes were collated and listed before moving onto the next phase.

Table 7.2 Examples of latent and semantic codes

Codename	**Data Excerpt**	**Code**
SLT 2	*I think it’s both, and I think for me, I wasn’t always happy with what I was doing. If you see a very incapacitated person who isn’t thinking for themselves and the family are doing everything to maintain this person, to keep them alive, I think I’ve begun to wonder if that’s correct.*	Past way of working was contrary to personal moral code (latent)
	And that’s a tough one, because obviously there are a lot of ethical considerations around all that, but I’m not sure it would have been the person’s choice if they were thinking to; what they would have thought when they were able to, and I’ve seen very poor quality of life and maintaining somebody alive for a long period of time by doing all the right things.	‘Doing ‘the right thing’ can harm in other ways (semantic)

Phase 3: Theme Development: This third phase of analysis is an active phase (Terry et al., 2017) with terms such as theme generation or development preferred by the authors as they are vehemently opposed to the passive idea of themes ‘emerging’ from the data (Braun & Clarke, 2019a). The researcher's role is fundamental in this approach, and it rejects the concept of themes *“‘in’ the data, waiting to be identified and retrieved by the researcher”* (Braun & Clarke, 2019a, p. 6). As discussed in section 7.3, there are different types of thematic analysis; some of these involve coding reliability approaches. These approaches require that members of the research team independently evaluate the codes' trustworthiness to ensure they accurately represent

the dataset (Braun et al., 2019). Reflexive thematic analysis does not involve coding reliability as this implies, as described above, that the themes already exist in the data primed for mining by the researcher (Braun et al., 2019). This approach acknowledges that different researchers are likely to see different things in the data and that each analysis is reflective of the researcher who has conducted the process. That is why it is essential for researchers to include their theoretical standpoint (see section 3.1), as the theoretical flexibility of reflexive thematic analysis does not equate to an approach operating in a theoretical vacuum (Braun & Clarke, 2019a).

In order to develop themes, they are examined and clustered, with the researcher deciding what is and is not relevant to the research question. The researcher examines the codes to develop a central unifying concept that is notable across the dataset and generates candidate themes (Terry et al., 2017). Braun, Clarke and Rance (2015, p. 191-192) suggest three key questions to consider when developing themes:

1. *Is this potential theme centrally relevant to answering my research question?*
2. *Is this potential theme evident across more than one or two of my data items?*
3. *Can I easily identify a central organising concept for this potential theme?*

Phase 4: Reviewing Themes: The themes generated up to this point are referred to as candidate themes, as the iterative nature of the process means that these themes must be reviewed against the individual data items and against the dataset as a whole before deciding to include or exclude them in the final analysis. This fourth phase involves reviewing the themes to ensure they reflect the meaning of the collated coded data and evaluating whether the themes are distinct (Terry et al., 2017). Appendix 9 shows the collated codes and their themes. If themes are overlapping, then collapsing the themes can be considered. The final part of this phase is deciding if the themes answer the research question.

Phase 5: Defining and Naming Themes: In this phase, it is suggested to write a definition of each theme and make decisions around which quotations will be used in writing up the report to clarify the *"essence"* of the theme (Braun et al., 2015, p. 194). The naming of themes is considered an important part of this phase as the names will help guide the report's narrative.

Phase 6: Producing the Report: Report writing is considered a separate phase in reflexive thematic analysis, where the analysis is woven together and connected to the literature. The next chapter presents the report.

7.4 Sampling and Recruitment

Mason (2002, p. 121) describes sample strategy selection as serving two purposes; it *"is likely to be as strategic as it is practical"*. For this study, this meant that the participants needed to be accessible to the researcher in a practical sense, and they needed to have expertise in the area of study that could answer the research question in a strategic sense. For that reason, the same sampling strategy described in section 4.3 was used for this phase of the study: purposeful and snowball sampling. Recruitment focussed on AHPs based in the Scottish NHS due to its unique policy and service delivery model within the UK. A singular system and policy context was chosen to support the ecological validity of the results. Alzheimer Scotland’s AHP consultant agreed to distribute the study information to her AHP contacts. This successfully recruited an initial cohort of participants who subsequently identified colleagues whom they felt would also be interested in taking part. Contact was also made with managers of adult services in NHS boards who were asked to distribute the study information to their staff. Inclusion and exclusion criteria are shown in table 7.3.

Table 7.3. Interview Study inclusion and exclusion criteria

Inclusion Criteria	**Exclusion Criteria**
AHPs with experience working with people with dementia and mealtime/swallowing difficulties in a professional capacity.	No experience working with people with dementia and mealtime/swallowing difficulties in a professional capacity.
Proficient in English	Non-English speaking
Over 18 years of age.	Under 18 years of age
Participants who also have personal experience of dementia may also be included but will be asked to consider their responses only in relation to their professional role.	

Contention exists among qualitative researchers on how best to determine sample size (Braun & Clarke, 2019b). A review of sample size in PhD studies found that from a cohort of 560 studies, the mean sample size was 31, the median was 28, and the most common sample sizes were 20 and 30 (M. Mason, 2010). This review looked at the concept of saturation in determining sample size but could not determine a pattern of how this has been applied to PhD studies (M. Mason, 2010). Theoretical saturation, when no new information emerges from the data, was first developed as a concept of Grounded Theory, and in qualitative research, saturation can also be thematic (J. Low, 2019). The concept of saturation has often been used as a measure of when to end data collection (Fusch & Ness, 2015), but the type of saturation and how it was determined is not always stated (J. Low, 2019). Furthermore, this method does not align with reflexive thematic analysis (Braun & Clarke, 2019b). In their recent review, Braun and Clarke (2019b) expand on their rationale for this deviation from data saturation and instead recommend that researchers take a more pragmatic approach based on experience and the research aims. For less experienced researchers, they suggest using ‘rule of thumb’ measures to determine sample size, with their suggested sample sizes being 6-10 interviews for a small project, 10-20 interviews for a medium project and 20+ interviews for a large project (Braun & Clarke, 2013). In this study, given the researcher's relative inexperience, this rule of thumb was applied in conjunction with Mason’s (2002) advice on being strategic and practical in application. A description of the respondents is included in the following section.

7.4.1 Interview Participants

The interviews were conducted with 21 AHPs working across the NHS in Scotland who considered themselves to have a specialist interest in working with people with dementia. Although every effort was made to achieve an even distribution of professions in the sample (five of each), the researcher could not recruit sufficient OTs and physiotherapists. On the other hand, a greater number of SLTs volunteered to participate, who were therefore used to achieve the recruitment target. The final breakdown of respondents was: 10 SLTs, five dietitians (DT), three OTs, and three physiotherapists (PT). Only one participant, an SLT, had this specialist interest recognised in their job title. Table 7.4 shows the profession, participant identifier, and the participant’s work setting. The participants worked in a range of settings and with a mix of inpatients, outpatients, and community settings, including care homes.

Table 7.4. Allied health professionals’ work setting and codename

Codename	**Participant’s Work Setting**
Speech and Language Therapy	
SLT 1	Community adult’s team: including care homes.
SLT 2	Acute hospital: inpatients
SLT 3	Acute hospital: in- and outpatients
SLT 4	Rehabilitation centre: in- and outpatients
SLT 5	Mental health services: inpatients
SLT 6	Acute hospital: in- and outpatients
SLT 7	Acute hospital: in- and outpatients
SLT 8	Community adult’s team: primarily care homes
SLT 9	Community adult’s team: primarily domiciliary visits
SLT 10	Community hospital: outpatients
Dietetics	
DT 1	Mental health services: in- and outpatients
DT 2	Acute hospital: inpatients
DT 3	Acute hospital: inpatients
DT 4	Community adult’s team: outpatients, domiciliary visits, care homes
DT 5	Community adult’s team: primarily care homes
Physiotherapy	
PT 1	Mental health services: inpatients
PT 2	Community hospital: inpatients
PT 3	Mental health services: inpatients
Occupational Therapy	
OT 1	Mental health services: inpatients and outpatients
OT 2	Mental health services: inpatients
OT 3	Acute hospital: inpatients

7.5 Anonymity and Confidentiality

Interview participants were required to sign consent forms which were stored in a University filing cabinet, separate from their recordings and transcripts. Interview recordings were given a code, uploaded to the University's secure cloud storage system and deleted from the recording device as soon as possible after the interview. Additionally, as the pool of Scottish AHPs working with people with dementia was also a small and potentially easy to identify group, precautions were taken. Any identifiable information was redacted from interview transcripts, for example, names, NHS board or work locations. No personal details were collected from participants beyond their job title and area of work. Efforts were made to access a geographically diverse sample of AHPs, and participants were recruited from six of Scotland's 14 NHS boards and from urban and rural areas. Given the small numbers of dementia-specialists AHPs across Scotland, a geographical profile is not reported. Furthermore, the gender and race profiles of participants are not included to protect anonymity. However, the profile aligns with the primarily female Scottish NHS AHP workforce (Information Services Division Scotland, 2019) and the NHS' overall race profile which is predominantly white Scottish (NHS National Services Scotland, 2019).

7.6 Summary

This chapter has outlined the methods used in the second phase of data collection and the analysis approach used. The next chapter will describe the results of this phase.

8 PHASE 2 – THE INTERVIEW STUDY: RESULTS

This chapter describes the findings generated from a thematic analysis of interviews conducted with AHPs with a specialist interest in dementia care. While the interviews centred around both mealtime difficulties and dysphagia, the main focus was on mealtime difficulties, given that not all AHPs had established roles in dysphagia management. However, the AHPs also frequently described issues they faced beyond mealtime and related to the wider systems they worked within. The interviews generated three overarching themes, as follows:

1. *Professional Roles*: an exploration of the roles played by AHPs in mealtime support and the broader perception of these roles.
2. *Decision-making is Individual:* this theme explores the participants' views on the importance of considering the individual with dementia's perspectives and context.
3. *The Realities*: centres around discussions on supporting mealtimes within the constraints of services and current practices.

Each overarching theme has several subthemes that illuminate these broader issues in more detail. A thematic map (figure 8.1) illustrates these ordinate themes and their subthemes.

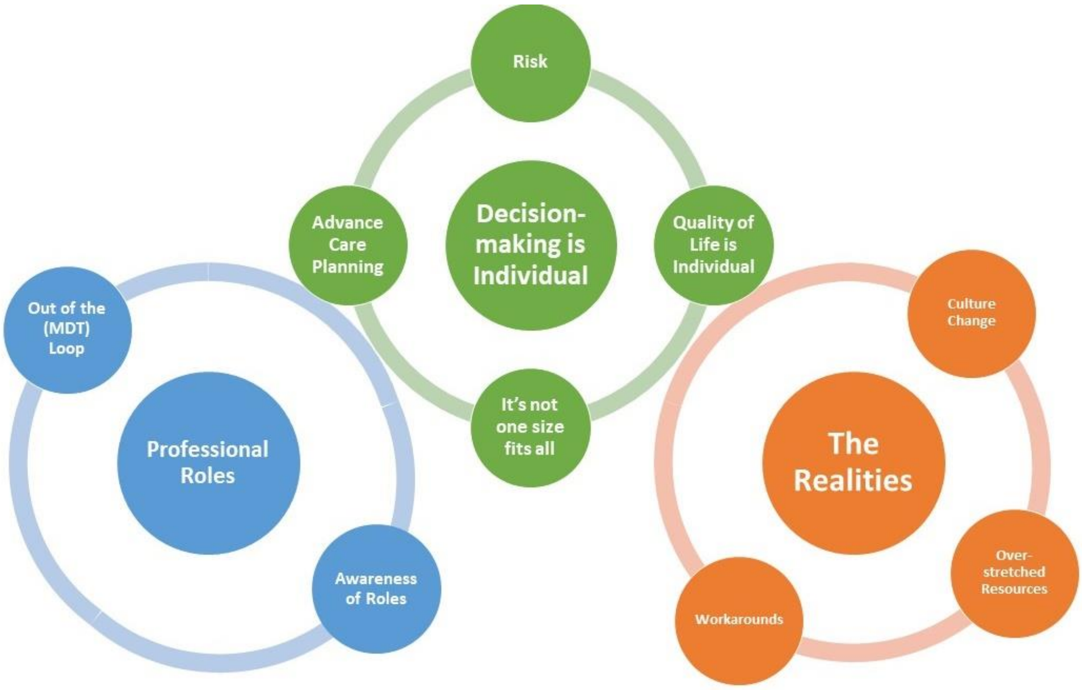


Figure 8.1. Thematic map of the primary themes and their related subthemes

8.1 Professional Roles

The theme of 'Professional Roles' encompasses the challenges and barriers faced by participants in carrying out their jobs as AHPs. Its subtheme 'awareness of roles' examines the participants' views on AHP roles and the understanding of AHP scope held by the broader systems. The second subtheme, 'out of the (MDT) loop', explores the challenges of MDT working and the implications for people with dementia.

8.1.1 Awareness of Roles

This subtheme focuses on the AHPs' perceptions of the understanding of their roles, including within different contexts. It examines how AHPs view their own and each other's roles, how their fellow MDT colleagues understand the AHPs' roles within clinical environments, and how people with dementia and their families and carers understand the AHP's contribution within their home environments. While the interviews focused on mealtime difficulties and dysphagia, participants felt that the wider systems they worked in tended not to be aware of AHPs and their roles. They indicated that some referral agents such as care home staff were not aware of AHP roles leading to incorrectly referring to the wrong AHP. For example, referrals for dietetics coming to SLTs: "*we quite often get a 'they're losing weight', so we get referrals that should be going to the dietitian coming to us*" (SLT 8). By contrast, the AHPs themselves had a consensus on their understanding of each other's roles at mealtimes. The AHPs' views were that:

- the physiotherapist manages seating and positioning, with the application of chest physio if required by individuals,
- the dietitian's focus is monitoring calorie and fluid intake, and encouraging weight gain or maintenance,
- the OT's efforts focus on modifying the environment around the mealtime and includes equipment provision, and
- the SLT's responsibility is managing dysphagia and recommending diet and fluid modifications.

When it came to overlap between AHP roles, the participants viewed this in two ways: overlap or over-reach. Overlap was a necessity and beneficial to their practice. For example, SLTs and dietitians felt that they could reiterate and reinforce the same message to carers to support their understanding of recommendations and diet and meal routine changes. They also considered sharing advice on behalf of each other as useful for people with dementia living in the community who may have delays in seeing each AHP. However, though the AHPs described a need for overlap in roles, an over-reaching AHP risks providing inappropriate advice to people with dementia and their carers. Several of the AHPs emphasised the need to act within the scope of their own understanding, i.e., avoiding over-reaching their knowledge. As one OT described overlap in roles: *"So even though it's one task, they're all, we've all got to keep, have our MDT hat on, but I think when it comes down to it, we're looking at it specifically from our profession-specific hats on" (OT 1)*. This statement emphasised that these specialist AHPs were only comfortable providing advice beyond their specific remit to an extent. However, as overlap occurs informally and unregulated in order to compensate for a lack of resources such as time, staffing, and access to their AHP colleagues, the potential for over-reach exists. One dietitian noted the potential hazards of overreaching your role:

> *because that's what we're trained for and nobody else has that training . . . that's [why it is] important that a dietitian is providing, or dietetic service is providing, that information. Because sometimes, the information that is provided from other healthcare professionals isn't necessarily correct. It can be off the telly, or internet or things like that (DT 1)*

This quote highlights the risk that AHPs overlapping their roles are taking, as over-reaching their understanding can lead to incorrect and potentially harmful advice. For some of the SLTs, limited access to their occupational therapy colleagues, in particular, meant that they sourced and recommended adaptive feeding equipment while acknowledging their limited knowledge on the topic. The subthemes 'out of the

(MDT) loop' and 'over-stretched resources' described in sections 8.1.2 and 8.3.1 explore these issues in more detail.

Interestingly, despite the AHPs having broad consensus on the nature of the other AHPs' roles, members of individual professions did not always view this traditional perception of their roles as reflective of the full scope of what they could offer. For example, one physiotherapist described how their role is refocusing to a more holistic interpretation, allowing them the opportunity to reinstitute practices that prioritise quality of life. They detailed how this current prioritisation means their interventions can go beyond what others would see as core physiotherapy care:

> *A lot of old school things that are coming back that we for a long time potentially wouldn't have the opportunity to do because we wouldn't have been seen as essential care. But we're starting to look again now at how can we improve people's quality of life? How can we make it easier better, make that person more comfortable, reduce the medication they're on . . . and I think, it's not a classic role that you would think for a physio to do, be involved in constipation management (PT 1).*

In this physiotherapist's view, constipation management had a direct link to mealtime support given the impact of constipation on appetite and feelings of well-being.

Similarly, the SLTs felt that their role was constrained by how their colleagues perceived it. Their AHP colleagues described a basic knowledge of the SLT's role and related their understanding of the role as modifying diets and suggesting thickened drinks:

> *I will refer to speech and language or I'll ask if they've seen a person with the thickeners, and they should [see them] . . . I think they've got a huge scope, but they're not able to maybe fit in as much . . . I would hope that I have some understanding, but I wouldn't say it was an in-depth knowledge (OT 2).*

And:

> *they will look at swallow, they will look at textured diets, they will look at any techniques that might be required, so they'll be looking at things. They'll be giving advice like the back of a spoon or extra swallows before the, before they're drinking. They'll be looking at thickened fluids (PT 1).*

The SLTs, however, viewed their role as more than just dysphagia and were keen to emphasise that: "*There's so much to look at with dementia; it's not just a case of can you swallow?"* (SLT 3). They described their role as supporting carers to offer compensation and feeding strategies to encourage safe eating and drinking for the person with dementia, not the blanket recommendation of modified food and drinks.

The SLTs felt that their role in working with people with dementia was also misunderstood by their MDT and healthcare support staff colleagues. For example, SLTs considered GPs' awareness of their role as mixed and described a reciprocal working relationship with GPs as having an element of the luck of the draw. For example, participants felt referrals were more likely if there was access to *"a very proactive GP" (SLT 10)*. Furthermore, the SLTs felt the benefit of their input was not always considered*: "other professions tend to think OT, physio, you know, dietetics, but they maybe don't think of us until the end-stage" (SLT 4)*. The SLTs agreed that a perception exists that the SLT's role with people with dementia was at the end of life when SLTs themselves felt their role was most limited. SLTs saw their role as being one across the course of the disease. They believed that the profession had a lot to offer people with dementia and that lack of SLT access is detrimental to their care.

> *There's referrals I wish I'd got so much sooner, absolutely wish I'd got so much sooner . . . I've never had one I've thought 'no it's far too soon', it's the other way. It's when they've come in crisis or way too late, and you think [I could have done more] . . . yeah, so I think if anything we get them too late [SLT 8].*

Several SLTs described too limited a focus on communication; they felt that this was a *"forgotten" (SLT 3)* aspect of their role. They described the profession becoming centred on dysphagia to the detriment of communication, *"No, my focus isn't that [dysphagia] ... that just tends to be what we're referred. So, my focus would like to be communication, but you are eaten up with this eating and drinking" (SLT 2)*. The SLTs described a preference for a more balanced caseload*: "I'm hoping we can start thinking about other things, and you know, focus on communication" (SLT 1)*. Two SLTs also reported efforts to advocate for their role in communication by including a communication assessment in their management and providing strategies and tips to care staff when they received a dysphagia referral:

> *what we said was that if we get referred somebody for dementia for assessment, dysphagia assessment, what we would try and do is think of*

> *one or two kind of really basic communication tips that might facilitate someone's communication . . . just to kind of raise the awareness of our role in communication, because I do think some people do seem to have sort of forgotten that we've got a role in communication in dementia (SLT 3).*

All AHPs considered that, in addition to their wider colleagues' limited understanding, the public also had limited awareness of their roles. The AHPs believed this was detrimental to people with dementia and their families accessing services, as: *"they don't know where to access us or when to access us as well"* (DT 1). Participants felt that, even when it existed, knowledge of the AHPs and their role existed with misconceptions. For example, dietitians viewed the public perception of their role as *"all about 'healthy eating, healthy eating, healthy eating'" (DT 2).* This lack of understanding was compounded by the breadth of individual AHP roles, as highlighted by one OT:

> *I think even OTs at times find it difficult to express what we do. So, we find it difficult because it covers such an array of different things . . . I think, you know, a lot of patients – and carers and families – really struggle with our role. (OT 3)*

Participants believed that if people with dementia and their families were made aware of AHP roles earlier in the disease process, this would reduce stress and support decision-making. A consistent view was that carers were facing challenges and difficulties and were trying to manage them independently, at a cost to their well-being and stress levels, as a direct result of this lack of awareness of AHPs. As one SLT described:

> *A couple of carers that I spoke to, they were experiencing swallowing problems, but they've not, they hadn't asked for help or anything like that. So, they were saying, 'oh yeah, my relative holds food in their mouth, they choke regularly'. And [they] didn't know they could access help, they didn't know about dietitian [sic], they didn't know about speech therapists. (SLT 3)*

The participants also highlighted a lack of awareness of the types of support that AHPs can offer specifically for people with dementia. Some linked this to a limited understanding of the dementia process and its impacts beyond cognition. SLTs felt that the effects of dementia on mealtimes and swallowing were unknown, as one SLT reported hearing: *"And well we didn't know that's why they were choking 'cause it was to do with the dementia, we just thought it was', you know [something else]" (SLT 7).* A dietitian reinforced this view, *"When I speak to the general public, they know they've got this label of dementia, but I don't think they totally appreciate how that really then can affect things like swallowing, eating and drinking in general" (DT 2).* Unknown impacts beyond cognition were also highlighted by other professionals, for example, the physical effects:

> *I still think people don't see the mobility loss or the physical changes as part of the dementia. I still often get the impression that people see that as an e- as a different condition or something else. They know about the*

> *cognitive changes, but it's never quite as, I don't think it's quite as well out there still: the physical changes are part of the dementia. (PT 1)*

These examples underscore how a limited understanding of dementia's impacts combined with a lack of awareness of AHP roles led to a perception among the AHPs that referrals often came too late in the disease process. This illustrates the importance of early engagement with AHP services in order to offer meaningful interventions and enable people with dementia to access the maximal benefit from intervention. Providing information on what to look out for could mitigate this:

> *But knowing that that might happen means that a spouse or whatever might be looking out. So, if someone's constantly choking or have a wet voice or losing weight unintentionally or . . . having one bite of food and then pushing the plate away, do you know. These are kinds of things you might think 'oh could it be a swallowing issue', you know that that person is having and given those kind of red flags if you like then I think it's important that people know that. But it's doing it at the right time. (DT 2)*

This highlights the need for early signposting, with several participants mentioning that *"it would help just to signpost that this is ... who to turn to if you notice these difficulties" (SLT 6).*

In addition, participants also described this limited understanding of the dementia-related changes as creating a need for expectation management of what therapy could achieve. Expectation management was particularly relevant at the end of life and was seen as necessary to support family and carers' well-being:

> *It is palliative at that point, you know, they are not going to get better. They are going to lose weight; they are going to become more frail. But it's, it's making it as dignified and as acceptable to both parties. So, keeping the patient as well as possible, for as long as possible and dealing with the expectations and emotions of the carer to say: 'this will happen, it's ok' (DT 3).*

Family and carers' lack of preparation for the end of life and palliative stages is discussed further in advance care planning section 8.2.4.

AHPs agreed that greater awareness of their roles and education around the broader implications of dementia were needed. Some participants felt that knowledge is slowly improving with awareness-raising campaigns and with families using the internet to learn about the condition. Still, it was clear from the interviews that AHPs felt that this was too slow to change and that more signposting and different strategies were needed. The lack of signposting is closely linked to the AHPs views on early involvement. A possible conduit for this awareness-raising was Alzheimer Scotland's dementia link worker programme, but it appeared that access to link workers varied across participants' caseloads. Early familiarisation with AHP roles also links to advance care planning, discussed in section 8.2.4.

8.1.2 Out of the (MDT) Loop

This theme developed from recurring comments about the benefits of MDT working, tempered with comments about the challenges of doing this in practice. Working closely within an MDT was described as almost an ideal world scenario, as service constraints made this an unlikely reality. Several issues impacted the AHPs' abilities to work within a team. For SLTs and dietitians, the problem was the nature of their work. These AHPs tended to be split across wards and services and rarely worked in the same place at the same time as their colleagues. All AHPs identified that their optimal working conditions would involve operating as part of a team but that speech and language therapy and dietetic services' mobile nature negatively impacted this. As one SLT noted, *"I think maybe if we were always in the same place at the one time, together, that [collaborating with MDT colleagues] might be easier" (SLT 4)*. The SLTs and dietitians viewed their large caseloads across multiple sites as impacting on their capacity to attend MDT meetings: *"I'm across so many sites that I just can't possibly do that. So, we're spread too thin to be able to go to the MDTs"* (DT 2), *"we don't go to the actual MDT meetings, just because there's so many and they all clash"* (SLT 7), and *"We don't go to MDTs, we don't go to any of the meetings. In terms of resources, we don't have that capacity"* (DT 4).

Their physiotherapy and occupational therapy colleagues noted the impact of the absence of SLTs and dietitians in their day-to-day work: *"They're not so easy to get a hold of because you guys dot about, you're not dedicated on a ward, you dot about everywhere"* (OT 3), and:

> *I think the difficulty comes with dietetics, with SALT [SLT], with services, podiatry, with services that are much more centralised and aren't really based in where we work. They cover such a wide area; they're in by assessment only. We don't see them as regularly, and that can sometimes impact on how much interaction you have*. (PT 1)

AHPs viewed the MDT as the key to person-centred care for people with dementia, and that on-site collaborative working enabled a holistic approach that was supportive of achieving goals:

> *you have to really think outside the box, and I think that's where our MDT does come into its own, because we have to look at something that's going to meet all their needs, and we're actually really going to put that person at the centre of every decision that we make (PT 1)*

The physiotherapists and OTs interviewed tended to be dedicated to one ward or one service, allowing them to build close relationships with the wider MDT. Just one SLT reported working in a single, fixed location, similar to the OTs and physiotherapists. They reported that the speech and language therapy cover where they worked had traditionally been a 'refer-out' service, where SLTs were based in a separate service but could be contacted on an as-needed basis. However, during restructuring, a new post had been created to prioritise multidisciplinary collaboration. Several of the AHPs felt that a dedicated presence enabled the team to focus on critical issues and to work creatively to achieve positive outcomes:

> *Everything is focused around us working together, physio, OT, nursing staff, for every single person . . . you just wouldn't have that same way with an SLT or a dietitian. It probably wouldn't be a practical, because they're just not going to be able to be in all the places at once, but I think it would be good (PT 2).*

On the other hand, the rest of the SLTs and dietitians felt isolated by the nature of their work. They felt that their unfortunate segregation from the MDT impacted their ability to contribute to the team and collaborate. One SLT described the potential for unnecessary duplication that this working model provided:

> *And so, I'm used to working multidisciplinary and I kind of miss that. You are quite, feel quite a bit isolated sometimes. You feel you go, especially because we're not part of the community team, so we feel like other people are working together, and then you come in as a separate entity, and you maybe do crossover things that would be better working together* (SLT 10)

This isolation from the team impacted decision-making. The AHPs recognised the implications, both positive and negative, of their recommendations on quality of life. They felt that outwith the team, there was more pressure on them when making decisions without others' perspectives: *"So it does leave you quite isolated professionally speaking. And sometimes it is difficult decisions and suggestions that you're making about people's well-being and their lives ultimately" (DT 1).*

There was also a view that physical proximity to colleagues enabled interaction and collaboration in a more frequent, informal manner than merely attending formal MDT meetings. These were described as watercooler-type discussions and meant that simple issues could be checked, clarified, or resolved in passing.

> *Well, myself, OT, and physio are all based in this department and dietetics are on-site and kind of around here quite a lot. So, we, we have quite a lot of multidisciplinary working . . . So, if there's anybody we have in common or, you know, that we share concerns about, you know, it's very straightforward to just have a chat* (SLT 5).

While the AHPs did acknowledge that their colleagues were usually contactable by phone or email, there was a perception that this was a more formal approach. The participants indicated that they did not always have a relationship with them or know the name of the person who covered their ward. They felt that this lack of a relationship created a barrier to collaboration as most AHPs felt that off-the-cuff conversations had a more immediate impact on people's care:

> *Something that you've just overheard, or you've just thought about it, and you go next door, and you say it. Whereas I sometimes find when services have been a bit more centralised in some areas, you don't have that same interaction. And it's a bit more difficult to plan ways forward and to plan to do things together and to move forward (PT 1).*

Several AHPs also acknowledged issues with communication in settings and across teams, describing information sharing as *"detective work" (SLT 5).* These issues included staying up-to-date with cases and knowing which colleagues were also working with their patient: *"I think it's probably hard if you're a speech therapist or whatever floating in, trying to find who's looking after who and what, you know, what's the situation with this one particular patient" (PT 2).* Communicating across teams within professions was also challenging, for example, sharing information when moving from AHP acute services to community services and vice versa.

> *Normally I would look, again, it's looking online, on the system to see if there's a, you know, a report or a previous referral. Or yeah, it's going 'round the offices to see what [information is available] . . . I do try and get that information if I can, but again if it's going to be too time-consuming or too complicated [I don't] (SLT 5)*

Often AHPs described the connections on the wards and between services as built and developed through personal relationships with outside colleagues, not through work channels. This informality could lead to links breaking down if colleagues move on or other structural changes occur.

In addition to issues interacting with colleagues in MDTs that they were already a part of, AHPs described needing to fight for their place and involvement in other teams where there was a need for their expertise. The physiotherapists felt that the OTs' role in mental health teams was widely acknowledged but that they needed to continually demonstrate the benefit of their presence. For example, *"you're not classed as one of the core mental health practitioners. Whereas consultants, doctors, psychologists, nurses, OTs are"* (PT 1), and *"the much smaller groups like physio, speech and language, dietetics, podiatry, don't necessarily get a seat around the table* *at things . . . they don't always get as much credit or as much in the limelight as other professions*" (PT 3). Other AHPs described actively canvassing teams to develop their awareness of their role to increase referrals and collaborative working. As with the previous theme, 'awareness of roles', the AHPs felt that they needed to continually make others aware of what they could offer. They described needing to knock down doors to break into services by making contacts, putting themselves forward and advocating for the role:

> *as I said, with me starting to get involved with the clinical governance meeting because as SLTs we weren't involved, we hadn't been invited . . . that kind of opened some doors, so that was good. And it's not for want of trying* (SLT 6).

It was clear that battling to be 'in the loop' of the MDT was a source of frustration for some AHPs. This reflected their concerns about the impact of a disjointed MDT on the quality of care they could provide. This frustration was also in tandem with a sense of isolation and links closely with the issues described under the theme 'the realities' described in section 8.3.

8.2 Decision-making is Individual

This theme addresses the participants' descriptions of the complexities of supporting people with dementia, *"because people don't just come with, as you know, come in isolation. They come like big combinations of everything" (DT 2)*. This theme explores the AHPs' perceptions of the implications of the unique physical, neurological, sensory, and social environments that influence every individual with dementia’s presentation. These perceptions are related to advance care planning, quality of life, and risk-taking with eating and drinking in the following sections.

8.2.1 ‘It’s not one size fits all’

This subtheme has two main segments: the uniqueness of every individual with dementia and the individuality of decision-making among evidence and service restrictions. The first of these segments frequently influenced decision-making for all AHPs. The AHPs often described people with dementia as individuals with distinct needs. As in the quote in section 8.2, their needs were often *“big combinations of everything”* (DT 2), referring to factors beyond their dementia presentation. These *“combinations”,* such as their personal and family history, cultural backgrounds, work experience, medical histories, and other aspects of their lives, influenced how the AHPs supported and worked with people with dementia. Knowing people with dementia’s background and personal circumstances was more relevant to the AHPs than knowing the diagnosis. As one AHP said: *“if I see a diagnosis of dementia, I keep that in mind, but it doesn’t necessarily mean anything until I meet the patient”* (PT 2). The AHPs also described how the previously noted *“combinations”* of factors could impact on meals and the healthcare staff's priorities, particularly as the person with dementia cannot always advocate for themselves. As such, understanding their biography enabled the AHPs to act in a person-centred way. For example, one AHP described a situation where staff were concerned about a patient’s minimal intake at meals. However, his wife informed the SLT: *“‘oh he never eats during the day. He only ever has a cup of coffee and a biscuit for lunch, so he won’t eat his lunch’”* (SLT

6). In this case, knowing his social history was essential to ensuring a more bespoke approach to meeting his care needs.

The concept of bespoke care recurred throughout the interviews. The AHPs' primary aim was maximising people with dementia's quality of life through their person-centred interventions. Therefore, they were keen to emphasise their views that *"everyone with dementia is individual and they are still people and just because they have a diagnosis of dementia doesn't make them any less of a person"* (OT 1). Accordingly, the AHPs felt that there should not be a standard approach to dementia care as this ignores people's individuality. However, they saw the dementia diagnosis as complicating this as it was potentially a source of stigma:

> *[you need to] see the patient not the condition, which we all feel that we do, but we don't . . . look at the personal history, get to know them, rather than just go they've got dementia, they need x, y and z. You wouldn't do that with any other condition, . . . so it's just, it's kind of reducing stigma amongst the staff and the population (DT 3)*

A differential dementia diagnosis was, interestingly, both relevant and superfluous information to the AHPs. For instance, though a differential diagnosis of the dementia type was not always available, it was seen as useful by some for the planning of management and to guide their expectations of the person's presentation:

> *I think it's very important for your planning to know if it is genuinely dementia, you know what I mean. And not like Parkinson's or not some other acute delirium or something like that because your decision-*

> *making is gonna be different as to whether that's gonna change or not* (PT 2).

And:

> *Whereas if you've got a diagnosis, you can have a fair idea of the things that are going to be tricky for that patient. Obviously, every patient is different, but it gives you a starting point. And yeah, for things like capacity or onward referrals, it's always helpful to have the diagnosis* (OT 3).

On the other hand, as alluded to by OT 3, the AHPs perceived every dementia as unique and capricious, with a differential dementia diagnosis not necessarily helpful for preparing the AHP for how the person with dementia will present: *"it's unpredictable, you know, I get that too. You know, you walk into a situation with somebody with dementia, and you just don't know the way it's going to go. It can be really unpredictable" (SLT 4)*. The AHPs emphasised that differential diagnosis could not predict what issues would be faced: *"there's that whole issue of not one thing fits all and not every dementia's the same, everybody has, you know, everybody's different. Just because they have this label of dementia, it doesn't mean they have the same condition." (DT 3)*. That a differential diagnosis provided little clarity for the AHPs was an interesting finding. Therefore, they relied much more on the personal aspects of what they learned about the people with dementia, and the need for a 'not one size fits all' approach to dementia came through strongly. The AHPs also believed that their role as dementia-specialists meant raising awareness of this among the wider environment, *"but I think it's our job to advocate that, actually, it's not one size fits* *all for these patients"* (DT 4). The paradox of the importance and unimportance of differential diagnosis was apparent from these comments:

> *At the end of the day, you approach any patient as you find them . . . if I see a diagnosis of dementia, I keep that in mind, but it doesn't necessarily mean anything until I meet the patient . . . so although it doesn't make a difference, then it obviously does make a difference* (PT 2).

And:

> *My gut reaction was 'yeah' [diagnosis is important], and I'm thinking, 'well, is it?' In a way, it is because obviously not every dementia, it's such an umbrella term, and there are so many different types, and I guess maybe there are certain things you would try with certain people. You're not going to try the same thing with everyone.* (SLT 10).

The view of the person as an individual influenced the planning of management. AHPs described working more indirectly with people with dementia than with other populations and relying on family or carers to provide input. This working arrangement had unique risks. For example, dietitians did not consider the person with dementia to have different nutritional needs to the general population, but meeting their needs required a different approach. Nevertheless, they were aware that this indirect approach created risks that were challenging to manage: *"Nutritional need is not different, but their risk almost is different because they can't self-manage, so their risk varies because they're relying on other sources to provide it" (DT 4).* AHPs reinforced the idea of management planning not being one size fits all and one without a fixed guideline, *"I've not got a bespoke 'this is what I do with people with dementia' [plan]"* (SLT 4). Part of this was being aware that good outcomes will be different for every individual, *"again I think that's because people think dietitians you've got, it's got to be about a healthy diet. But actually, what's healthy for that person might be totally different"* (DT 1). However, it also involved recognising that the standard goals of care can be inappropriate. For example, government policy is to minimise time spent in the hospital, but this may be inappropriate for some people with dementia who do not have suitable supports in the home. This OT described how mealtime challenges could impact discharge:

> *Are you setting them up to fail again? Are they going to go deteriorate? Because here they're getting regular meals, regular medication, they've got the socialisation going on, they've got access to the likes of myself, all professionals have seen them. So sometimes you think, well, this is a double-edged sword: send them back home, and they stop eating and drinking, then what? Not realising their fluids are restricted, or not realising they're diabetic and the impact that has or. So that's all considered.* (OT 2)

The 'not one size fits all' approach to management faced challenges when it came to outcome measurement. Commissioning of services and demonstrating the benefits of AHP involvement rely on outcome measurement. However, most standardised outcome measures are not suitable for people with dementia, and as the interventions used in dementia are not standard (discussed further in section 8.3.2) they are challenging to measure. The AHPs fundamentally agreed that outcome measurement was necessary but decried the lack of available tools, *"if I could invent that I would be rich and famous" (OT 2)*. The AHPs, without suitable outcome measures, documented their intervention outcomes in different ways:

> *I use a lot of clinical reasoning because the outcome measures we are all primed to do and all use, meant to use all the time, most of them actually aren't validated for* advance care dementia. *But it's really difficult sometimes to use standard outcome measures with the patients that I work with, and you have to . . . look at things in a lot more individualised basis* (PT 1).

And:

> *I'm quite definite about making, goal planning with both people with dementia and their carers . . . I don't know if you would say improvement as that – possibly in quality of life, yes. I would hope for some, and that's we do our outcome measures here as well, and I've often said 'oh, my patients are deteriorating, the scores go down!', you know. But actually, there is a quality of life measure within that as well. And yes, their function may well deteriorate, and their abilities can deteriorate, their general health can deteriorate, but you would be aiming hopefully for some improvement in, in how they feel about it and how they cope with it* (SLT 10).

The focus on maximising quality of life was a high priority for AHPs and is described further in the following subtheme.

8.2.2 Quality of Life is Individual

The subtheme of ‘quality of life is individual’ shares some overlap with ‘it’s not one size fits all’ as it relates to the individuality of people with dementia. However, it examines how this relates to individual quality of life. Discussions with the AHPs explored the different meanings of quality of life for individuals and related this to eating and drinking.

The AHPs acknowledged the importance of mealtimes' social aspects for maintaining people’s quality of life and enjoyment of eating and drinking. They described mealtimes as *“a crucial part of the patient’s day”* (DT 2) and related efforts to encourage communal mealtimes in care settings positively: “*it’s just more of a social mealtime environment, it’s good”* (SLT 6). The AHPs recognised the positive impact that socialising at meals could have on mealtime performance and food intake, but that this was challenging to maintain in practice*: “we should have more dining rooms, encourage socialisation. We don’t have the environment for it”* (DT 3). However, within the recognition of the benefits of socialisation at mealtimes was understanding that for many people with dementia, a busy mealtime environment was not appropriate:

> *Some don’t cope with a big social environment; you do need quieter spaces. But all our research-based evidence out there in terms of malnutrition tells us that oral and dietary fluid intake can improve up to 25% in an individual if they’re in a social setting. So, the knowledge we have behind us is that we’re encouraging people to be social, but we still have to allow choice* (DT 5).

For these individuals who could not tolerate a busy mealtime environment, AHPs felt that more could do more to individualise their care: *"patients that really struggle that have lots of distractions trying to get them single rooms or . . . stagger mealtimes so that some people are in the dining room having a meal with fewer people"* (SLT 7).

Furthermore, the AHPs felt that opportunities for social mealtimes were reduced at times because of how the person with dementia ate and drank. One OT described it as *"a lot of the time it's about people being separated because they're messy eaters or it's not pleasant to sit opposite them, and you know the impact for both sides has to be looked at"* (OT 2). Another reason for mealtime segregation was a lack of available spaces for meals: *"they're at their bedside, with an over-bed table . . . There's no dining rooms; there's no quiet rooms; there's nothing"* (OT 3). AHPs described feeling uncomfortable with witnessing people with dementia eat alone at the bedside: *"one of the things that used to bother me was everybody sat by their beds individually with their [meal], and I think that's pretty much still happens. In fact, the new hospital they all have their own individual rooms. Which for a person with dementia is really not ideal"* (SLT 10). The AHPs' concerns about these mealtime experiences were the impact it had on a person's quality of life and well-being. The AHPs viewed socialising at mealtimes as the norm, *"it's quite sad when you walk up and down at lunchtime if you go and see someone at lunch because there are so many people sitting at a bedside by themselves eating. That's not what you do"* (SLT 6). The removal of socialisation opportunities, for whatever reason, was, therefore, perceived to be detrimental to the person with dementia's quality of life.

Food and pleasure in meals were seen by AHPs as a central aspect of quality of life, "*if I have to pick one, I would say, yeah, one is I want this person to be enjoying mealtimes and eating and drinking, yeah. Food is such a big part of life I want someone to be enjoying everything about it*" (SLT 8). AHPs perceived this view of promoting quality of life through meals as one that family members shared. They described family members or carers viewing food as a final pleasure, "*they see food and fluids as being something that's comforting and nurturing. So, if they feel that there's nothing else, and you hear this quite often, you'll hear people say, 'they've nothing else in their life'*" (DT 1). This view of food as pleasure also linked with the perception of food as care.

Due to carers' perceived connection between feeding and food as a final means of showing their love and care, AHPs faced dilemmas with the stress this put on family members to continue supporting their loved ones to eat and drink. For example, one AHP recalled a conversation with a patient's wife that encapsulated this strain: *"and she was saying, 'I can cope with everything, but I can't cope if he can't eat and drink'"* (SLT 4). AHPs considered this view as influencing families and carers to be more flexible with recommendations, a move perceived as a means to improve quality of life. However, AHPs wanted family members to be aware of the negative consequences of relaxing adherence to AHP recommendations that could reduce the person with dementia's quality of life before making this decision:

> *And there'll be some people who [think] because she's that old, or because she's dementia, this is the only pleasure she has in life, so we're going to continue to give it. And it's about explaining: 'well, actually, if*

> *you continue to do that, she's going to get more confused and maybe cause much more problems with repeated urine infections or constipation or whatever. Or however it affects. And therefore, length of stay's going to be longer, or trying to get placement elsewhere is going to be difficult getting home'. So, it's just about that communication* (OT 2).

AHPs shared the view that quality of life was about balance:

> *Overall, I think it's the patient outcome. It's that they're safely being managed, it's that they're enhancing the mealtime experience . . . It's then having that discussion about risks, comfort, patient choice. So, I think it's patient safety paramount, but also the overall mealtime experience and eating and drinking enjoyment* (SLT 8).

Nevertheless, this balance was also about understanding risk, described in section 8.2.3, and understanding the nature of dementia. AHPs felt that when family members had limited knowledge of dementia's course and did not recognise its progression, this impacted decisions to balance quality of life and quantity of life.

> *"I don't think families and carers fully understand that quite often each time something happens, there's more of a risk that they're not going to get back to the baseline that they were before because there's a progression of their dementia"* (DT 4).

The AHPs personal views of how they would want to live influenced their perceptions of how others would want to live. It was a perception that doing the 'right' thing was not always right for the person with dementia's quality of life. Additionally, while

AHPs accepted that quality of life means different things to different people, they did not always believe that the families' efforts to keep someone alive were supporting what their loved one would have wanted. Two SLTs described their personal views:

> *I think for me, I wasn't always happy with what I was doing. If you see a very incapacitated person who isn't thinking for themselves and the family are doing everything to maintain this person, to keep them alive, I think I've begun to wonder if that's correct. And that's a tough one. Because obviously, there are a lot of ethical considerations around all that, but I'm not sure it would have been the person's choice if they were thinking to - what they would have thought when they were able to. And I've seen very poor quality of life and maintaining somebody alive for a long period of time by doing all the right things* (SLT 2).

And:

> *We've had families who have absolutely demanded that their relative is tube-fed and that relative has been kept alive for three and four years with what I perceive, personally, as no quality of life. You know, they can't manage their own secretions; they constantly have so many chest infections from oral care issues. Ah, it's just an existence, certainly not something I would want for myself . . . So, it is difficult, isn't it? Because a lot of it becomes quite a personal 'I wouldn't want that for myself', but it's hard to know what people… I think feeding's such a, a highly evocative topic isn't it?* (SLT 4).

The AHPs perceived that better education about the natural course of dementia and planning for the end of life was needed. However, they did not know whose role this was. This links to the subtheme of advance care planning, section 8.2.4, which explores the impact of understanding people's wishes on planning their care.

8.2.3 Risk

Discussions around risk were recurring in the interviews and included mealtime-related risks and broader risk decisions relevant to the person with dementia. OTs and physiotherapists described *"risk enablement"* (OT 1) and *"positive risk-taking"* (PT 3) as standard management. They viewed positive risk-taking as a means of enabling independence, promoting a good quality of life, and as something everyone should be entitled to do. As one OT said, *"just because you have dementia doesn't mean that you shouldn't be allowed to take risks. We all take risks in our daily life"* (OT 1). The OTs and physiotherapists considered themselves less involved in risk decision-making at mealtimes. Their risk enablement remit was related more to mobility and completion of activities of daily living. Eating and drinking-related risk decisions were perceived to be the role of SLTs and dietitians.

From the SLTs' perspective, the risk primarily implied an aspiration or choking risk. Further to this, while dietitians were aware of aspiration, they mainly considered nutrition and hydration risk. In contrast to the OTs and physiotherapists' descriptions of "*positive risk-taking"* and "*risk enablement*", the dietitians and SLTs phrased their discussions around the risks themselves. For example, they described people with dementia as being "*at risk of aspiration*" (SLT 8), malnutrition or dehydration, and did not describe enabling risks but rather assenting to "*agreed* *risk[s]*" (DT 5). The SLTs acknowledged that with dementia progression, the aspiration and choking hazard posed by eating and drinking increased, but they agreed that enteral feeding in the later stages of dementia was generally not appropriate. However, the team faced an ethical dilemma if they could not minimise the risk posed by eating and drinking. Should they support people with dementia to eat and drink with risk? Place people nil by mouth? Or advocate for inappropriate enteral feeding? The SLTs described moving their services towards acceptance of "*oral feeding with accepted risk*" (SLT 2) or *"comfort feeding"* (SLT 6), with one SLT postulating that *"the whole business about risk decision-making is a really thorny one at the minute"* (SLT 1). SLTs viewed their role as assessing the risk, discussing the risk, and managing the risk, as described by these two SLTs:

> *I think our role is a lot to do with sort of facilitating conversations about what's acceptable in terms of risk . . . To be clear that there is ongoing risk, even with not very modified diet and that there's nothing else we can do about that . . . It's about the family accepting risk and accepting and understanding that everything that they take is is difficult . . . part of our role there is to minimise that risk as much as possible, but I think also to be clear in all of our documentation that the risk remains* (SLT 4).

And:

> *I think it's such an important part that the patient has that ability to have the choice. It shouldn't be a, 'you're safe one day, you're not safe one day, you're not safe the next day, you're therefore nil by mouth'. You should still have an option of, 'well, you could try this, here's the likely*

> *outcome', and having that discussion. I think, yeah, absolutely so important. It's our role; we shouldn't be closing the door at the point of someone not being able to swallow. We still have a role in supporting some kind of oral intake* (SLT 8).

However, both dietitians and SLTs recognised that the strategies used to minimise aspiration risk, chiefly modifying food texture and fluid viscosity, could impact individuals' quality of life. They viewed it as essential that the rationale for these approaches was understood by families and by nursing and care staff:

> *[the] same would go for someone with swallowing problems is making sure that they totally understand why we're doing this. We're not doing it to be difficult; we're doing it to keep the person safe, you know, or to make it easier for the person (DT 2).*

Nonetheless, while focused on different types of risk, all AHPs agreed that risk, in whatever form, needed to be managed, i.e., the necessary precautions taken to minimise the risk:

> *So I think one of the things that I learned was about you know quality of life and when you're making the decision about, when you're making a decision about risk and consequences then you need to weigh up the benefits as well as the risks, so actually making that part of your decision-making of actually if it means the world to Mrs Bloggs to get from here to there and it means everything to her, then for her quality of life then that's a risk worth taking sort of thing* (PT 2).

Again, the AHPs personal beliefs appeared to influence their decision-making. What the AHPs considered as an acceptable risk was subjective and unstandardised: *"I say to lots of people there's nothing that I wouldn't give or do for a patient that I wouldn't do on my ninety-three-year-old gran"* (PT 3). The variation in approach to risk was recognised as a challenging decision and one related to an individual's background: *"That's about, you know culture, upbringing, and where you work in your life – my tolerance for risk could be different to your tolerance for risk"* (OT 1). There appeared to be a bias among the AHPs for maximising what they perceived as good quality of life over a cautious approach, but this balance was a challenge:

> *I'm probably I'm, yeah, I'm more risky than others definitely. More risky than my colleagues, probably. It's, it's about what, actually what risk? Is it risk of well-being? Is it risk of nutrition? Is it risk of aspiration? I would see well-being kind of trumps, in many cases. And, I think, as a profession, we have focused on risk of aspiration a bit much* (SLT 9.)

Some linked these issues in separating their own preferences from the person with dementia to advance care planning:

> *You make the comparison to something like MND where, you know, there is that discussion, . . . around what the potential difficulties might be and what the options are at that earlier stage. So, you know if you had that similar discussion happening in dementia, it might make the management of those, of getting that balance right, and being, knowing what, what actually somebody's wishes were and that would be quite useful* (SLT 5).

However, while risk enablement was empowering to people with dementia, there was an acknowledgement by the AHPs that NHS structures were not always on the same page:

> *I think it's because of the culture of the NHS and things like that as well, that you know, people are very scared of complaints coming in and damaging people, if you like. So yeah, risk aversion is huge just now, yeah, definitely* (DT 1).

The AHPs repeatedly emphasised that before risk was enabled, it had to be understood by the family, and if possible, the person with dementia. They considered risk enablement as a team decision and a compromise:

> *As long as the relative and the patient understand the risk, then if they want to do it their way, then it's about trying to facilitate a safer way of doing that. So, there's never any kind of; we're never at loggerheads, we always try and find a way around whatever the issue is* (OT 3).

The AHPs also discussed the need to balance the risk and prioritising risk-enablement based on a team discussion and plan.

> *So yeah, it's having a chat with the medical staff and a chat with dietetics if it's intake issues, and nursing staff and family and just trying to get that, that consensus about what the biggest risk is and yeah, and being aware of yes there's a risk of something happening, but actually, it's, there's other priorities* (SLT 5).

In an effort to balance these risks, some SLTs worked within services that had developed or were developing protocols for feeding with accepted risk. Most SLTs thought protocols were necessary to ensure processes were transparent:

> *"it's quite important to have that kind of a protocol in place, so that if the patient does want to be eating and drinking, or if they are not able to make that decision but the family want them to be, then they should be allowed that* (SLT 7).

They also felt that although protocols could not cover all eventualities and that variation in SLT decision-making would still exist, an agreed procedure could provide a guide for discussion:

> *I would imagine there'll still be some kind of an element of needing to make a clinical decision because obviously, every patient's not kind of x, y or z. There's lot of variations and different situations that might mean that you would advise something else instead . . . But I do think it will be good to have something there on paper, even to use to be able to kind of refer to when you're speaking to family or medical staff. Because at the moment it's a bit more of a 'well normally, in this case, I would say', but then d'ya know if [colleague] went into the ward she might say something a wee bit different to what I would say* (SLT 7).

However, not all SLTs thought protocols were a good idea in the absence of planning discussions with the person with dementia while they had capacity. They felt that a risk protocol could not quantify the impact that the risk had on quality of life and that this would be unique to individuals, *"I mean they want some kind of risk protocol, but you know how do you measure somebody's quality of life?"* (SLT 1).

Still, SLTs also reported facing dilemmas when feeding with accepted risk was causing distress to an individual.

> *I mean, sometimes you get patients; they have horrendous aspiration. It's coughing and choking - very, very distressing for them . . . But no, she was a difficult one because you just think you know 'I really can't recommend anything for comfort'* (SLT 3)

This predicament was a rock and a hard place decision. How could risk and comfort be balanced to enable a good quality of life? This risk decision-making was challenging to the clinicians personally and was an area where they felt there was no right decision:

> *And it's distressing. I almost think it's easier if you're silently aspirating, and then you become unwell. I'd much rather that myself than this really distressing choking and, you know, coughing up everything that's on your plate or in your cup, in a busy dining room where you're acutely distressed* (SLT 4).

The AHPs also acknowledged that it was challenging for nursing and care staff to feel responsible for risk. While risk may be discussed and agreed upon by the MDT and the family, the AHPs recognised that at the end of the day, if a member of the nursing or care staff was providing direct day-to-day support to the person with dementia, this could be stressful and challenging to them.

Another issue faced with risk decision-making related to the 'ownership' of risk decision-making; this linked to the subtheme of 'out of the (MDT) loop' discussed in section 8.1.2. SLTs working within hospitals viewed risk decisions as a team discussion, usually with the consultant making the final decision. They described providing their findings and recommendations but never having the final say, *"I'd see it more as just an MDT discussion and decision with the consultant having the overall decision, does that make sense?"* (SLT 3). Community SLTs, on the other hand, felt responsible for facilitating the risk decision-making process with family and merely keeping the GP up-to-date on the decision.

> *Otherwise, it would be being very clear with the person and their carer - and the GP in a report - what was being advised and that the risk was still not, hadn't been alleviated by these recommendations, but that it had been discussed and that they felt that they were, they wished to go ahead, and continue with oral feeding* (SLT 10).

Some described decision-making in conjunction with GPs; however, this was not always feasible, as noted in section 8.1.2. The decisions around risk repeatedly related back to advance care planning, discussed next.

8.2.4 Advance Care Planning

Advance care planning was a frequent focus of the AHPs' interviews, and it linked closely to the subthemes of 'awareness of roles', described in section 8.1.1, and 'risk'. AHPs considered MDTs in other progressive conditions to engage in advance care planning much sooner than in dementia. They also acknowledged that these conditions had clearer care pathways and closer MDT working; both of which could be beneficial for people with dementia:

> *I think it would be a benefit and I mean you kind of see that in other conditions like MND, Parkinson's, those kind of things, where you know you have that big MDT approach and kind of looking at that bigger view, and, and I suppose you can definitely see the benefit of that for dementia. . . . So, I think the issue is about the capacity of the service to, to do that* (SLT 5).

The previously described issue of people with dementia and their families or carers often not being aware of the disease's course, and therefore not necessarily knowing what they need to plan is one of the issues impacting advance care planning.

The AHPs had two schools of thought on this. On the one hand, the general view of the AHPs was that information about disease progression and functional decline were things that people would not want to know. They felt that providing details of the course of dementia and likely outcomes could be very upsetting to people at that time:

> *So, I think it can be hard when someone's been given such a big diagnosis, certainly in the sort of early phase of either waiting to hear what their diagnosis is or they've just had it, to also hear 'oh and by the way, swallowing might be an issue as well'* (SLT 4).

AHPs frequently linked their view of people not wanting to know more information at diagnosis to their personal perception of what people would like to know, *"people* *don't want to discuss these things"* (SLT 4). It appeared that AHPs were not instigating these conversations regularly. In addition to this, AHPs felt that the differing trajectories of dementia meant that it was, at times, difficult to predict what issues would be faced and therefore challenging to identify what information to share.

> *I don't know if it's a harder trajectory to predict because, of course, you can predict what you'd expect to see within certain dementias, but I think because it's a more variable presentation and course. I think quite often, the swallow doesn't present as a problem; everyone's different, but maybe until further down the line* (SLT 8).

Some of the AHPs had a perception that sharing information on dementia's impact on eating and drinking could be equivalent to scare-mongering and lead to adverse effects:

> *because it could totally scare somebody and actually might have an impact on their overall well-being, their mood, and that's the last thing you want to do. You want to support somebody; you don't want to make them feel worse and make them feel that it is inevitable and that everything's going to happen to them, when swallowing issues might not be the thing that kills them, ultimately* (DT 1).

However, other AHPs acknowledged that this was a balancing act. In 'awareness of roles', section 8.1.1, the AHPs described how they felt referrals were coming too late as awareness work was not at the stage it needed to be. Protecting people in the early stages could lead to problems in the future: *"you don't want to scare the person by* *saying this is going to happen, that's going to happen, but I've found . . . that people come, and they don't really understand how it's going to affect them"* (DT 2).

In contrast to the AHPs view that people do not want to know, one SLT acknowledged that they could not predict who would wish to hear the information: *"not everyone will want to hear that, some will. [It] can be surprising. Sometimes it surprises you who does want to know"* (SLT 2). Another SLT who spoke to carers of people with dementia as a part of a quality improvement project found that there was a desire to have information sooner:

> *But then actually it came out overwhelming that people wanted the information earlier because they felt that if you knew about something, you could cope with it better. And a lot of the carers I spoke to said that they weren't expecting swallowing difficulties, so they were quite surprised and didn't really know what to do when they happened. And they didn't know anything about SLT being associated with swallowing difficulties or helping with that* (SLT 3).

Although just a small number of the AHPs, perhaps this indicates that the AHPs personal views may not reflect what people with dementia and their families would prefer. A different subset of the AHPs thought that information sharing and planning were necessary in the early stages to support advance care planning when people with dementia could make decisions and choices about their care:

> *When you get involved earlier on, it's a bit easier to, I guess, kind of prepare people for what may or may not happen in the future . . . I guess*

> *knowing people's opinions early on before . . . they then can't communicate it themselves* (SLT 7).

AHPs acknowledged that awareness-raising with people with dementia in the early stages required staff and time capacity that they did not have; section 8.3.1 describes this in more detail. However, they did not consider general, untailored information to be appropriate. They found training other healthcare professionals to provide this education and planning without an individualised assessment to be challenging. One dietitian described the process as:

> *very hard then as healthcare professionals to say 'this is the information that you would need when someone is diagnosed' because they're so far down their kinda journey maybe when they are diagnosed . . . I find that's really hard without [an assessment]. It's hard to, to train other healthcare professionals that 'this is what you do at this stage, and this is what you do at that stage* (DT 2).

Universal among the AHPs was the acknowledgement that changes in cognition and capacity to understand risk as the disease progressed meant that in later stages, people's wishes were unknown, and this challenged AHPs to provide care with a lack of context of their preferences. It was evident that advance care planning is in its infancy but has potential, *"I wouldn't say advance care planning is where it should be now, but you can imagine it in the future"* (SLT 6). An additional challenge to advance care planning is that, in reality, AHPs felt it was unclear who should be carrying out this planning with the people with dementia:

> *I think anticipatory care planning is definitely the way to go. Again, who does that? It is a bit of a can of worms, but definitely . . . It would be really useful to know what that patient would have wanted, rather than try to guess and do what you think's in their best interest. Actually, they've always said, 'you know this is what I want'. And it would be better for family as well, and power of attorney, it would be much better for them to have an idea what that patient wanted. (OT 3)*

Overall, AHPs felt that with government policy and charity body agendas, advance care planning was becoming more widely known and considered. However, the planning tended to be limited to power of attorney decisions and planning the extent and escalation of care, such as do not resuscitate orders. The AHP did not feel that it was near a stage where it would be appropriate to plan food and fluid-related decisions. They were not sure that these decisions would be tenable in the later stages when the actualities of dysphagia and mealtime difficulties were present. Some AHPs felt that people could not envision what dysphagia would be like:

> *But I think until you're in that situation it's difficult isn't it, because I don't think you really… Swallowing is something that we've done, you know, since we've been a baby. To suddenly not be able to . . . I think that's just such a difficult thing to, to understand and to get your head around* (SLT 4).

While interventions such as modifying diet texture and fluid viscosity were unpleasant in theory, they could be preferable to experiences of choking:

> *and I think that actually you can't, necessarily anticipate what you will feel you know in the later stages and, you know, somebody, you know a lot of people are horrified at the idea of thickener, but when it comes to it, when they're actually struggling to swallow thin fluids, it can be a relief. So, in those respects, it can be really difficult to, to plan ahead* (SLT 1).

The AHPs felt that it may not always be appropriate to follow advance care plans to the letter if it became apparent in the later course of the disease that these decisions negatively impacted health and well-being.

The subtheme of advance care planning also examined the AHPs' views of support for people with dementia at the end of life. Many AHPs felt that people with dementia were not supported to make decisions about their death in a timely manner. They also felt that death was not being discussed openly with family members:

> *And, you know, when somebody's dying, and I've come across this quite a lot, that even GPs and Care Homes can be very reluctant to actually address that and acknowledge that somebody might be dying and have you decide. And, you know, it isn't our role to make that decision [if they can eat or drink]* (SLT 1).

AHPs also reported finding themselves in situations where a person with dementia was at the end of life, but the family member or carer was not aware of this. AHPs had experience recognising the signs of approaching end of life and the process of dying: *"And I think to us, it's quite obvious. Like you can look at a person and think 'they're* *dying', but for the family, it's not"* (SLT 3). They found that family members were not aware that food refusal could be an indicator of the end of life approaching and that this caused great upset with family members not wishing to 'starve' their loved one to death, linking back to section 8.2.2. AHPs did not consider it their remit to inform families about end of life, but this put them in challenging positions. An SLT described feeling very distressed by an event where a GP had not identified that this was an end of life situation before they made a house visit:

> *And the man, her husband, was in bed, dying. I mean, on his last day, I think he died the next day, and we weren't given any information . . . And, you know, we were not prepared for that. He was dying . . . it was a really difficult position to be in because the doctor had put us in that situation with the... Clearly, the wife was not prepared for her husband's imminent demise, which happened, I think, the next day* (SLT 4).

The AHPs felt that the absence of education and preparation for the course of dementia and the end of life caused unnecessary stresses to family members and AHPs.

8.3 The Realities

Finally, the subthemes of 'the realities' describe the strain that limited resource places on the AHPs' abilities to do their jobs. The 'realities' of their constrained working are mainly encapsulated in the theme 'over-stretched resources' but are also reflected in the AHPs' need to 'workaround' the resource issues they face. The subtheme 'workarounds' also discusses the sometimes unorthodox nature of practice when supporting people with dementia in order to account for their unique needs. The final subtheme, ‘culture change’, explores the AHPs’ views of the need to change practice and change the culture of settings where people with dementia are seen.

8.3.1 Over-stretched Resources

This theme reflects the undercurrents that ran through all 21 interviews: The service offered would be improved if there was a greater resource. The AHPs, as self-identified dementia specialists, viewed themselves as at the cusp of a new revolution in management. This revolution would see individualised care for people with dementia, from staff and services who understood dementia and its impacts, that would enable people with dementia to live dignified lives, with comfort and quality of life at the forefront. The reason this is not already happening was clearly linked to a lack of resources.

One of the primary resources identified as over-stretched was staffing. As well as the previously discussed feelings of segregations, isolation, and a general ‘out of the loop’ state within the MDT, there were issues of limited staffing and the impact on care. The symbiotic, almost cyclical, nature of the MDT was clear in this example by a physiotherapist: *“because, you know, definitely diet and getting up enough energy for lots of our patients is sort of key as well. But again, there's not enough of them [dietitians] to be around to do that”* (PT 2). The limited dietetic team meant limited input for the people seen, meaning physiotherapy goals were more challenging to reach in light of limited nutritional gains. This was something that both parties in the example felt:

> *But trying to deliver what you would want in terms of quality for the individuals because of resource issues or whatever is not, it’s not the, you*

> *know, what you would want to deliver . . . Sometimes you feel that you're falling short of delivering what you'd want to deliver.* (DT 2)

Comments like this were recurring. AHPs felt that the service they would like to offer was not the service they could offer, considering limited resource.

> *I often think there probably is a whole load more that you could do, but you're just not able to because of time, constraints of, you know, how many patients you can see in a day, what you can do in your day, and then you go back the next day to see the patient and you realise they've gone to the nursing home already, and then you're kind of passing them onto somebody else and you feel like you haven't actually sort of finished what you wanted to do with them* (SLT 7).

This feeling of not being able to offer what was necessary was disheartening to the participants. There was a sense from the participants that they were overwhelmed. Words like *"firefighting"* and *"tsunami"* were relatively common and often used to describe how their service was coping with referrals and the impact that this had on other services offered, particularly training, for example:

> *because we've got the tsunami of referrals, we're just firefighting, basically. So, we're trying to get through all these patients. And probably the staff training that we should provide as a regular basis, it is gone by the wayside* (DT 3).

As described in section 8.1.1 awareness of roles, there were cases where the AHPs viewed it as appropriate to offer advice on behalf of other AHP colleagues. This was not seen as an issue where AHPs were not operating beyond the scope of their own knowledge and practice. However, due to limited staffing and limited resources, some AHPs felt that they did not have the capacity to maintain hard lines on the scope of their role: *"There's a lot more OTs than there is dietitians so we kinda, can't be too precious… We can't be too precious about it really, we can't."* (DT 1). This almost defeated attitude to care capacity could have wider implications for people with dementia if standards of particular roles are not maintained due to lack of resource.

AHPs acknowledged that it was not just their professions who were under pressure; they also identified that nursing and care staff were susceptible to resource over-stretching. Nevertheless, the AHPs believed that nursing and care staff had roles in providing first-line management of certain issues. For example, dietitians considered food-first nutritional care to be within this remit, *"it's actually a basic nursing care to provide nutrition and hydration for patients"* (DT 3). Additionally, SLTs thought that these staff should have basic feeding skills and the ability to recognise and modify basic feeding and drinking issues through behavioural and compensatory strategies. However, the SLTs in the interviews shared the view from the survey that staff should only recommend thickener or food modification as an interim measure until SLT assessment. When first-line strategies were not known or implemented by nursing and care staff, AHPs felt that this added unnecessarily to their workload.

> *How we can reduce a tsunami of dietetic referrals? Making sure, improving nutritional care at ward level, empowering nursing staff to take on a very basic role so that dietitians are definitely being a*

> *consultant on the ward and dealing with the most complex dietetic and nutritional problems. As opposed to just turning up on the ward and saying: 'can that person drink some more full-cream milk and can you order them some snacks?', which should be done already* (DT 3).

Yet, despite the recognition of resource issues, there was a sense of frustration from several AHPs towards nursing and care staff colleagues who they believed were not always providing this first-line management adequately: "*I think these things should be thought about and attempted to be rectified or supported before they get referred to us"* (DT 4). This was almost seen as care and nursing staff not working to the full remit of their role. What was under-acknowledged was, who is responsible for educating nursing and care staff about these first-line strategies? The pressure to complete multiple tasks with limited staff and the impact that this had on mealtimes was acknowledged:

> *because I think, with the best will in the world, for many carers, not all, it just becomes another task, routine, task, system, part of their day. Get it out of the way quickly, tidy up, move onto the next thing* (SLT 4).

These discussions around the need for nursing and care staff to provide more first-line interventions at the mealtime came from a place of AHPs viewing themselves as over-stretched and feeling that this was an element of the role that care and nursing staff were neglecting. What was interesting was how this linked to comments about training. As with the SLT survey results, several of the AHPs, as above, reported a lack of time to provide training. They also identified other barriers to training such as getting staff released, *"ultimately it's staff time and trying to get staff released for* *training . . . trying to get staff released to be able to do that training is difficult"* (DT 1). Furthermore, the AHPs had similar hopes to the survey respondents. They hoped that training would have an impact on the quality of care and quality of referrals:

> *I hope it would reduce the routine ones, or they maybe come to us at a point of 'we've tried to self-manage, we have self-managed, but we're now at a point of we're a bit stuck'. So yeah, it would be, we'd get them later on in the journey or the more complex stage* (SLT 8).

However, they noted that training was not a requirement for staff and that they felt that care staff did not get enough:

> *I think they get informal. I think it has been a bugbear for years amongst all of us that they don't get enough. You know, they don't get from us, statutory wise. You know they're not; they don't have to get from us, which I think they should (SLT 9).*

They also noted that these changes in practice were difficult to sustain: *"[training] worked brilliantly, absolutely fantastically, made changes, did really, really well with it. Sustaining it? For us was very difficult. So, it's all that change of staff and things like that"* (SLT 9). And:

> *We've done a lot of live training, and they like live training, but we know from experience that it doesn't have a lasting impact . . . we felt that initially, the referrals we were getting were more appropriate, but within three or four months, it had all gone back to normal. Even though staff turnover isn't high* (SLT 1).

It was evident from the interviews that AHPs saw a benefit in providing training and that this training was in their remit. However, training was not central enough to the role to sustain when their capacity was stretched thin, and these views reflected a limited sense of ownership of training from the AHPs. For example, the comment by DT 3 above about training *"gone by the wayside"* and an SLT's comment that *"they were asking for training and we didn't because we were firefighting everything"* (SLT 2) demonstrate that training was not a non-negotiable part of their role. There was almost a sense that if not provided by AHPs, nursing and care staff would still be aware of AHP roles and first-line strategies, without any rational considerations of who would provide this information. There was a perception that some of these strategies were just *"common sense":*

> *There's all these things that you can do first that are, you don't need a degree in, you don't need training in, it's really kind of common sense and it's getting them to think about that first of all* (DT 3).

> *But I think that's just human common sense, isn't it? It's not really any kind of... anything that anybody else wouldn't do if you know what I mean? But it surprises me how little people notice things like that, that's really important. Meals are really important (PT 2).*

In addition to their own over-stretched resource, AHPs described limitations to the services offered and unclear pathways for people with dementia moving between services. As described in section 8.1.2, the individual AHPs to refer to were difficult to track down, described as a *"grey area"* (OT 2), and it was also challenging to identify an appropriate service. AHPs described services with restrictive criteria, *“there's a lot of different community teams, and they have a lot of different criteria, and unfortunately, people over 65 don’t really fit into anybody's criteria”* (SLT 10), and the non-existence of services, *“[colleagues based in acute hospitals think] in community there will be this huge army of AHPs waiting to deal with it all. That's not happening”* (SLT 2). It was evident that the services for people with dementia across these various Scottish boards were not meeting the need.

8.3.2 Workarounds

In the subtheme of workarounds, the AHPs describe the adaptability and solution-focused approach they take to manage the challenges of supporting the unique demands of people with dementia in constrained environments.

The first challenge described is how AHPs adapt their interventions in response to the cognitive changes inherent to dementia. Directly engaging the person with dementia is difficult due to changes in attention and reasoning. As one PT described, *“some individuals just won’t engage, so you have to try and work it as best you can with what you've got”* (PT 3). They thereby needed to utilise a more adaptive approach with more extensive environmental supports. The AHPs reported engaging more frequently with family and carers when supporting people with dementia than those without the condition. They ‘workaround’ the cognitive deficits by reducing the cognitive load required, and on occasion, using the cognitive deficits as a support to the desired action. For example, *“for me, sometimes you can use some deficits to your advantage, so if somebody's got motor perseveration, where they would keep doing the movement, then you can use that quite effectively when it’s eating soup or pudding.”* (OT 2). Notably, AHPs described their practice in dementia as non-standard. They felt that the steps they took to mitigate the challenges of dementia did not always look like standard care, which could be viewed negatively by others if the rationale for it was not understood. For example, DT 2 described adding sugar or sweetener to savoury food to encourage greater food intake. They reported that this strategy was viewed negatively by some care staff due to concerns about the impact on blood sugar levels if sugar was used, or of potential cancer risks if sweeteners are used. Nevertheless, despite adverse reactions, the AHPs' view was that an imperfect strategy was better than a perfect one if a necessary action was facilitated: *"We sometimes have a concept of what's perfect; the perfect way to do something. And as time has gone on, you start to think, well, it may not look perfect, but it's safe, and it's, it's repeated"* (PT 1).

The AHPs went on to describe the constraints of the systems they worked within. AHPs working in acute settings felt that *"from an acute point of view, we're quite restrain, restricted in what we can do"* (OT 3). They believed that acute hospital environments prevented them from making positive changes at the mealtime, such as reducing distractions and promoting social aspects of the meal: *"Yeah, I think there's definitely things that could be changed . . . it's hard isn't it, because you could suggest all these things that would help and everything, but then actually in an acute hospital how realistic is it?" (SLT 3).* AHPs considered encouraging family members to be present for meals as another means to improve the mealtime experience. The presence of family members was seen to have two benefits, freeing up staff and making the person with dementia more comfortable. However, one of the barriers to this was the culture of closed mealtimes within hospitals. The AHPs considered these to be counter-intuitive, *"For the nurses as well, to have a family member, a carer who's familiar with the person, who's going to keep them calm. If they're willing to come in at mealtimes, why aren't you letting them?"* (SLT 10). AHPs who worked in settings with open visiting where family members could attend mealtimes found this system to have several positive benefits:

> *the opportunities for carers and family members to come in and be part of that mealtime, so they actually feel that they're part of their, you know their family member's or friend's care, that's really important . . . They'll encourage family members to bring things in for their families that that they'll know that they'll enjoy to try encourage them to eat if they're struggling with eating. So yeah, I think all of those components are quite good* (PT 3).

AHPs in acute or ward settings believed that the mealtime environment was more adaptable in care home settings, saying things such as *"it may not always happen in a ward but maybe in a care home that could happen"* (DT 4). However, AHPs in care home settings also felt constrained by the environment they worked within and its regulations. As one SLT working with care homes to change mealtime environments noted, *"absolutely we'd look at it. In terms of modifying it, it's probably a wee bit harder . . . I do think it's our role, but it can be quite difficult I think to really make changes there"* (SLT 8). AHPs noted that mealtime accommodations such as providing favourite foods or different flavours were challenging due to food hygiene recommendations and the policies within certain settings. One AHP described the workaround to this as ignoring it in favour of what they described as common sense:

> *Obviously, we've got more and more rules and regulations now for bringing food in, and it has to be, you know, we're not really supposed to be bringing food in, but I think when it comes to the difference between somebody eating and not eating then common sense has to prevail as long as it's been stored safely, and we know when it's been purchased and all* (OT 2).

The AHPs also felt the need to work around the MDT struggles described in more detail in section 8.1.2. They indicated that they needed to be adaptable to cover each other's roles at the mealtime: *"I think we have to fill the gaps in whatever situation we're in . . .you know at the moment we see a need and we meet the need" (SLT 1).*

8.3.3 Culture Change

The participants described the need for a change in culture in mealtime management in several ways. One area in need of change was feeding practices within services. Several AHPs described witnessing unsafe practices: *"We do see terrible feeding practice, and that's, you know, feeding two people at once. Or starting to feed somebody who's completely dependent and then saying, putting it down and saying, 'I'm off for my break'"* (SLT 4). They also described how viewing the mealtimes as a task to get through impacts the quality of the mealtime:

> *And if we're task-driven, we've got fifteen feeders, as they call them, we've only got an hour to do this task. Are we going to sit and try and observe and read their body language? No, they're not. So, you've got the time constraints of the system and how that's managed to deal with.* (DT 5)

The AHPs felt a need to emphasise the mealtime as an experience: *"I think there's a lot more work that we need to do on that and kind of highlight that awareness of the mealtime experience, it's not just what's on the plate"* (SLT 8). The AHPs described the need to change the culture at mealtimes by empowering their nursing and care colleagues to apply the knowledge and skills they had:

> *we need to take forward with our colleagues to say: have you thought about this? Have you looked at that? Are you confident in making, having those conversations with the team and saying, 'we can all have a part in this?' This isn't just a dietitian. I am not going to solve this; however, we could all do something'* (DT 3).

AHPs felt that many systems in their current form disempowered care and nursing staff from using their initiative and that these systems lacked trust in their abilities. For example, one dietitian described a culture of mistrust within a care home that precluded its staff from providing food and drink outside of mealtimes by a management system that did not trust the staff not to steal the food. These systems negatively impact the unique needs of residents with dementia through *"practices within the care homes that can limit or restrict getting the right food at the right time for the right person"* (DT 5). The same dietitian described an *"endemic culture of the care home; 'this is the way we've always done it why do we need this change – this is going to upset too many people'"* (DT 5) that made culture change within care home settings a particular challenge.

AHPs described the need to approach a change of culture carefully:

> *I think it's really important to keep it really positive. A lot of the time because if we're, if we're negative and berating it never, it doesn't come across and people just, it gets people's backs up, and you're not actually going to get the solution. So, it's much more about trying to, trying to look at changing culture* (PT 1).

Although there was a sense of frustration at the pace of change and how difficult it could be to make changes: *"that can be frustrating because even though they've got the knowledge, it doesn't seem to change the practice on the ward . . . how do you get that good practice, just agreeing to become an everyday practice?"* (DT 2). The AHPs felt that they could model and implement change with a regular physical presence in a ward or service. The need for a consistent presence was frustrating to SLTs and dietitians whose capacity prevented them from doing this:

> *I think it, it possibly [would] be easier if I was in the same place all the time. But, because I'm so many different places, you find yourself going in, modelling, spending time with carers or relatives, you know, and it's like little, tiny projects each time you go out to see someone, rather than maybe a whole 'I'm going to focus on this ward or this care home'* (SLT 4).

Whereas the OTs and physios noted that because they could be a regular visible presence, in combination with training, that there was a culture change in implementing strategies and supports:

> *Quite a lot of the nursing staff have been here a long time, and so they do things automatically that maybe, in an acute medical ward, wouldn't be getting done. So, because they've had previous training sessions or previous individual sort of sessions with somebody saying this is what's happened or this will be good, they've kind of remembered that and use it in their everyday practice* (OT 2).

The need to change the culture of dementia care at mealtimes from AHPs links to a need for awareness-raising, training and education, and empowering the people involved in care to use this awareness and knowledge.

8.4 The Interrelationships between Subthemes

It is clear from the summation of the results that there are linkages and overlaps between the themes and subthemes presented in this chapter. Figure 8.2 presents this visually. Though it is a subtheme and not an overarching theme, 'it's not one size fits all' is centred in the diagram and enclosed in an orange and blue line to represent its centrality to AHPs' approaches to supporting people with dementia. The pervasive impact of 'over-stretched resources' is also recognised by encircling the subtheme in the three colours. The diagram also demonstrates the links between the individual subthemes. The diagram demonstrates the links between the respondents' feelings of being 'out of the (MDT) loop', needing to use 'workarounds' in their practice', and the impact of poor MDT relationships on 'advance care planning' and 'risk' decision-making. This is also linked to 'over-stretched resources' as the AHPs felt that their separation and segregation from MDTs often came down to a lack of time and resource. To reflect these connections, 'out of the (MDT) loop has been resized and

Figure 8.2. The interrelationship between subthemes

enclosed in a green and orange circle to represent its impact on other subthemes. ‘Advance care planning’ also has links to ‘awareness of roles’, as the AHPs believed that without an understanding of the impacts of dementia and the AHPs’ roles in managing them, planning for the later stages and advancement of dementia was a challenge. The subtheme ‘risk’ links with ‘culture change’ as the AHPs perceived the promotion of positive risk-taking and risk enablement as new to the healthcare culture and, therefore, they perceived a need to educate and change the culture of risk avoidance and paternalising people with dementia.

8.5 Summary

This chapter has described the three main themes and subthemes generated from interviews with AHPs specialising in dementia. Although each subtheme represents unique views from the interviews, there are also multiple connections within and across the subthemes. The inter-connections, shown in Figure 8.2, visually demonstrate the complexities faced by the AHPs providing services to people with dementia, specifically focusing on mealtimes and swallowing difficulties. These results illustrate that a lack of awareness of AHPs and their roles frequently complicates the management of these difficulties. The AHPs feel restricted in their roles and limited in the changes they can create in the services they support. These findings demonstrate that better links between all MDT members, carers and families, and the services accessed across the course of the disease are essential. The next chapter will discuss these findings in greater detail.

9 PHASE 2 – THE INTERVIEW STUDY: DISCUSSION

This chapter discusses the results of the second phase of this study which examined a range of allied health professionals' perspectives on the mealtime needs of people with dementia and how they managed these mealtime difficulties. The results of these interviews outline the current reality of mealtime management for a sample of Scottish AHPs with a specialist interest in dementia care. They uncovered some of the challenges and barriers that AHPs face when supporting the diverse and challenging needs of people with dementia in a Scottish healthcare context. This chapter discusses the three themes and their subthemes generated from the interviews and relates them to the literature and three of the mealtime models introduced in Chapter 2.

This phase of the study aimed to (i) establish AHPs' perspectives on their roles in managing mealtimes of people with dementia and (ii) understand the issues they face when supporting people with dementia and mealtime difficulties. The theme of 'professional roles' and its subthemes provide insight into the AHPs' perspectives on their roles. It also contributes to our understanding of these roles and that perceptions are not clear cut. The challenges the AHPs faced in having their roles recognised and understood are discussed in section 9.1.1. Perceptions of roles are also influenced by issues such as workplace dynamics, team organisation, and available resources as illustrated in ‘out of the (MDT) loop’ and ‘over-stretched resources’ discussed in section 9.1.2 and 9.3.1. The themes of ‘decision making is individual’ and ‘the realities’ primarily relate to the second aim of the study and reflect the challenges faced by AHPs in their goals to provide person-centred and quality care to people with dementia with mealtime and swallowing difficulties. Sections 9.2 and 9.3 explore these issues in greater detail.

The current results are also related to three mealtime models (initially described in section 2.2.1) in section 9.4. These models are the ‘Making the most of mealtimes (M3) conceptual model’ (Keller et al., 2014), the ‘Social ecological model of factors that influence eating performance’ (Liu et al., 2016), and the ‘Model for the provision of good nutritional care in dementia’ (J. L. Murphy et al., 2017). The following sections discuss the themes, relates them to relevant literature, and outline future directions for research. The discussion is presented in the same order as the results chapter, beginning with ‘professional roles’.

9.1 Professional Roles

The theme of “professional roles” and its sub-themes raised serious questions about how healthcare systems integrate AHPs and other health professionals and how they understand each other’s roles. This theme also considered the current state of public awareness of AHP roles, and this awareness was perceived to impact how people with dementia and their carers accessed services. These issues are significant for two reasons. In the first instance, the systems and wider teams that AHPs operate within need to understand AHP roles in order to generate referrals and to offer appropriate care to people with dementia. Furthermore, people with dementia need systems and mechanisms that support their transitions between services, and the various healthcare teams they interact with need knowledge of AHPs to achieve this.

Secondly, for AHPs to provide a useful, meaningful service, it is essential that the public, particularly people with dementia and their carers, are aware of their existence. Undoubtedly, it is limitations at the macro-level of policy, funding and regulation that significantly impact these two areas. This section will begin by discussing the impact of limited awareness of AHP roles on mealtime issues and will then look at the effect of being ‘out of the (MDT) loop’ and the role of teamwork in dementia care.

9.1.1 The Impact of Limited Awareness of Allied Health Professionals’ Roles

The first subtheme of ‘awareness of roles’ described the public and professional awareness of AHP roles in the context of the Scottish healthcare system. This section begins by discussing the AHPs’ understanding and awareness of each other’s roles when managing mealtime difficulties before considering the impact of limited awareness among families of people with dementia and other healthcare colleagues on the delivery of care. It also considers what structural supports could increase awareness of AHP roles and improve access to their services.

9.1.1.1 AHPs’ Understanding of Each Other’s Roles

Awareness of colleagues' professional roles is a core clinical competency (MacDonald et al., 2010), and the participants described their perceptions of each other’s roles and their views on areas of overlap between these roles. For the most part, the AHPs’ views of each other’s mealtime roles in dementia mirror what is suggested as their roles with other caseloads. The SLT’s role is dysphagia identification and planning interventions to minimise risk; the dietitian is involved in maintaining appropriate nutrition and hydration; physiotherapists support gross motor function and monitor individuals’ chest status; and the OT maximises fine motor function, adapts to sensory needs, and provides equipment (Hamilton et al., 2012; Harding & Wright, 2010). The AHPs considered these same tasks to encompass the scope of their own roles and had consistent views on what they and their AHP colleagues could offer. The AHPs also highlighted that their roles at mealtimes were interdependent, and breakdown in any process could impact the other AHPs and other MDT members' activities and efforts. For example, people with low energy intake will find it more challenging to engage in rehab tasks to rebuild muscle tone and mobility. This will impact their ability to engage with activities of daily living which include eating and drinking, thereby impacting the amount of food and drink consumed. In turn, this will affect energy levels which will impact their ability to engage in rehab tasks. Furthermore, interviewees indicated that time and capacity significantly impacted their ability to provide services to address these issues.

The AHPs interviewed considered role overlap to be necessary and preferred to work as part of an MDT. These findings align with those of Borbasi et al. (2006), who found that health professionals supporting people with dementia in acute hospitals advocated strongly for MDT-working in providing the best care for people with dementia. Their study included medics and AHPs but primarily focused on nurses' perspectives. They found that although their participants considered overlap in roles as usual practice, each team member would bring their perspective (Borbasi et al., 2006). This view is similar to how OT 1 described "*MDT hat*[s]". The SLTs and dietitians' views that their roles were symbiotic to a degree are also reflective of Heiss, Goldberg, and Dzarnoski's (2010) findings that dysphagia management requires a partnership between speech and language therapy and dietetics. However, despite the overlap in their roles, it was vital to the AHPs that their colleagues understood their roles and what other team members can offer to the team. This view is supported by research that found that clinical goal achievement is supported when this knowledge is in place (Cutler, Morecroft, Carey, & Kennedy, 2019). Unfortunately, specialist positions appear to be very rare for AHPs with a particular interest in dementia.

Despite the relative consensus, there appears to be some discrepancy in how AHPs viewed the scope of their roles compared to how their colleagues viewed them. Some AHPs, such as physiotherapists, felt that the other AHPs' understanding of their role was somewhat limited and coloured by traditional expectations. However, they acknowledged that, for the most part, the view was accurate. The SLTs also felt that their role was pigeonholed. They considered their role to be more than dysphagia management and their mealtime involvement to be holistic. In contrast, the other AHPs effectively viewed SLTs as prescribers of thickening agents. This view is not entirely surprising given that SLT questionnaire data revealed that food and fluid modifications are indeed the primary means of addressing dementia-related dysphagia and mealtime difficulties. Moloney & Walshe's (2019) survey of SLTs’ management of quality of life for people with dysphagia after diagnosis also found that their respondents were unhappy that MDT colleagues considered speech and language therapy as a profession focused on minimising aspiration risk. The implication of this view is that the SLTs may not be able to work at the full extent of their role to the detriment of people with dementia who would benefit from support with communication at mealtimes.

The SLTs’ desire for a greater focus on communication in dementia was similar to findings from another study of SLT perspectives (Hopper et al., 2007). Hopper and colleagues’ respondents also felt that medical colleagues view the SLT’s roles as dysphagia focused and an over-focus on dysphagia in dementia inhibited their ability to address communication issues. The SLTs’ wish for more involvement in communication management is particularly interesting given that in the phase one results, just under 35% of respondents reported evaluating communication while assessing people with dementia referred for dysphagia and mealtime difficulties. This finding may indicate that while SLTs appreciate the importance of communication to successful mealtimes, they continue to consider dysphagia and communication as separate entities in their assessment approach. Evidence from an unpublished doctoral thesis suggests that SLTs managing feeding challenges in dementia should consider feeding and communication assessment and management as a continuum, not opposing areas of focus (Henton, 2003). For instance, Henton (2003) described supporting communication between care staff and people with dementia during mealtime tasks as a feeding partnership and noted that this communication dyad requires specific focus. As such, it can be argued that SLTs should be assessing communication as standard practice when people with dementia are referred with suspected mealtime difficulties.

Though broadly speaking, understanding of roles was clear, the limits to understanding AHP roles in managing mealtime difficulties and constraints to accessing their colleagues, discussed in section 8.1.2, may reflect the lack of resources and the limited information offered by professional bodies. AHPs in Scotland are regulated at a UK-level by the Health and Care Professions Council (HCPC), which set standards of practice, ensure education standards are met and hold a register of professionals. They do not, however, provide guidance on roles and responsibilities for specific conditions or settings. Professional bodies usually promote AHP roles in this way. For the AHPs in this study, the professional bodies are the RCSLT, the British Dietetic Association (BDA), the Royal College of Occupational Therapists (RCOT), and the Chartered Society of Physiotherapy (CSP). None of these professional bodies provide explicit guidelines for their profession's roles in managing mealtimes. Though the RCSLT mention the impact of cognitive changes on eating in their dementia resource and commissioning manual, they do not elaborate on the extent of the SLTs' role in their management (RCSLT, 2013). Furthermore, the SLTs who responded to the questionnaire referred to the OT's role in providing specialised or adaptive equipment. However, some of the SLT participants indicated that they were fulfilling this role, which raises questions about role ownership. Professional bodies need to develop the necessary clarification and guidance to support AHPs to work to the full extent of their roles.

9.1.1.2 The Impact of Limited Public Awareness on Referrals

The current study provides previously unheard insights into the issues caused by limited public awareness. The AHPs believed that limited awareness of their roles led to issues in how carers of people with dementia understood the individual's changing needs and accessed appropriate services. The AHPs identified that many carers and families of people with dementia did not recognise that dementia is more than a memory issue. This view is concordant with the literature, which highlights that the full impacts of dementia are not always understood and that dementia is not always recognised as a palliative condition (Poole et al., 2018; Van Der Steen, Van Soest-Poortvliet, et al., 2014). It is disappointing that in the ten years since a UK study found that people with dementia and their families lacked information about the condition and this impacted on care (Thuné-Boyle et al., 2010), that the AHPs in the current study continue to describe carers with similar information needs and a limited understanding of dementia. This also links to the survey findings discussed in section 6.8 that family carers had limited understanding of mealtime issues and their consequences. As section 1.2 addressed the consequences and adverse outcomes for people with dementia with mealtime and swallowing needs and section 6.3 discussed issues around screening for cases and capturing SLT referrals, it is evident that these gaps extend beyond speech and language therapy and encompass other AHP groups.

There is a need to quantify the number of people with dementia who are not known to AHP services, despite the potential for benefit. Unfortunately, there is no data available on AHP referrals to evaluate the impact of the lack of awareness of AHP roles on referrals. As the majority of AHPs work within the public system, this information would likely come from NHS data capture. Although the Scottish NHS is a relatively unified system in comparison to that of the NHS in England, which operates as multiple, separate bodies (Asthana, Jones, & Sheaff, 2019; Leighton et al., 2019), it still faces challenges in monitoring referrals, contacts, and other management activities. The primary challenge is coordinating data capture across the country due to variation in data systems and a slow-moving transition to electronic documentation across services and boards (Honeyman, Dunn, & McKenna, 2016). As such, it is difficult to encapsulate the scale of the issues and where gaps in service and pockets of good practice exist. A data capture system that collates information on service delivery could enable review and reform of services to improve access to and support people with dementia. In Scotland, recognition of the need for improved awareness of the AHP roles in dementia care is evident from Alzheimer Scotland initiatives to increase awareness of their roles among people with dementia and their carers. As part of their *Connecting People, Connecting Support* awareness-raising campaign, they provided a light-touch introduction to AHPs and the services they can offer and do not detail the support available for specific issues such as mealtime difficulties. This initiative is a step in the right direction though it is too early to tell its impact on services. From the current results, we can see that the AHPs believe that lack of awareness of their services impacts their service delivery. Future research is needed to modernise how AHP care is accessed and understood.

9.1.1.3 The Multidisciplinary Team's Awareness of Allied Health Professionals' Roles in Managing Mealtime Difficulties

This study identified that the limited awareness of AHP roles was a pervasive issue that extended to other MDT colleagues. It was evident from the interviews that all the AHPs felt that other health professionals, such as medical and nursing colleagues, had a limited understanding of the different AHP roles and the value they could add to an MDT. The consequences they perceived as a result of the limited awareness of their roles impacted the frequency and nature of the referrals that they received, leading to delays and impediments to people with dementia accessing services. The AHPs believed that referrals for people with dementia were coming "*too late*" in the disease process, at a point where their intervention and management options were more limited. This issue reflects the challenges identified in section 6.3, where the SLTs who completed the survey noted that the absence of standardised referral and screening procedures had implications for accessing services. It was also interesting to note the similarities between the interview participants perceptions of an engaged GP being the "*luck of the draw*" with the survey's findings that communication with GPs is "*often all one way*". This similarity is noteworthy as the survey respondents consisted only of SLTs, while the interview participants were a mix of AHPs, thereby indicating that this issue is a pervasive one. These findings may reflect GP resource issues as well as GPs' awareness of AHP roles. For people with dementia living in home-like settings, the GP is often the primary contact, though their contribution as case manager is often an informal and perhaps unwanted role. A case management approach has the potential to streamline access to support services for people with dementia; in its absence, people with dementia are at risk of not receiving the services they need. Having a case manager to coordinate care has benefits to the person with dementia, such as delaying moves to care homes and improved quality of life (Koch et al., 2012). However, such an approach will have limited benefit to managing mealtime difficulties if the wider MDT does not understand AHPs' roles in their management.

A dementia disease register, like that used for motor neurone disease (MND) in Scotland, could allow improved access to coordinated care and circumvent the limited awareness of AHP roles among people with dementia and their carers. These registers are active data files that contain the details of all cases of a disease (Krysinska et al., 2017). The MND register in Scotland combined with an electronic record system, the Clinical Audit Research and Evaluation of MND (CARE-MND) platform, has yielded unparalleled opportunities for unified care, access to services and professionals, access to research, and monitoring of care across Scotland (Leighton et al., 2019). The data generated has benefitted AHPs by enabling them to streamline their processes, for example, by identifying the need to develop a guide to thresholds for augmentative and alternative communication delivery. This registry has enabled MND advocacy groups to advocate for specialist AHP positions. The coordinated care system for MND also enables these specialist AHPs or specialist nurses to act as a case manager for individuals with MND and direct them to relevant services and professionals (Leighton et al., 2019). Unfortunately, such a platform does not exist for people with dementia in Scotland, but the Scottish Dementia Research Interest Register is taking steps towards data integration (Russ et al., 2015).

Although there is no disease register for dementia in Scotland, the dementia link worker programme aims to provide post-diagnostic support to people with dementia and coordinate their care needs due to dementia-related changes (Scottish Government, 2017a). However, not all people with dementia are diagnosed in the early stages of the disease and gaps in access to link workers exist (Ryan & Nolan, 2019). A recent report reveals that over 50% of people newly diagnosed with dementia in 2017 and 2018 were not referred to the link worker programmes (NHS Information Services Division, 2020). The gaps in carers’ understanding of dementia highlighted in section 9.1.1.2 are likely compounded by people with dementia being restricted from accessing these post-diagnostic services. Furthermore, even when these services were accessed, the AHPs interviewed had concerns about link workers’ abilities to identify and direct people with dementia and their carers to appropriate supports. The previously described health systems’ limitations gaps in data collection hinder the care of people with dementia further down the chain. Moreover, the lack of clarity about the skills and knowledge of case managers such as link workers also creates barriers to care. The current findings are highly valuable in highlighting the on-the-ground issues faced by the AHPs and their views on their roles and scope. The next section further discusses the impact of breakdowns in MDT working on AHP management.

9.1.2 The Implications of being ‘Out of the (MDT) Loop’ on AHPs in Dementia Healthcare

This subtheme focused on the AHPs’ perspectives of working in MDTs when supporting people with dementia and the value they placed on those connections. Interprofessional working is a core element of healthcare in the UK and is a strategy that elicits greater results than any individuals in the team could provide (Wei, Corbett, Ray, & Wei, 2020). However, variation in definitions of what it is, who should be included in collaboration, and what activities are involved in such a collaboration hinder the application of interprofessional working (Sonya Morgan, Pullon, & McKinlay, 2015). The AHPs interviewed strongly believed that MDT working was central to providing person-centred care. This view aligns with the surveyed SLTs who indicated that working as part of an MDT was extremely important to them and that their role managing mealtime difficulties should only exist within an MDT. Despite their views on the MDT's importance, the AHPs in the current study viewed a connected MDT as aspirational, not a reality. They regarded their MDT working as fragmented and piecemeal. Their work practices and access to team members varied across settings and services, and workload and resource issue placed a burden on teamwork. They indicated that the strength of team relationships was dependent on the frequency and ease of contact, which left some AHPs feeling isolated from the team. In their opinion, a disjointed and isolated MDT directly impacted the immediacy of care offered to people with dementia, risked duplications of service or missed opportunities, and impacted decision-making processes. The working practices of SLTs and dietitians particularly influenced the dynamics among AHP teams. SLT interview comments about the nature of their practice moving across wards and services aligned with the survey finding in section 6.1 that very few SLTs work in one setting. Other findings from the survey speculated that SLTs' fragmentary working practices were leading to challenges with the implementation of their recommendations and their relationships with care staff was speculated on (section 6.8.3). It became clear from these interviews that it also impacts their engagement with the MDT.

Morgan and colleagues (2015, p. 1218) define interprofessional collaboration as a three-tier system, and as "*an active and ongoing partnership often between people from diverse backgrounds with distinctive professional cultures and possibly representing different organisations or sectors, who work together to solve problems or provide services*". This definition could certainly apply to the ideal scenario of managing individuals with dementia-related mealtime and swallowing difficulties' needs. However, the reality of the work environments described under this theme is incongruous with the "*active and ongoing*" elements of this definition. There were challenges in communication among the AHPs, with AHPs viewing face-to-face and off-the-cuff conversations as preferable and more efficient. Some AHPs described the need to fight for their place on teams and that their role was not always viewed as an established and necessary part of dementia care. They considered consultants and medical colleagues to have a lesser appreciation for their input. These issues likely link to the previous subtheme, 'awareness of roles', as it is likely to be challenging to appreciate the need for an AHP service if the nature of the role is not understood. As such, the MDT is not collaborative but operating in silos. Interestingly, Schot, Tummers, and Noordegraaf (2020) posited that systemic factors such as those described have less of an impact on interprofessional collaboration than the professionals’ working relationships. The current results do not support this view. While the AHPs in the study described inadequate working relationships with their colleagues, which would impact care, it is the effect of systemic and structural factors curtailing their ability to build these relationships rather than personal factors. Harrod and colleagues (2016) found that team building is an ongoing cyclical process that requires review and evaluation to consider if teams were working effectively. Some nursing homes research has found that what is perceived to be collaborative working is “*situational and fragmentary organised*” (Tsakitzidis et al., 2017, p. 600). That is likely the case for the current participants who described the need to fight for their places on MDTs and prove their contribution in settings repeatedly to achieve buy-in from services. Consequently, it is unlikely that they are working collaboratively, and even more improbable that team functioning reviews are happening.

The results of this theme also highlighted that the AHPs considered their limited access to each other to directly impact on care for people with dementia by preventing them from having formal conversations at MDT meetings or off-the-cuff discussions and consultations with each other in social moments. The broader issues that prevented the development of strong working relationships hampered the development of team relationships where members felt respected and understood, which has implications for the management of pervasive mealtime and swallowing needs. They also impact at the micro-level in terms of AHP well-being and professional collaboration. Limited opportunities to collaborate also impacted the AHPs' well-being, with some participants describing feelings of isolation. While it is under-investigated, some preliminary research indicates that attendance at MDTs and the opportunity to share burdens with colleagues can be protective of healthcare professionals' well-being in the workplace and reduce their risk of burnout (Gorbenko, Mendelev, & Keefer, 2019). Attendance at MDT meetings can improve inter-professional communication and collaboration (Waring & Bishop, 2010), and opportunities to engage on a personal level can contribute to the team's success (Harrod et al., 2016). This level of interaction is not feasible in the current work environment for the AHPs interviewed.

The off-the-cuff conversations that the AHPs described have been called "*water cooler moments*", and these have been shown to contribute to patient care in the following ways (Waring & Bishop, 2010, p. 335):

1. *Critical reflection: Assists experiential learning and the identification of potential and actual sources of risk.*
2. *Collective sense-making: Contributes to the formation of a shared and less ambiguous understanding of work events.*
3. *Functional contribution: Contributes to problem-solving and dealing with change in context.*
4. *Communication and follow-up: Assisted colleagues in decided on future action and reporting.*

5. *Supportive and emotional: Provides a cathartic outlet and emotional support to anxious colleagues.*
6. *Cultural and professional: Reinforces the expectations, norms and values of professional socialisation, practice and identity.*

These contributions are essential to team-working and are also necessary for reflective practice and forward planning. Forward planning for chronically understaffed healthcare teams has been described as "*a necessary evil*", but a state of uncertainty and flux undermines managers' forward planning capabilities and is a source of anxiety and stress for teams (P. K. Miller, Waring, Bolton, & Sloane, 2019, p. 48). As such, for successful MDT working that promotes person-centred care, there is a need to demonstrate the positive outcomes for people with dementia with early and complete access to AHP support. It also requires recognition that successful team working requires effort, commitment, and communication (Sargeant, Loney, & Murphy, 2008) and that effective collaboration requires team members to recognise and accurately represent "*their own role, special skills and competence*" in order to share and meld roles with colleagues (Birkeland, Tuntland, Førland, Jakobsen, & Langeland, 2017, p. 202).

9.2 Decision-making is Individual

The theme of 'decision-making is individual' reflects the areas where the AHPs felt challenged in supporting people with dementia and mealtime difficulties to make decisions across their illness to maximise their quality of life. The concepts and issues underpinning the four sub-themes of this theme connect and intertwine. The individuality of people with dementia will influence their perception and decisions around their quality of life, which, in turn, influences their attitudes towards risk and their willingness to take risks or exert caution. These factors influence the themes bi-directionally and are underpinned by the subtheme advance care planning. If advance care planning has been conducted, it enables health professionals and family members to plan for and enable risks that will support the maintenance of the quality of life of the individual with dementia. This links to the concept that ‘it’s not one size fits all’ when it comes to dementia care, and people with dementia cannot be treated as a homogenous group (Wendrich-van Dael et al., 2020), supporting the promotion of individual care. Unfortunately, when advance care planning has not been completed in a timely and person-centred manner, AHPs cannot be confident that their interventions and supports enable a good quality of life and truly support the individuality of people with dementia in their care. In such cases, the individuality and person-centred nature of care is diminished.

The concept of person-centred care is the primary driver of this theme, and the subtheme of ‘it’s not one size fits all’ is central to the thought processes of the AHPs who supported people with dementia. This centrality is demonstrated visually by its central positioning in figure 8.2. These results align very closely with ‘the model for the provision of good nutritional care in dementia’ (Murphy et al., 2017), as its guiding principle is person-centred care. The concept of person-centred care also underlined for the AHPs that decisions to promote quality of life must be tailored to individuals wishes. This was occasionally challenging to the AHPs, given their views on quality of life, discussed further in section 9.2.2. Section 9.2.3 discusses how decision-making around ‘risk’ was contentious for the AHPs and something of a balancing act. Definitions of person-centred care and approaches to its application vary, making the true application of person-centred care challenging to measure and operationalise. The noted challenges of advance care planning (discussed in section 9.2.4) mean that for AHPs supporting people with dementia they are unable to ensure “*that individuals' values and preferences are elicited and, once expressed, guide all aspects of their health care*” (Brummel-Smith et al., 2016, p. 16). The decisions that needed to be made around ‘advance care planning’ provided the biggest challenge to the AHPs, given a lack of consensus and guidance. This is discussed in section 9.2.4.

9.2.1 The Uniqueness of People with Dementia and its Influence on Management

This theme of *‘It’s not one size fits all’* reflected the variability that the AHPs felt in how people with dementia presented to them and the means they could use to manage challenges. The AHPs recognised the individuality of everyone with dementia and highlighted the need to provide care that aligned with this uniqueness in a person-centred manner. They advocated for the necessity of knowing the person with dementia, their background, their social supports, and their preferences to achieve this. Though just one AHP directly referenced Kitwood’s (1997) work, described in section 2.2.1, it was evident from the interviews that the principles of person-centred care and personhood infused the AHPs’ approach to working with people with dementia. This is not entirely unexpected as in 2004, Brooker commended the UK’s care systems for its acceptance and application of person-centred care principles, citing the publication for person-centred care standards for UK care homes (Alzheimer’s Society, 2001) as evidence of its ubiquity. However, in that paper, Brooker argued that the term's application could be “*woolly*” (Brooker, 2004, pp, 221), meaning different things in practice to different people and settings. Moreover, although the paper is almost two decades old, the issues that Brooker identified were primarily the same issues described by the current participants. These issues primarily relate to the following subthemes in this theme: issues in evaluating quality of life, a lack of guidance on risk enablement, and poorly delineated support for advance care planning make the application of person-centred care a challenge. Additionally, the issues discussed in the subthemes of ‘the realities’ reflect challenges in applying person-centred care.

Initially discussed in section 6.7, issues of delays in diagnosis and diagnosis documentation (Bradford et al., 2009; Cappetta et al., 2020; Crowther et al., 2017; Innes et al., 2014) also became apparent in the interviews. The implications of diagnostic challenges for people with dementia are stark, and their access to services is hindered if they do not have a diagnosis. For the AHPs in the current study, having access to a confirmed diagnosis of dementia was both helpful and superfluous. On the one hand, knowing the diagnosis was useful for roughly predicting disease trajectory and course. It enabled them to manage expectations in discussions with families, such as deliberations around progress and management. Nevertheless, as with the SLTs who responded to the survey, they indicated that their management was not dependent on a diagnosis, and they did not need a differential diagnosis to direct their assessments and interventions. They felt that differential diagnosis could not provide definitive information on an expected presentation of someone with dementia. This is also likely to reflect the lack of dementia-specific assessments and interventions. It also aligns somewhat with a recent study that suggests that the lack of effective treatments for dementia mean that a differential diagnosis has no clear benefit for people with dementia and may negatively impact their emotional well-being (Aldus et al., 2020). However, rather than not valuing a differential diagnosis, it may be the case that due to challenges in accessing this information, AHPs have learned to make clinical decisions without it. This finding directly links to the findings in section 6.7 where the SLTs described their limited access to diagnostic information and confirms that this issue is broader than SLTs.

Though the AHPs said that a differential diagnosis was less critical, they still felt that an umbrella dementia diagnosis influenced their management. In their view, they did not provide care to people with dementia in the same way as they did to people with other conditions. They described working more indirectly and not actively attempting to rehabilitate people with dementia. This indirect approach relates to the survey's finding that active rehabilitation approaches were the least used. This view of people with dementia not being suitable for rehabilitation has been criticised in the literature as not being a person-centred approach to dementia care (Goodwin & Allan, 2019). It has also been criticised as a view incongruent to the principal aims of AHPs, as rehabilitation is a primary aspect of their job scope (Kempenaar, 2005). The AHPs' (including the SLTs who responded to the survey) rationale for indirect approaches to care was that cognitive impairment and memory challenges made direct interventions unsuitable. This view has been challenged, as AHPs should be adapting their approaches, not expecting people with dementia to adapt to them and their services, a principle of person-centred care (Goodwin & Allan, 2019). Ideally, clinicians would consider both the individual's presentation, and their understanding of the expected dementia presentation. In order to provide person-centred care and to provide tailored supports in line with the evidence, the next direction for research must be the development of specific assessment tools and interventions that evaluate and target the known deficits in different types of dementia.

However, considering these AHPs as 'un-person-centred' is incompatible with the views captured in the subtheme 'workarounds' where the AHPs described the need to be solution-focused and adaptable in their interventions. Resistance to providing rehabilitation to people with dementia has been linked to negative attitudes towards dementia and limited knowledge and understanding of dementia (Bamford, Wheatley, Shaw, & Allan, 2019). It is unlikely that the AHPs in this study have a negative attitude towards dementia as they self-report a specialist interest in supporting people with the condition. Rehabilitation in dementia care is described as *"new learning, relearning, use of compensatory strategies, or a combination of these"* (Clare, 2017, p. 2). Though the evidence base for rehabilitation in dementia is weak (Cations, Laver, Crotty, & Cameron, 2018), the AHPs in both phases of the study appear over-reliant on compensatory strategies. In the absence of a negative attitude towards dementia and a presumed understanding of dementia given their self-reported specialist interest, this finding begs the question: why are AHPs focusing on indirect compensation in dementia care? The answer to this is likely related to systemic factors discussed further in section 9.3 in the third theme of the interviews, ‘the realities’ of supporting people with dementia.

Another concern for the AHPs was the planning of discharge from inpatient services for people with dementia with mealtime difficulties, particularly in light of the impact of unmanaged nutritional challenges on muscle mass, frailty, well-being, and independence. This was primarily influenced by personal factors such as support in the home. For many people with dementia, admission to hospital means the likelihood of returning to their home plummets as their care needs increase or they are found to be unsafe in their home environment due to their cognitive decline (Emmett, Poole, Bond, & Hughes, 2013). Discourse and debate around describing older adults as ‘unsafe’ is occurring in the field of health and social care (P. Doyle et al., 2020; Hyslop, 2020). Additionally, there has been a movement to change the language used to describe older adults in order to change the narrative of ageing (Lundebjerg, Trucil, Hammond, & Applegate, 2017). The AHPs had concerns about the ‘risk’ and consequences of these dementia-related mealtime and swallowing difficulties being unmanaged or inappropriately managed if they returned home. The centrality of ‘risk’ decision-making to person-centred care and how these decisions impact well-being is discussed further in section 9.2.3.

One area where ‘it’s not one size fits all’ and a person-centred approach were particularly challenging to the AHPs’ practice was in outcome measurement and demonstrating the impact of their interventions. The AHPs’ view was that good outcomes for people with dementia will vary and will not always occur in improvements that can be captured on standardised rating scales. They found outcome measurement to be a challenging part of their role and did not feel that the nature of person-centred care lent itself well to measuring outcomes. The development and standardisation of outcome measures in dementia is an accepted challenge (Webster et al., 2017), though work is underway to develop measures that are suitable for people with dementia and their carers and that can be used in research across the trajectory of the disease (Mountain, 2015). Most of the literature on outcome measurement in dementia is from a research evaluation perspective, and little of the work examines outcome measurement in practice. To that end, the RCSLT recognise the challenges that outcome measurement poses to clinicians and have adopted therapy outcome measures (TOMs) as the most suitable outcome measure across a range of conditions (Moyse et al., 2020). TOMs are based on the International Classification of Functioning, Disability and Health (ICF), a framework that considers the impact of conditions and diseases under the categories body structures and functions, activities, and participation, which are influenced by personal and environmental factors (WHO, 2001). TOMs measure outcomes with consideration of these headings and have several different scales that can be applied to different conditions (Moyse et al., 2020). Though TOMs include a scale for dysphagia, there is no scale for mealtime difficulties making its application to people with dementia challenging. Furthermore, despite its adoption by the RCSLT, TOMs have been criticised as lacking specificity, requiring compromise in application, and being unsuitable for complex cases (Tyerman & King, 2015). It is clear that specific outcome measures for dementia are needed, and more specifically, measures for mealtime difficulties and dysphagia in dementia. Further research is needed to develop outcome measures that are adaptable across the course of dementia, reflect the areas of greatest priority to people with dementia, and take into consideration their unique personal, social, and cultural presentations.

9.2.2 The Relevance of Mealtimes to Quality of Life

This section refers to the findings of the subtheme 'quality of life is individual'. Quality of life has been described as "*a fluid construct, shaped by current health, relationships, care location, prior experiences, and other factors*" (Snyder & Amjad, 2017, p. 1059). Given the fluidity of these influencing factors, it is difficult to define what quality of life means to individuals and, as such, how to measure and quantify it. In line with this definition, the AHPs in this study considered quality of life unique to individuals. Therefore, the measures needed to ensure and preserve it vary across individuals and the AHPs found it challenging to measure and to understand how their interventions impacted it. Furthermore, it is generally accepted that mealtimes and food are opportunities for socialisation, to engage in a pleasurable activity, and to partake in cultural traditions and practices. Consequently, for many people, they influence quality of life. As such, it is important to consider how mealtime difficulties and dysphagia in dementia influence the quality of life of people with dementia and their carers. As with quality of life in general, there is limited research evidence available. A broad, rapid review of SLT interventions to improve participation, inclusion, and quality of life for people with dysphagia found only five relevant studies (Bryant & Hemsley, 2018). It is likely that even fewer deal specifically with the impact of dementia-related dysphagia or mealtime difficulties, thus reinforcing the AHPs' concerns about knowing if their interventions positively impacted quality of life.

Both the AHP participants and the literature note that mealtimes provide socialisation and connection opportunities important to good quality of life for both family members and people with dementia (Henkusens, Keller, Dupuis, & Schindel Martin, 2014; Keller et al., 2007). Further to this, they viewed food and eating as pleasures to be relished and savoured. However, dementia interfered with the opportunities to enjoy this indulgence. The AHPs considered family members to view food as one of the few pleasures their loved ones could experience, and as a means of caring for them. This view of food as care was perceived by the AHPs to be a source of stress to caregivers, as the carer conflated a loved one refusing to eat as not providing care to them. This somewhat aligns with the findings of Papachristou et al. (2013), who reported that family caregivers saw their role as adapting to the mealtime needs of the person with dementia as their dementia progressed in order to care for them. However, the carers in that study did not view the refusal to eat and appetite changes as unmanageably stressful. Nevertheless, the AHPs' views do align with Gillies' (2012), who found that family carers felt increasing stress and loss with increasing care needs.

Food and mealtimes can be markers of routine and normality for carers, and "*food enables people to think about, monitor and make sense of the embodied illness of a family member*" (Ellis, 2018, p.363). In this way, the view of food as care was also a potential risk to people with dementia. Some AHPs viewed family members as having an ‘anything goes’ approach to quality of life, where eating as a pleasurable activity superseded consideration of the risks involved and the detrimental effects of going against recommendations. This relates to the questionnaire's findings, where the SLTs in that study described issues with adherence to modified diet and fluid recommendations. The AHPs also described concerns that the complications and ramifications of non-adherence to recommendations were not fully understood, which enabled the family members to be more inattentive to recommendations as they did not see their purpose.

Furthermore, as discussed in section 9.1.1, the AHPs in the interview study considered family members to have a limited understanding of dementia, particularly end of life in dementia, and, as a result, they did not understand that food refusal and loss of appetite were a natural progression of the condition. The onset of food refusal and a reduction in oral intake can be a prognostic signal that an individual is entering the end of life phase of the condition but that this is not always understood by family members (Clark, Raijmakers, Allan, Van Zuylen, & Van Der Heide, 2017). However, some research has described how carers attempt to maintain a sense of normality and a sense of a social bond with their loved ones by maintaining usual approaches to eating and drinking (Wallin, Carlander, Sandman, Ternestedt, & Håkanson, 2014). Therefore, it can be argued that the family carers are not disregarding the recommendations with no regard for the ramifications, but instead, they are dealing with the consequences and complications of a progressive condition the best way they know.

Moreover, the AHPs' personal views of quality of life influenced their views of the decisions families and carers made for their loved ones. This was evident when AHPs talked about decisions family carers had made for their loved ones with advanced dementia to prolong their lives, such as tube feeding. Some AHPs described seeing people with dementia that they perceived as having an unacceptable level of quality of life being "*kept alive"* and viewing that as something they would not want for themselves. This personal view could influence the advice and support that they offer to families in the absence of guidelines. This aligns with a report commissioned by RCOT, which describes occupational therapy as a complex intervention (Pentland, Kantartzis, Clausen, & Witemyre, 2018). Some research also indicates that OTs apply their values to their decision-making in practical but unpredictable ways, despite the profession's shared culture and knowledge-base (Y. Thomas, Seedhouse, Peutherer, & Loughlin, 2019). These findings are similar to literature that indicates that SLTs value their own experience and knowledge in decision-making above other factors (McCurtin & Carter, 2015; McCurtin & Healy, 2017). This unpredictable application of personal values has implications for the care of people with dementia.

For example, the AHPs did not know if instances where they viewed someone as being "*kept alive"* actually reflected the wishes of the person with dementia and if staying alive with all available measures was, in that individual's view, quality of life. By applying their own values and beliefs, they risk discounting or disrespecting people with dementia's wishes and values. Alternatively, the application of extreme measures may reflect families' limited understanding of the end of life in dementia. When family members had not prepared advance care plans with their loved ones' input, they felt that their decisions could make them responsible for the death of their loved ones (Sellars et al., 2019). Furthermore, it has been shown that carers’ understanding of dementia as a terminal condition influences the comfort of people with dementia at the end of life and has raised concerns that people with dementia may have suffered unnecessarily at the end of life (van der Steen, Onwuteaka-Philipsen, Knol, Ribbe, & Deliens, 2013). The issues around end-of-life care and what counts as quality of life are challenging. Given the challenges of measuring quality of life in dementia, particularly as the disease progresses (Bowling et al., 2015), in order to facilitate interventions and lifestyle changes that will compensate for any mealtime difficulties and dysphagia issues, clinicians must begin to take into account the desires and values of people with dementia. As such, early involvement and discussion is key. However, the AHPs described early involvement with people with dementia as hampered by lack of awareness of roles and limited and unfruitful access to MDTs. This directly impacts their ability to provide person-centred care that respects and elevates people with dementia’s personhood. This links in closely to the issues discussed in section 9.2.1 and to risk decision-making and advance care planning issues which will be discussed in section 9.2.3 and 9.2.4.

In order to deliver person-centred care, people with dementia and their families and carers need to understand the risks inherent to the condition and the risks of the management options available to them. With the cognitive changes of dementia, it is not possible to have these discussions as the need arises, requiring advance care planning to be brought to the forefront. The next two sections will discuss the AHPs' perceptions of risk in dementia and how advance care planning, or its absence, impacts their work.

9.2.3 The Centrality of Risk Decisions to Person-centred Care

Risk management in dementia care is an area of discussion and debate in both this study and the literature. Little guidance is available to healthcare professionals to support their discussions, planning, and decision-making for risk-taking with people with dementia and their carers. The best available guidance is a decade old best practice document, *'Nothing ventured, nothing gained'*, developed by England's then Department of Health (Manthorpe & Moriarty, 2010). This document advocates a person-centred approach to risk that balances the positives and negatives of risk-taking. It suggests that identified risks should be discussed with all relevant stakeholders and documented in risk management plans. These plans should:

> *summarise the risks and benefits that have been identified, the likelihood that they will occur and their seriousness, or severity, and the actions to be taken by practitioners to promote risk enablement and to deal with adverse events should they occur*" (p. 9).

There is no similar guidance available for health professionals working in Scotland, and as a result, it is unclear whether a similar approach to documenting risk is taken. A multidisciplinary expert group from Canada suggest that current perceptions and practices in the management of risk are not person-centred and that the voice of the individual is missing (Egan et al., 2017). However, it is unclear if this applies to a Scottish context.

In this study, approaches to the risks discussed varied depending on the AHP's professional group. The OTs and physiotherapists discussed risk as standard practice using the terminology of "*risk enablement*" and *"positive risk-taking"* in relation to their work supporting people with dementia to be independent in their mobility, their homes, and their activities of daily living. From the OT and physiotherapist perspective, their descriptions of enabling risk and supporting positive risk-taking imply that their management is for the benefit of the person with dementia's quality of life. It supports the idea of promoting good quality of life through empowering people with dementia to take risks and recognising that risk is an unavoidable part of life which aligns with other research on discharge for older adults that "*life is risky*" (Atwal, Mcintyre, & Wiggett, 2011; T. Murphy, Butler, & Kidd, 2018, p. 15). It is also supported by literature that suggests viewing people as 'safe' or 'not safe' is paternalistic and that people should be supported to determine the risks they wish to take (Hyslop, 2020). This view of paternalism in risk assessment mainly appears to apply to people with dementia, and concerns have been raised in the literature about how people with dementia have their autonomy taken from the point of diagnosis (Dickins, Goeman, O'Keefe, Iliffe, & Pond, 2018). This links into the challenges of advance care planning discussed in section 9.2.4.

However, it is crucial to note that not all risks are created equal. A study of families' thoughts around risks found that the risks they were most concerned about were falling, their loved one getting lost, concerns about using electrical appliances, and financial risks, with family members being most concerned about the consequences of the risk, not the likelihood that it would occur (Stevenson & Taylor, 2018). Many of these risks relate to memory decline in different ways, and they do not consider other aspects of the impacts of dementia, perhaps reinforcing the findings from 9.1.1, that families and people with dementia do not have total comprehension of the full impacts of dementia. Otherwise, it is hard to comprehend, given that eating and drinking are an integral component of daily life, how the risks and consequences of dementia-related mealtime difficulties and dysphagia do not feature on such a list.

This study demonstrates that AHPs have roles in managing different risks, and due to the nature of these risks, their approaches and perceptions of risk-taking are disparate. In particular, it seems that the risks of mealtime difficulties, with or without dysphagia, require specific considerations. In contrast to the terminology of *"risk enablement"* and "*positive risk-taking"* used by the physiotherapists and OTs, the SLTs and dietitians expressed their thoughts using phrases like "*at risk"*, "*accepted risk'* and *"agreed risk"*. This difference in semantics implies a different perception of the consequences of risks and the harm that may occur as a result. It may also imply differences in the likelihood of risks and the strategies that could be put in place to mitigate them (Robbins et al., 2008). For example, if a fall's harm can be reduced, and its likelihood is also reduced, then, if it happens, the fall is less likely to have serious consequences. Unfortunately, for the SLT, it can be more challenging to mitigate the risks of aspiration as it is often impossible to reduce or eliminate its likely occurrence in advancing dementia, and repeated aspiration may have cumulative effects. Similarly, the effects of repeated food refusal are cumulative, and the resulting malnutrition and dehydration have significant consequences for the person with dementia (Volkert et al., 2015).

The AHPs views on different tolerances to risk aligned with the literature that suggests: "*all individuals situate concepts such as risk in the context of their cultural, personal, and professional experiences. Therefore, no two individuals are likely to have the same perspective on a single risk*" (Dickins et al., 2018, p. 73). The AHPs described the influences on their tolerance of risk as coming from these three experiences, as well as relating their tolerance for risk to the treatment they would wish for their own loved ones. Morgan and Andrews (2016, p. 125) described this as "*values-based practise*" and suggested that if these values are unexamined, they can negatively impact practice. They described this risk from the perspective of paternalistic and stigmatised views of people with dementia (S. Morgan & Andrews, 2016). For example, some research suggests that OTs and physiotherapists have a negative perception of people who want to take risks in their care (Atwal et al., 2011). Interestingly, some of the AHPs in this study prioritised their perception of good quality of life over a cautious approach. As one SLT expressed, well-being and their perception of quality of life *"trumps"* caution. However, without policy guidance and advance care planning, the care that people with dementia receive and the risks they and their loved ones are encouraged to take may not be true to the individual's wishes. Some AHPs actively expressed the wish for greater insight into the wishes of the person with dementia to reduce the influence of their own views and ensure they acted in a person-centred way.

What arose from these discussions around risk was the sense that the healthcare system that the AHPs worked within was not equipped with the structures and policies necessary to support risk enablement. The healthcare system focused on in the current study, the Scottish NHS, was described as having a culture of risk aversion and concern about complaints. This perception is supported by research that critiques Scotland's Care Commission as having "*a risk-based approach to regulation*" (Asenova, Stein, & Marshall, 2011, p. 859). Furthermore, adapting to risk-taking is challenging for care home managers who view their role as keeping their residents safe while considering the needs of all residents, not just individuals (Evans et al., 2018). Health and social care staff are encouraged to think of risk-taking as making "*defensible decisions*" where they take all possible steps to minimise harm, and the risk decision is made with someone's best interest in mind (Dix & Smith, 2010, p.19). The AHPs in this study acknowledged the challenge that nursing and care staff felt as the people who were responsible for enabling the risks in practice.

The SLTs, in particular, described risk decision-making as "*thorny*" and their role as one of risk facilitation - as opposed to enablement - and education around the ramifications of the risk. The movement towards positive risk-taking and risk enablement is challenging for SLTs and dietitians because it can, at times, imply that taking risks is the only route to quality of life when balancing risks is a unique challenge. It is also complicated by the lack of consensus on nomenclature discussed in section 2.6. The variation in terms reflects findings that decision-making about risks of aspiration and quality of life at the end of life in dementia is a source of "*moral distress*" for SLTs (Berkman et al., 2019, p. 996). Risk feeding decisions are complex in all circumstances, but particularly when an individual does not have the capacity to express their preferences (Miles, Watt, Wong, McHutchison, & Friary, 2016). In addition to this, the SLTs described lacking specific guidance on how to proceed with, and support, risk feeding decision-making. The SLTs felt that their hands were tied by instances where oral feeding was a source of distress and discomfort to the person with dementia. They also felt restricted by evidence that enteral feeding is not appropriate at the end of life, though, as per the survey study findings, they considered it appropriate in some cases. Many services are developing their own protocols (Sommerville et al., 2019), and the RCSLT are also developing guidance for SLTs. However, in the absence of this guidance, there is an apparent struggle.

Furthermore, the available evidence is not sufficient to determine if such protocols effectively improve care (Soar et al., 2020). This finding reflects the view of this study's SLTs. These SLTs had mixed feelings about adopting protocols as some felt a protocol could not capture the nuances of individuals' needs. On the other hand, while other SLTs accepted that a protocol could not cover all issues and that they would need to rely on some clinical decision-making, they welcomed some structure and consensus on appropriate decisions. The desire for official protocol also links to the challenge the SLTs faced with ownership of the risk decisions. The literature suggests that the decision should be a multidisciplinary one (Fong et al., 2019; Miles et al., 2016), which was agreed upon by the AHPs. However, SLTs working in community settings felt responsible for facilitating the discussions and decision-making on feeding risk decisions. This discrepancy based on setting has real implications for how practice develops and adapts. Going forward, the protocol under development by the RCSLT must consider the different needs and MDT access and availability of community settings.

9.2.4 Advance Care Planning: A Nebulous and Moral Challenge

Advance care planning is a somewhat contentious topic as experts have not agreed on its full definition and scope. Furthermore, its application vacillates in different health conditions, and legislation varies between countries (Nimmons et al., 2020). Broadly speaking, it is the *"process of discussing and recording priorities and wishes for future care and treatment . . . so that when a person is no longer able to communicate, wishes and preferences can be met"* (Sampson, 2010, p. 165). Alongside its various interpretations, a thought-provoking conceptualisation of advance care planning as a moral exercise has been put forward by (Robins-Browne, Palmer, & Komesaroff, 2014, p. 959):

> *"Decisions made in anticipation of a future inability to participate are moral decisions; they are about how individuals see themselves, how they are seen by others, what matters to them and what matters to those to whom they are close".*

These challenges and this view of decisions as "*moral*" flavour this subtheme. In many ways, the dilemmas and obstacles the AHPs described reflect the ethical and moral challenges the literature describes around advance care planning in dementia. The need for advance care planning procedures to be standardised has been in discussion for many years (L. Robinson et al., 2012). However, there appears to be little success in achieving this aim, and the areas of advance care planning that best lend themselves to standardisation are yet to be determined (Hall, Rowland, & Grande, 2019). Indeed, there are caveats that standardisation should not lead to advance care planning becoming a perfunctory process (Robins-Browne et al., 2014).

Further to this, there are issues in determining who is responsible for having these discussions. Some research has suggested that GPs do not feel that supporting advance care planning, an essential aspect of case management, is within the scope of their role (L. Robinson et al., 2012). The issues of who, when, and what were also discussed by the AHPs; indeed, they described it as "*a can of worms*". Palliative care and advance care planning experts agree that advance care planning with a multidisciplinary approach has benefits to people with progressive conditions such as better symptom management and the reduction of family and carer stress at the end of life, but that little evidence exists to support its implementation (D. J. Oliver et al., 2016). In addition, much of the literature around advance care planning highlights the lack of a definitive definition of what it entails and what it should include (Kermel-Schiffman & Werner, 2017). It is also unclear if advance care planning is meeting these aims, as measures do not exist to capture its effectiveness (Johnson, Butow, Kerridge, Bell, & Tattersall, 2018), and there is very little evidence for effective advance planning interventions (J. Bryant et al., 2018).

The AHPs also held views on how advance care planning in dementia compares to other conditions as they believed that advance care planning in conditions such as MND and Parkinson's disease is better established. However, the literature suggests that advance care planning is challenging and under-developed across the board with issues such as healthcare professionals' preparedness for the task and the nature of the conditions. In Parkinson's disease, for example, some studies show that the associated clinical apathy can make people with the condition reluctant to engage with future planning (Lum et al., 2019). Furthermore, as the public are often unaware of the association between Parkinson's Disease and cognitive changes, they do not perceive any urgency in planning discussions, and it can be challenging for healthcare professionals to initiate the conversations at early stages (Sokol et al., 2019). Advance care planning in MND can afford the individual "*peace of mind and a sense of control*" while also reducing carer anxiety as the end of life approaches by reducing the decision-making burden (L. Murray et al., 2016, p. 476). However, healthcare professionals' limited knowledge and uncertainty on the timing of these discussions mean they are often not carried out, leading to carer stress and anxiety that can have a lasting impact (L. Murray & Butow, 2016; Whitehead, O'Brien, Jack, & Mitchell, 2012). In fact, one study found that advance care planning was most likely to occur with "*patients who are older, are white, are female, are well educated, and have cancer or comorbidities, and the preferences of people from other social groups and/or with conditions other than cancer appear to be less well understood*" (Hall et al., 2019, p. 330).

These findings raise the question: why did the AHPs in the current study consider advance care planning to be more established in other progressive conditions? Looking closely at the AHPs' comments, they associated 'better' advance care planning with clearer care pathways and closer MDT working. Parkinson's disease and movement disorder clinics are a standard offering of NHS care, and as established in 9.1, MND has well-established care pathways in Scotland. As such, it may be the case that AHPs who have had connections with such teams recognise the benefit of an integrated team working together early in the disease course and how this impacts advance planning. Indeed, there is some evidence from a Scottish context that suggests that people with Parkinson's disease who attend movement disorder clinics have significantly better quality of life than those who attend general medical clinics (Rochow, Blackwell, & Brown, 2005). This difference was associated with their access to a specialist MDT and stronger clinician-patient relationships. More evidence is needed to establish if specialist multidisciplinary clinics would benefit advance care planning for people with dementia and their carers.

Notably, there are discrepancies in the amount and quality of the information provided to people with dementia in the UK who receive their diagnosis via memory clinics (Hailey, Hodge, Burns, & Orrell, 2016), and it is unclear how this impacts care. There is also some evidence that memory clinics fail to initiate advance care plan discussions due to healthcare professionals' perceptions that the point of diagnosis is too early to instigate them, and there are insufficient follow-up appointments to address planning at a later point (Moore, Goodison, & Sampson, 2019). No AHP in this study was affiliated with a memory clinic, and they were not instigating these conversations on a regular basis. They expressed confusion about their role and on ownership of the process. This reflects the literature, which suggests that healthcare professionals in primary care viewed advance planning as the memory clinic's job, and they also were not the ones to initiate them (L. Lee, Hillier, Locklin, Lee, & Slonim, 2019). The study also suggested that healthcare professionals were happy to engage with the discussion if the person with dementia or their family instigated it. People with dementia and their carers do not always recognise dementia as a terminal condition (Van Der Steen, Radbruch, et al., 2014), and this is often not explained to them in memory clinics (Moore et al., 2019). If healthcare professionals expect memory clinics to conduct these conversations, and they do not, then it is unlikely that these conversations are happening at all. The impact of these missed discussions was felt by AHPs in this study who had encountered families unprepared for end of life, with some describing colleagues' reluctance to address imminent end of life. Furthermore, there is evidence that delaying these conversations and relying on carers to make end of life and care decisions on behalf of the person with dementia at the end of life is stressful and upsetting (Fetherstonhaugh, McAuliffe, Bauer, & Shanley, 2017; Hennings, Froggatt, & Keady, 2010). Discrepancies between the decisions people with dementia would make, and the decisions their family members would make for them (Dening, King, Jones, Vickestaff, & Sampson, 2016; Poole et al., 2018) reinforce the need for the person with dementia to be provided with opportunities to express their views.

Uncertainty around the timing of initiating discussions highlights how advance care planning can be seen as moral decision-making (Robins-Browne et al., 2014). This was evident in how the AHPs described their views on looking forward and discussing prognosis with people with dementia. Many AHPs were adamant that people "*don't want to discuss these things"* and that the unpredictable trajectories of dementia meant that anticipating future care could be unnecessarily confronting to people with dementia and their families. Other AHPs recognised that some carers felt the discussions came too late and that they needed information sooner. The AHPs also described their concerns about family members' understanding of dementia and its progression and where they perceive challenges in planning exist. There is some support for the view that advance planning is a not always positive experience for families as they may need time to deal with the shock of the diagnosis (Hall et al., 2019; Robins-Browne et al., 2014; Sellars et al., 2019) and that the timing of discussions should be tailored to individuals (Fried et al., 2010; Wendrich-van Dael et al., 2020). However, there is little guidance on what this means in practice (Piers et al., 2018). Despite the lack of certainty around its implementation, advance care planning is recognised as being necessary for good end of life care in dementia (Bamford et al., 2018; Bartley et al., 2018). Therefore, the apparent solution is that these discussions need to take place.

In Scotland, two of the pillars in Alzheimer Scotland's five pillar model of post-diagnostic support are based around advance care planning: planning for future care and planning for future decision-making (Alzheimer Scotland, 2015). The other three pillars are: supporting community connections, peer support, and understanding the illness and managing symptoms. While the inclusion of advance care planning in this model is commendable, the issues with post-diagnostic support and the inconsistent access to link workers identified in section 9.1.1 make achieving these aims aspirational rather than the reality for people with dementia in Scotland. Building on their five pillar model, Alzheimer Scotland and the Scottish Government recommend that an expert team including specialist AHPs should coordinate care in advanced dementia (Alzheimer Scotland, 2015; Scottish Government, 2017a). However, the question must be asked, is this coordination of care coming too late? Based on the previously discussed findings of the impact of delayed conversations on family members and the views of the AHPs in this study that people with dementia and their carers are not fully aware of the implications of their diagnosis, it is evident that advance care planning is in its infancy. The AHPs in this study perceived themselves to have insufficient time and resource to educate people with dementia and their carers in the earlier stages of the disease. Several of the AHPs expressed a wish for earlier involvement and consultation but felt this was not a feasible option for them with their workloads. They also felt it was challenging to train other healthcare workers, such as link workers, to provide this education given the complexities of predicting the trajectory of dementia. The issues with planning boil down to two issues, people with dementia and their families' lack of awareness and understanding of the need for planning (Moore & Crawley, 2020; Ryan, M-Amen, & McKeown, 2017), and, as discussed above, healthcare workers' uncertainty about who should initiate the conversations and when (L. Lee et al., 2019; Ryan et al., 2017). It is generally understood that advance care planning should be an ongoing and iterative process (Jimenez et al., 2018; Wendrich-van Dael et al., 2020), yet this is challenging in light of this uncertainty.

As such, there is a clear and evident need for further exploration and guidance on how teams conduct advance planning in dementia and when these discussions should take place. This is particularly true for decisions made around mealtime and swallowing changes, as many issues at the end of life, such as aspiration, have no straightforward solution (Hughes, Volicer, & van der Steen, 2018). As noted by the AHPs, preparing people for changes to swallowing is a challenging task. The AHPs perceived it as difficult for people to understand how an automatic, habitual, and life-long process could become uncomfortable and unsafe. As discussed in section 9.2.2, the SLTs faced uncertainty when dealing with feeding decisions at the end of life and when ‘comfort feeding’ was not actually a pleasant experience for the person eating or the carer supporting them to eat. As advance care planning is in its infancy, Hughes and colleagues (2018) raised the question if this planning is prepared to address the level of detail needed to manage feeding decisions such as the refusal of hand-feeding. Furthermore, advanced dementia is ill-defined, and the literature does not tend to differentiate between advanced dementia and the end of life, thereby not acknowledging the need to plan for a sometimes prolonged advanced stage (Holmerová et al., 2016). The AHPs in this study were uncertain about how appropriate it would be to make decisions in the early stages of the disease that may not provide comfort and good quality of life when eating issues emerged in the later stages. They considered that with current practices, perhaps advance care plans should contain the spirit of what a person with dementia would want, for example comfort and safety or risk and minimal changes to their premorbid lifestyle. This would then allow their loved ones to make decisions when the time comes.

As stated in the heading, the issues in advance care planning are nebulous. The system-wide challenge in implementing and integrating planning for people with progressive conditions has led to AHPs being uncertain and hesitant in supporting and planning these decisions. The complexities of the timing of discussions and who should be involved reinforce the point that these decisions are moral ones and are never clear cut. Future research specific to advance care planning in dementia needs to consider the condition's impact on mealtimes and its consequences on people with dementia and their families. This research should support the development of policies to address these issues and ensure that people with dementia's voices are heard from diagnosis to end of life.

9.3 The Realities

For the AHPs interviewed in this study, 'the realities' of supporting people with dementia and mealtime difficulties meant being under-resourced and feeling unsupported in their efforts to make systemic changes. This theme primarily reflects systemic issues that challenge their ability to provide person-centred care. The subtheme of 'over-stretched resources' explores the specific areas where the AHPs felt that changes were needed and how the current systems they work within impact the care of people with dementia. The words they used, including *"fire-fighting"* and *"tsunamis"*, paint a picture of services at breaking point. This is compounded by the challenges faced in their attempts to 'workaround' a lack of resource and the unique challenges of dementia. Within the theme 'workarounds', the AHPs describe how dementia requires a different approach to care and where they see breakdowns in services. This further relates to the subtheme 'culture change', where they discuss their efforts to change the culture of where they work. The AHPs shared a belief that the culture could be changed by empowering care staff and positive reinforcement, while acknowledging that changing culture is time-consuming, a source of frustration, and hindered by issues explored in other themes. This theme reflects many of the barriers to supporting people with dementia at mealtimes and thereby primarily answers the second research aim of this phase of the study, which sought to uncover the issues and challenges impacting on AHPs. The next section will explore the impacts of 'over-stretched resources'.

9.3.1 How Over-stretched Resources Impact AHP Services

'Over-stretched' and limited resources will not be an unfamiliar notion to anyone who has worked within or used the UK's NHS. In fact, insufficient resources due to cuts to public spending are generally accepted as the reality of working in the NHS (Elton, 2016; Keogh, 2016). Furthermore, what has been termed as 'over-stretched resources' in this study is equivalent to the theme "*walking the tightrope*" from another study of healthcare professionals' experiences of supporting people with dementia to continue living at home (de Witt & Ploeg, 2016, p. 228). In that study, the tightrope was the finely tuned balancing act of managing and meeting professional responsibilities in the context of cutbacks, limited resources, and a lack of support. In essence, the same challenges and issues described by the AHPs in this study.

Such resource issues led to feelings of disheartenment with the AHPs using words such as "*tsunami*" and "*firefighting*". The American Geriatric Society argues against using this kind of metaphorical language to describe the challenges of working in healthcare systems with changing demographics (Lundebjerg et al., 2017). They argue that these word choices are inflammatory, that they 'other' the ageing population, and contribute to negative perceptions of ageing. Nevertheless, this is the language that the AHPs felt best described their workplace experiences. The imagery evoked by these words is powerful. It emphasises the challenges faced by the AHPs and the overwhelming discouragement they handled trying to do their jobs when faced with too many people who needed their support and not enough resource to provide it. The AHPs viewed themselves at the cusp of a new movement in dementia care. They felt that person-centred care had not been implemented as well as it could in dementia care up to now. As described in section 9.2, person-centred care aimed to meet the quality of life needs of the people that the AHPs saw, but they did not feel that they could provide this care to the extent they wished due to resource and staffing issues, and, as discussed in section 9.3.3, attitudes towards dementia. This echoes the survey findings, where the SLTs felt they did not have enough resources to address dementia-related mealtime difficulties and provide education and training. As such, the AHPs wanted to focus on redesigning services to ensure the care provided was personalised and individualised for each person with dementia.

The main challenge to their role that the AHPs in this study faced was understaffing, an issue identified as the NHS' Achilles heel and a primary reason for public dissatisfaction with the NHS (Appleby et al., 2019; D. Oliver, 2017). As described in section 9.1.1, not all of the AHPs liked to overlap their roles as they felt that they could not account for the quality of their colleagues' input. However, in the context of 'over-stretched resources', several AHPs felt they had no choice but to over-reach their roles. A report from 2014 described AHPs' contribution to the healthcare system as "*hidden, overlooked or potentially undervalued*" and highlighted that there is very limited information available about what AHPs do, how they do it, when they do it, and the quality of the care they provide (Dorning & Bardsley, 2014). The overlapping and over-reaching that the AHPs described is unlikely to be well-coordinated, given the team-working challenges explored in section 9.1.2. Therefore, it cannot be definitively known if standards of care are maintained. This again reinforces the data collation needs identified in section 9.1.1. The first phase of this study captured SLT practices, while the interview study has generated insights into the barriers and challenges facing the wider AHP professions. As such, there is a palpable need for further research that quantifies and measures what AHPs offer in terms of mealtime support and the wider benefits this has on care.

Unfortunately, the AHPs acknowledge that their care and nursing colleagues were also over-worked and understaffed, which has been shown to have a significant impact on mealtimes (Reimer & Keller, 2009). Research suggests that a resource-poor environment engenders a lack of empathy among nursing staff for people with dementia and their activities become task-driven (Digby, Lee, & Williams, 2018), thus leading to an impoverished mealtime environment. Care assistants often feel pressured to complete tasks, and this task-based approach to care is detrimental to person-centred care (Talbot & Brewer, 2016). In addition, even though care staff appreciate its importance, they often feel overburdened by paperwork, and excessive paperwork requirements do not lead to quality care (Warmington, Afridi, & Foreman, 2014). Task-based care risks have potential links to issues with the poor implementation of the first-line strategies and adaptive feeding skills that the AHPs in this study believe that care and nursing staff should provide. These first-line strategies include activities such as initiating food fortification when weight loss is first noted, as well as implementing person-centred feeding strategies and observing for changes in mealtime and swallow functions. However, if meals are seen as task-based exercises where the goal is simply an empty plate, then there is no reason for staff to consider areas of breakdown, potentials for improvements, and ways to provide person-centred care to the person with dementia during the meal. The AHPs saw the use of first-line strategies as key to quality care and a means of reducing unnecessary and inappropriate referrals while also generating more appropriate referrals. This view links closely to the survey findings where referral issues due to lack of knowledge were a source of stress to the SLTs.

A task-oriented approach to mealtimes has already been discussed as a risk factor for aspiration at mealtimes in section 2.2 (Gilmore-Bykovskyi & Rogus-Pulia, 2018), and there have been calls to adapt mealtime environments to enable the provision of person-centred mealtime care, but this still appears to be an aspiration (Beck, Poulsen, Martinsen, & Birkelund, 2018). Though the AHPs in this study understood the stresses and pressures their nursing and care staff colleagues faced, they were frustrated when they felt that they were not completing the first-line strategies the AHPs considered a core part of the caring role. They viewed it as these staff not working to the full scope of their roles. However, it is in these issues that the intersection of overworked AHP colleagues and under-resourced and possibly under-trained care colleagues collide. Research indicates that the knowledge and skill of the carer has an impact on mealtimes (C. C. Chang & Lin, 2005; Watkins, Goodwin, Abbott, Backhouse, et al., 2017). As such, if the AHPs believe that care and nursing staff should be implementing strategies such as those described, how do they believe they should be learning about them? The answer to that is unclear.

The AHPs felt they had a role in providing training and carried out training how and when they could. However, the influence of understaffing and resource issues meant that training provision was downgraded from being a core element of their roles. This finding echoes the questionnaire's findings that training was being delivered on an ad hoc, case by case basis and significantly impacted by systemic issues such as staff availability and management buy-in. The AHPs who were interviewed appeared to have a limited sense of ownership of mealtime training and education needs. One dietitian notably described training provision as having "*gone by the wayside*", and others said that they did not have the capacity to provide requested training. The AHPs also highlighted the issues of sustaining training changes, which again links back to the survey findings. Furthermore, some AHPs felt that staff should know these "*common-sense*" strategies. Perhaps this was a means the AHPs used to justify their own curtailment of services in the face of excessive stretching of their own time and resource, combined with ever-shrinking services. This also links back to the AHP report that highlighted how ill-defined AHP practices are (Dorning & Bardsley, 2014). It remains unclear where the buck stops with the AHPs for providing this training and education. For instance, though Scotland's Health and Social Care Standards acknowledge people's rights to food-related care that is respectful and personalised, they do not outline minimum training requirements for staff (Scottish Government, 2017b).

The other issue that AHPs saw was the limitations of the service pathways for people with dementia. Services with specific acceptance criteria were insufficient to meet the needs of people with dementia. They also were aware that there were misperceptions of what they could offer, and limited resource meant there was no "*huge army of AHPs* [waiting] *in the community".* The term care pathway is contentious in some healthcare areas, as it is an unclear expression (Samsi & Manthorpe, 2014). Furthermore, there has been criticism of the gaps in services and the impacts this has on people with dementia (Fitzgerald, Curry, Olde Meierink, & Cully, 2019; NHS Information Services Division, 2020), and standard care conditions do not typically meet the needs of people with dementia. These findings reinforce the suggestions from section 6.8 and 9.1.1 that case management approaches for people with dementia need to be further developed to ensure continuity of care and ensure services meet their needs.

9.3.2 Compensating for Dementia and for the Environment

This subtheme of ‘workarounds’ described two key issues: the need to work around cognitive impairment and unsupportive environments to deliver person-centred care. The AHPs identified the primary challenge of working directly with people with dementia was adapting to their cognitive changes. Changes to attention and executive functioning and the development of apathy are well-documented challenges to supporting people with dementia (Firbank et al., 2016; Harrison, Aerts, & Brodaty, 2016; McDonald, D’Arcy, & Song, 2018; van Dalen et al., 2018). The AHPs described these difficulties as impacting engagement with and focus on activities, and as they cannot be eliminated, they need to be worked around. As a result, they aimed to reduce the cognitive load of tasks through adaptation and also described using some cognitive changes such as perseveration to support actions and interventions on a case by case basis (Benigas & Bourgeois, 2016; Wu, Lin, Wu, et al., 2014). The importance of independence at mealtimes has been highlighted in section 2.23, and these approaches have the potential to achieve that aim. Unfortunately, there do not appear to be guidelines or a strong evidence base integrating these interventions into care, though the practice-based evidence of the AHPs in this study highlights their potential. The AHPs also applied this principle beyond mealtimes to other activities of daily living and safe mobilisation. Future research needs to consider the aspects of mealtimes that are amenable to preserved cognitive channel manipulation or the utilisation of emergent processes such as perseveration in order to maintain independence at the meal.

The AHPs described their management practice as non-standard and as such, that they did not always appeal to the carers and family members who were asked to implement them. For example, strategies such as adding sugar or sweetener to savoury food to appeal to the changing tastes of the person with dementia or appearing to restrain an individual by using a high table as a standing support for an individual who was calmer while standing at meals did not always appear to be respectful or appropriate practice. However, the AHPs were keen to emphasise that any changes they made were generated from an individualised assessment and designed to achieve person-centred goals. Furthermore, they felt that an imperfect strategy that supports a goal's achievement is better than a perfect one that does not. Where these workarounds became particularly challenging to AHPs was in measuring outcomes. This again relates to section 9.2.1, where the need for specific outcome measures for dementia, in particular, mealtime interventions, was established.

The AHPs felt constrained by the systems they work within and limited in how they could implement the workarounds that they needed. They were constrained in improving people with dementia's mealtime experiences by rigid environments. The AHPs described the need to use more extensive environmental supports and to engage more frequently with people with dementia's families and carers to 'workaround' these cognitive and engagement challenges. They often relied on family members and carers to implement their identified strategies of care. For example, they touted the benefits of open-visiting policies where familiar faces can provide mealtime assistance, but this was not the norm for all settings. Open visiting improves communication and trust between families and staff, although a barrier to its implementation is the mistaken belief that it hinders routines and care delivery (Hurst, Griffiths, Hunt, & Martinez, 2019). However, lack of resource and limited opportunities to provide training and education opportunities may make the implementation of these strategies challenging. Some aspects of this issue relate to the need to change cultures within care homes and services that people with dementia attend. For example, care staff have identified issues with the systems they work within prohibiting their ability to make person-centred changes at mealtimes (Ericson-Lidman & Strandberg, 2015; Hammar et al., 2016), and communication challenges were identified by the survey and discussed in section 6.8. These communication challenges were also identified within the literature. They included concerns about the dissemination of recommendations among staff and no shared ownership of the implementation of recommendations while also linking to the availability of AHPs within these environments (Bennett et al., 2015; Ross et al., 2011; Smith-Tamaray et al., 2011). There is, therefore, a need to change culture and practices to support people with dementia at mealtimes.

9.3.3 Changing Culture and Promoting Person-centred Care

The topics discussed in this section bring together many of the issues that were raised and discussed in more detail in the previous sections. What the AHPs in this study recognised and promoted is that ‘standard’ care is not suitable for people with dementia. Throughout the course of the interviews and fundamental to the subthemes described here, the need for flexible and person-centred care for people with dementia-related mealtime difficulties and dysphagia is highlighted. Many of the challenges to delivering this care are issues beyond the control of the AHPs, such as the limited awareness of their roles that impacts referrals, the organisational structures in which they work that prevent them from working cohesively as an MDT, and the landscape of limited time, staffing and resource that they work within. However, one of the biggest challenges to their practice is the culture of the settings and services that they work within.

Dementia stigma and limited understanding of the condition are not new issues. In fact, for almost two decades, there have been ongoing obstacles to people with dementia receiving diagnoses, accessing services, and being provided with person-centred care (Brodaty, Draper, & Low, 2003; Burgon et al., 2019; Cations et al., 2020; Poole, Wilcock, Rait, Brodaty, & Robinson, 2020). Although symptoms and behaviours associated with dementia are a source of stress to nursing and care staff (Hazelhof, Schoonhoven, van Gaal, Koopmans, & Gerritsen, 2016), and there are clear issues with dementia knowledge among care staff (A. Robinson et al., 2014), research indicates that the opportunity to meet and work with people with dementia and learn about the condition can result in better attitudes (Chen et al., 2018; A. Kane, Murphy, & Kelly, 2020). Furthermore, some research illustrates that care staff do see people with dementia as people experiencing the world in a unique manner and the need to tailor care to their views, though there are challenges in moving away from task-based ways of working, namely the environment in which they work (Talbot & Brewer, 2016).

Many of these mealtime delivery issues link back to resource issues, with evidence suggesting that when time and resource are limited, care tasks, such as eating and drinking, are frequently left unfinished, with potentially significant consequences for people with dementia (Ludlow et al., 2019). In this study, many of the AHPs established a clear need to change mealtime practices and culture from just another task to a person-centred, sociable, and enjoyable experience. They described observing "*terrible feeding practice",* "*task-driven*" staff (discussed in more detail in section 9.3.1), and a need to emphasise that "*the mealtime experience, it's not just what's on the plate*". They also described observing instances of unfinished meals, or "*unfinished care*" as per Ludlow et al. (2019, p. 1). This is not how one would expect person-centred mealtimes to be described, yet this reflects how the literature describes the challenges of moving towards person-centred care (Carvajal et al., 2018; Grealish, Simpson, Soltau, & Edvardsson, 2019; Ludlow et al., 2019). Therefore, it reinforces why the AHPs saw their interventions and education as necessary to instigate changes in the culture of mealtime care. Many of the AHPs identified issues with knowledge levels, compounded by training provision challenges and their limited presence and availability to staff. This has led to them observing ongoing issues with how mealtimes are delivered.

Indeed, much of the culture change literature centres around the need for care homes to adapt from task-based care to person-centred care. The literature acknowledges that while culture change is possible, it is unclear which mechanisms are most effective (L. Low et al., 2015; Shier, Khodyakov, Cohen, Zimmerman, & Saliba, 2014). There is some suggestion that change in care homes is more successful when specific tasks, such as oral hygiene, are targeted, rather than changing overall care philosophy (L. Low et al., 2015). The AHPs aimed to change the mealtime culture from a rushed task to an enjoyable experience by empowering staff with knowledge about how they could positively or negatively influence a meal, and education is recognised as one component of culture change (Caspar et al., 2016; Nolan et al., 2008). However, the issue was the AHPs' previously discussed limited resource to provide training, which echoed the issues raised by the survey in section 6.6. A systematic review of training literature identified several factors necessary to ensure effective training and education (Surr et al., 2017). Some of these factors included individualised training materials, the inclusion of experiential or simulation-based learning, time for discussion and debate, a total duration of at least eight hours with a minimum of 90 minutes of individual engagement, and activities that support the attendees to apply learning to their practice. Aside from the training outlay of at least eight hours, the development of individualised materials tailored to organisational needs, in addition to carrying a caseload, would be incredibly time-consuming. The AHPs in this study recognised the need for training and education to change culture, but from their interviews, it is clear that none had the resource to apply this kind of approach. From the SLT surveys and AHP interviews, training was well-regarded, but that practice change was slow to come and difficult to sustain.

The pace of change was frustrating to them, and they found it very challenging to break the cycle of *"this is the way we've always done it"*. Interventions with reinforcement have been shown to change practice (Caspar et al., 2016), but the AHPs noted that their efforts to change perception were hampered by issues with availability and presence on wards and in services. This relates back to section 9.1.2 and the survey findings, where occupational therapy and physiotherapy presence on the wards made them directly accessible to their ward colleagues, but the SLTs and dietitians who were required to move between numerous settings did not have the time and opportunity to build rapport. It also reflects an issue identified in the survey, that very few SLTs were providing training follow-up. As such, it stands to reason that their training interventions were not changing culture and practices.

Further to training challenges, organisation culture and leadership style are recognised barriers to culture change (Kirkley et al., 2011; Nolan et al., 2008). The AHPs in this study identified that care staff were often disempowered by the systems that they worked within. Some AHPs even identified trust issues between staff and management that impacted their ability to apply person-centred care. They sought to make changes from a place of encouragement and positivity, but in the absence of management buy-in, also an issue identified by the survey, they faced an uphill battle. Lack of resource and inadequate staffing are barriers to person-centred care in care organisations with both high and low ratings of their standards of care, but lower-rated organisations also report administration and culture issues impacting their ability to provide person-centred care (Engle et al., 2017).

Furthermore, across health settings, organisations with positive workplace cultures are associated with better patient outcomes (Braithwaite, Herkes, Ludlow, Testa, & Lamprell, 2017), and in Scotland, a difference in the quality of care has been shown between public and third-sector care providers and for-profit care homes (Bach-Mortensen & Montgomery, 2019). These findings may indicate that for-profit organisations are less concerned about ensuring person-centred care is implemented or that not-for-profit organisations have stronger clinical governance mechanisms. Further to this, a more positive approach to dementia was shown among care staff in public care homes than for-profit homes (Islam, Baker, Huxley, Russell, & Dennis, 2017), indicating that there may be a difference in the care homes' culture and that they may have received different training. Interestingly, organisations that view themselves as focusing on changing their care culture have better patient outcomes with no difference in staffing or resource when compared to organisations that are not attempting to address their culture (Grabowski et al., 2014).

Culture change on the ground can be achieved through awareness-raising, training and education, and staff empowerment, the endeavours the AHPs have been focused on. However, the literature supports the idea that culture change must occur from a top-down decree and that without management buy-in and changes to services, the AHPs efforts to change culture on the ground are destined to fail. There is a clear and evident need to focus on education and training at a service-provider level to generate the necessary changes to make person-centred care standard in care organisations.

9.4 Comparing the Results of this Study to the Mealtime Models

Several mealtime management models were initially discussed in section 2.2.1, and some of the overarching issues that have been discussed up to this point will now be related to three of them. Comparison to these three models, the ‘Making the most of mealtimes (M3) conceptual model’ (Keller et al., 2014), the ‘Social ecological model of factors that influence eating performance’ (Liu et al., 2016), and the ‘Model for the provision of good nutritional care in dementia’ (Murphy et al., 2017) enables a coherent presentation of the wide-ranging issues raised in this chapter. These models were chosen as they address the complex policy, organisational, and cultural factors that impact on mealtimes. Two of these three models utilise a macro, meso, and micro-structure to reflect the organisation of the factors impacting mealtimes. This structure visually represents the complex and multi-faceted inter-relationships between policy, environment, the individual, and the mealtime experience. The macro-level refers to government and regulatory body factors and influences, the meso level refers to local policy and institutional practices, while the micro-level refers to individual factors, either carer factors or the individual with dementia. Though the model by Murphy et al. (2017) does not utilise the same structure, it too shares a primary focus on the impacts of the interactions between organisational and individual factors, with person-centred care acting as the lynchpin of the model. However, one thing that is important to bear in mind is that the chosen three models relate to the organisational impact of a care home environment. As such, they do not directly generalise to the current results as not all AHPs worked in or with care homes.

Interestingly the results of the current study both align and diverge from the issues depicted by the models discussed. The AHPs interviewed were impacted by many of the same organisational factors described in the three models, but they were also affected by factors beyond the scope of these models. These results primarily sit outwith the direct experience of the individual, the micro-level, and speak to how wider systems at the meso and macro levels are influencing care. Figure 9.1 was developed based on the findings of the current study. It depicts the structure of the environment the AHPs work within and the additional factors that also impact their role. The nested circles on the left-hand side of the model represent the general structure of the settings the AHPs work across. This is similar to those described in Keller et al. (2014) and Liu et al.’s (2016) models but reflects the Scottish context with specific examples. What this study adds is a consideration of how these issues impact AHPs, and it reflects the additional factors that they must take into consideration. The factors presented in the inverted triangle on the right-hand side directly impact the AHPs. The yellow circle representing the meal illustrates the additional concerns raised by the AHPs when providing person-centred information, assessment, and management. These person-centred factors are captured in Liu et al.’s, Keller et al.’s and Murphy et al.’s models, but these models do not reference the AHPs who are often responsible for coordinating mealtime care and making recommendations.

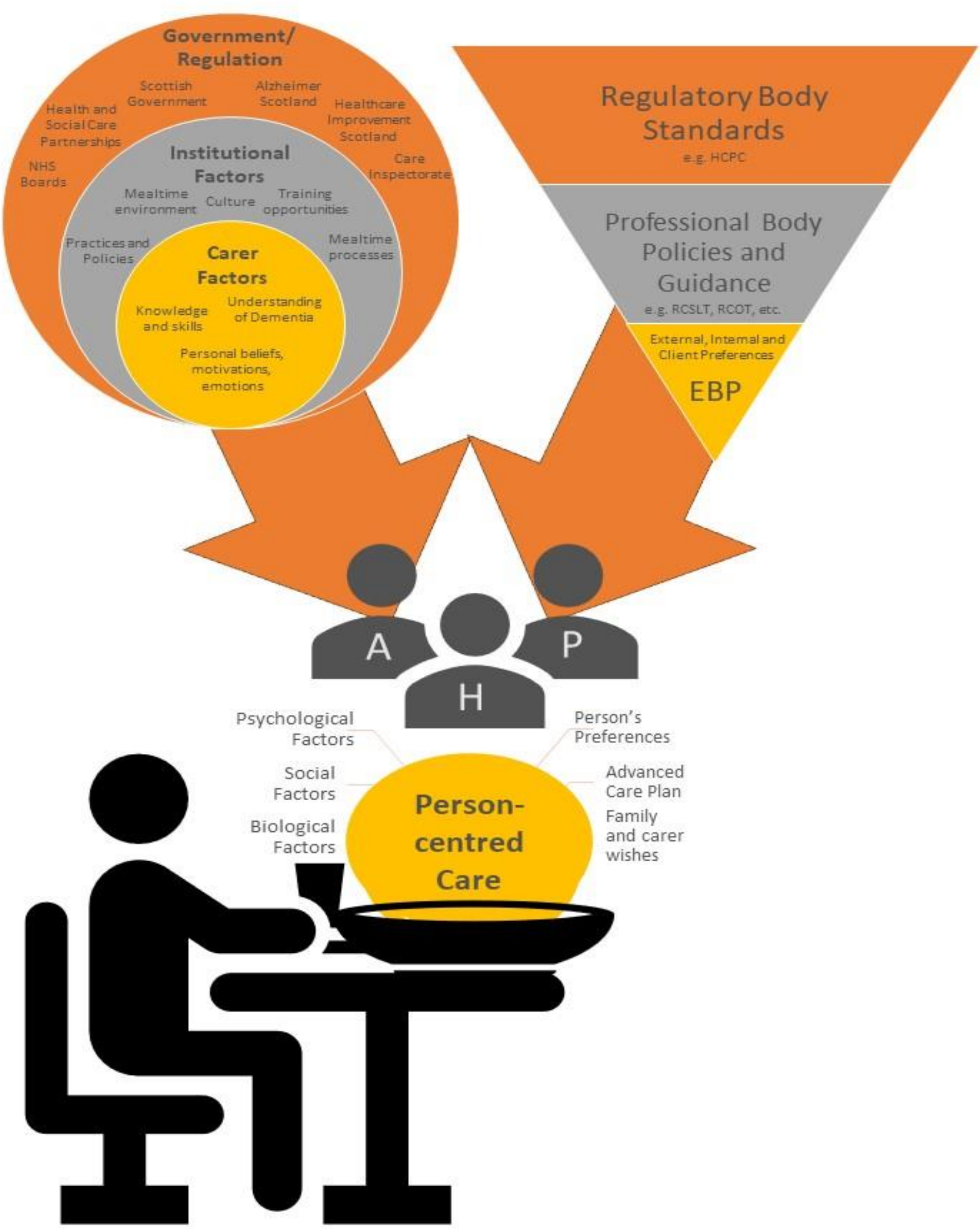


Figure 9.1 The macro, meso, and micro factors influencing the AHPs

The right-hand side of the model represents the AHPs unique environment. As described in section 9.1.1, AHPs working in the UK must register with HCPC. This registration ensures a basic level of knowledge and competence, and AHPs must adhere to this regulatory body's policies. Furthermore, most AHPs in the UK will be members of their profession-specific professional body: the RCSLT, the BDA, RCOT or the CSP. These bodies provide specific guidance to AHPs on the remit of their role in different populations. For example, the RCSLT (2014b) published a dementia position paper to outline the role of the SLT in communication and swallowing disorders in dementia. However, there does not appear to be similar guidance available for the other allied health professions through their professional bodies. The AHPs referred to the influence of evidence-based practice, although the results of these interviews reinforced the idea that they prioritise clinical expertise over research evidence. The third component of evidence-based practice, the preferences of an informed client, had the most significant influence on management. Limitations to understanding and addressing the preferences of a fully informed client are considered in the second theme.

On the left-hand side of the model, at the macro-level, the Scottish government's policies and available funding influence the management offered by AHPs. For dementia policy development, the Scottish government liaise closely with Alzheimer Scotland, endorsing many of Alzheimer Scotland's policies which in turn influence the regulatory bodies such as Health Improvement Scotland who are responsible for regulating hospitals in Scotland and the Care Inspectorate who regulate

Scottish care homes and home care providers. Government policies also influence the Health and Social Care Partnerships (HSCPs) across Scotland. HSCPs integrate social and healthcare administration in Scotland by joining NHS boards with local authorities with the aim of providing joined-up care for people when they need to access both health and social care services, for example, transitioning from home to hospital to a care home. At this macro level, the systems in place, such as regulators and governing bodies, do not recognise and prioritise the role of AHPs in supporting people with dementia at mealtimes. This is demonstrated through limited funding that would enable AHPs to work at the full extent of their roles.

The meso level of the model represents the institutional factors that influence the mealtime environment. Broad and overarching many areas, this level is influenced heavily by policies and funding provision. For example, the Care Inspectorate's regulations for minimum staffing levels will influence the number of staff available at mealtimes, and the funding available will influence the quality and variety of food provided. Most people with dementia in Scotland will access NHS facilities and care, and all participants were NHS employees. The NHS is funded and governed by the Scottish government, and their policies and limited funding will directly impact the care provided, for example, the number of SLTs assigned to a service or areas.

The impact of limited government and health service funding for the recruitment and retention of AHPs that leads to high caseloads is a macro issue with a direct influence on the meso levels. Issues such as working across multiple sites, limited opportunities to engage with colleagues, and high caseloads that prevented attendance at scheduled team meetings, represent how the macro issue of funding impacts the meso level. This impact could be seen in how health services stretch their AHP budget by assigning SLTs and dietitians to multiple wards and settings to ensure breadth but not sufficient depth of coverage. At a meso level, the systems the AHPs worked within were under-resourced. The AHPs felt unable to prioritise and manage the needs of people with dementia in the way they would prefer, which links to the micro level. At this micro level, this impacts on professionals' ability to collaborate, to co-design intervention, and to manage the needs of people with dementia appropriately.

At the meso and micro levels, there may be interactions between carers and the culture of their work environment. For example, care homes that do not have a person-centred culture and who do not provide training on mealtimes may have staff who do not have appropriate skills to adapt mealtimes and provide a safe and quality mealtime experience for people with dementia. Additionally, on the ground, staff or family members may also lack the knowledge to flag issues and seek an onward referral to AHPs to resolve mealtime issues. The micro-level of this model represents the person with dementia. At this level, there is limited awareness among people with dementia and their carers about AHPs and their rights to access them. As such, one of the most significant consequences of limited awareness of AHP roles is the risk of delayed or missed referrals to AHPs with potentially harmful health and well-being consequences for people with dementia.

The AHPs’ experiences drawn out from the interviews tended to refer to the interaction between meso and micro factors, and, in reality, there is significant connectivity between the two levels. The AHPs considered their impact on the experience of the mealtime and its contribution to providing adequate nutrition and hydration, as well as an enjoyable eating experience for people with dementia. However, multiple organisational factors impact the current results, and future research must target and address these challenges to create person-centred mealtime environments. Future policy must consider the interactions of these levels, and the impacts of funding cuts and austerity measures on services to people with dementia must be redressed.

9.5 Summary

This chapter presents a discussion of the results of the second phase of this adapted explanatory sequential mixed methods design. It takes an in-depth look at each theme’s constituent parts and their connotations while relating them to the findings of the first phase of the study and the literature. The flexibility of the semi-structured interview method enabled the discussion to uncover issues beyond the interview schedule. Though the study information primed the AHPs that the interview topics were based on their management of mealtimes, or the micro level, discussion frequently turned to the meso and macro levels. This added richer insights to the study by uncovering the policy, service, resource, and management issues that impacted the care AHPs can offer in dementia and, as a consequence, their mealtime interventions. These results describe the public health and social support context of dementia and how these structures support or inhibit people with dementia and their carers to engage with healthcare systems. They examine the systemic issues faced in the working environments of AHPs, the influence of the AHPs' personal values on their work, and how all of these factors interact to impact the person with dementia. Therefore, what these results add is the previously unheard AHP perspectives and the real-world issues they face. What can be inferred from these results is that it is the wider systems have the most significant impact on the delivery of mealtime support and that micro-level interventions should not be the focus of drivers of change. The next and final chapter outlines the overall conclusions developed from the results discussed so far further, as well as discussing the study limitations and directions for future research.

10 CONCLUSION

The introduction to this thesis began with a quote from Wendy Mitchell, a person living with dementia, where she eloquently described her changing relationship to food and the meaning it had in her life. Her quote contrasts with Levenson and Walker (2019, p. 954), who declared that *"eating and drinking are a biological necessity, a universal pleasure, and a basic human right".* While there cannot be an argument with the truth of the first part of their statement, this thesis' findings reflect the complexity of the interplay between mealtimes and pleasure, and in turn, quality of life. The two-phase adapted explanatory sequential mixed methods design revealed the complex reality of ensuring that people with dementia's mealtimes meet their biological needs while also providing enjoyment and pleasure. The first phase uncovered the experiences and practices of speech and language therapists supporting people with dementia-related mealtime difficulties and dysphagia. The second phase built on these findings by bringing to light the factors that influence their management by AHPs with a specialist interest in dementia. This concluding chapter will summarise the main findings of this thesis, discuss the implications of these findings, outline the contributions of this thesis, and relate the limitations of the study.

10.1 The Main Findings and Contributions to the Research Evidence Base

This study is believed to be the first to elicit the practices of SLTs in the UK and Ireland and AHPs in Scotland working with people with dementia-related mealtime difficulties and dysphagia. The first phase of this research provided a snapshot of SLTs' practices when managing dementia-related dysphagia and mealtime difficulties in the United Kingdom and Ireland. It also uncovered SLTs' opinions, perspectives, and experiences of the challenges and facilitators to practice they faced. The second phase of the study established AHPs' perspectives on managing mealtime difficulties of people with dementia. Furthermore, it revealed the issues and challenges impacting AHPs who support people with dementia and mealtime difficulties. It uncovers the voices of practitioners with a specialist interest in dementia and elicits unheard insights into the current challenges in delivering services to people living with these dementia-related conditions.

The findings will be of particular interest to researchers in the field of mealtime difficulties as they add important and unheard perspectives. Much of the research to date relates to nursing and care staff's management of the issues, and this study provides invaluable insights into AHP roles and viewpoints. Uncovering this information will allow the development of these roles and further advancement of care and service pathways for people with dementia. It also provides practical information about barriers to practice. The two phases of the study revealed a number of individual findings, though there were some overarching sentiments. Many of the issues that surfaced across both phases of the study related to resource issues, awareness of AHP roles, training concerns, variation in practice, and the evidence-base.

The impact that limited resources had on SLTs' ability to provide a service to people with dementia-related mealtime difficulties was one of the main outcomes of the study's first phase. In particular, lack of resource influenced the SLTs' ability to deliver services and led to long waiting times for people with dementia. These issues were also a dominant theme in the study's second phase and are encapsulated mainly by the theme 'the realities'. In this theme, the AHPs elaborated on the challenges they faced with understaffing and their ability to provide training and education. These findings are consistent with previous research (Bennett et al., 2019; Hopper et al., 2007), though the present study offers specific insight into the issues facing AHPs working with people with dementia. These resource issues influenced many aspects of SLT and AHP practices.

Issues with awareness of mealtime difficulties and dysphagia and AHP roles in their management also arose in both phases of the study. For the SLTs, this was most evident in the issues they faced with referrals and their belief that inappropriate referrals are tied to a lack of knowledge. Awareness of the need for referral to AHP services also became evident in the AHPs' interviews. The AHPs associated care staff knowledge directly with the quality and quantity of referrals they received. These findings indicate that people with dementia may not receive fair and equitable services for mealtime difficulties and dysphagia. This is strongly influenced by the lack of awareness of AHP roles among broader health professionals and lack of care pathways. In the interviews, the AHPs expanded on this further to describe carers' limited understanding of dementia and its impact on accessing services. On the face of it, this could suggest that opportunities to provide and engage with training are an important factor in creating awareness and knowledge among key stakeholders. The AHPs considered their limited ability to provide training as having a direct negative effect on the care people with dementia received and their access to AHPs. These findings have significant implications for funders and highlight the need to evaluate the impact of missed access to services on people with dementia. Funding decisions have implications for clinical practice, and it is clear from the findings of this study that AHPs have found limited funding, resource, and staffing detrimental to the services that they offer. The AHPs felt their management was further hindered by unclear service pathways and misconceptions and inaccuracies in understanding the roles of different AHPs. This study has raised important questions about the impact of limited resources on AHP activities, particularly training, and its implications for the care of people with dementia. Going forward, clear development and implementation of policy on AHP roles and people with dementia's rights to access AHP services is essential to ensuring that funders are obligated to supply resources to ensure people with dementia receive adequate and appropriate care.

The study also contributes to our understanding of how AHPs' values impact their work and how this may lead to variation in practice. The findings suggest that maximising individuals' quality of life with dementia was a decisive motivational factor for the AHPs. It influenced their delivery of care by modifying the means they used to deliver therapy and reconsidering typical outcome measures and approaches to risk and advance care planning. In the absence of standard guidelines, the AHPs used their own values to guide their assessment and treatment recommendations to support their personal view of comfort and quality of life. This is interesting when compared to the SLTs' decision-making in assessment and management uncovered by the survey. The SLTs described such decision-making as choosing from "*tools that I have to hand which I can use if necessary".* They did not indicate that their values impacted their decisions, but their experience did play a role. These findings broadly align with those of researchers such as McAllister's work from an Australian context and McCurtin's from an Irish perspective, who found that SLT decision-making is an iterative process influenced by their clinical experience and their specialism and that decision-making is an on-line process. This approach will produce management practices that appear varied and unpredictable. The AHPs identified that management in dementia needs to be varied as it needs to take individual factors, concerns, and environments into account as in the theme 'not one size fits all'. These interconnected issues and themes described by the study emphasise a need for national guidance on approaches to risk management and advance care planning for people with dementia. As discussed in previous chapters, research into their implementation is underway internationally, but this is of limited value to healthcare professionals who are required to make and support decisions on a day-to-day basis. This research highlights that in the absence of standardised guidelines, AHPs will adapt using their own values as a guideline. The implication of this on clinical practice is that healthcare providers cannot guarantee that this approach ensures beneficence to people with dementia, and the potential for unintentional maleficence exists. As such, this study strengthens the rationale for the development of guidance, which should be a priority for policymakers. The challenge then will be to ensure that the appropriate systems, services and support for people with dementia are provided with the tools and funding needed to implement these guidelines.

This study's findings enhance our understanding of the issues that influence and impact AHPs completing their roles and make several contributions to the current literature. Taken together, they suggest a need to consider how resource limitations and AHPs’ values and experience interact and respond to the unique presentations of mealtime difficulties and dysphagia and how this concurrence influences outcomes for people with dementia. These findings also recognise an urgent need to widen the evidence base for effective interventions, establish more insight into how and why SLTs and AHPs make the choices they do when managing dementia-related dysphagia and mealtime difficulties, and to disseminate this information among the professions.

10.2 Future Directions

This study lays the groundwork for future research into the management of mealtime difficulties and dysphagia and provides evidence for the need to clarify roles at a policy level. First, the survey and interview analysis of AHP practices undertaken here has extended our knowledge of the impact of limited resources on care delivery. The research also makes strides towards refining our understanding of the boundaries and scope of AHP roles but needs to be considered in a broader context. Future research should consider if these views are coherent across care staff and AHPs and different care settings. This research should investigate the information and intervention needs of people with different types and stages, and policy should outline the AHPs’ roles at each stage. Applying the methods and expanding the scope of this study to other professional groups and services across the UK could enable comparison, uncover further issues, and enable the development of nationwide guidance.

Secondly, the findings highlight how policy implementation breakdowns directly impact day-to-day care of people with dementia, for example, the impact of inadequate advance care planning. Without consideration of their wishes and care priorities, people with dementia may not receive the care that they would wish for. It also causes stress and upset to family members. The field of advance care planning in dementia is in a state of flux as a whole, but there is a clear need for AHPs to be involved in the research and development of guidelines. This involvement would enable policymakers to understand the often unheard and misunderstood voices of AHPs. Policy development also needs to consider how AHPs are supported to enable risks and what this means for SLTs and dietitians, particularly when dealing with severe mealtime difficulties and dysphagia.

Further research should be undertaken to explore how AHPs can effectively raise awareness of their roles supporting people with dementia-related mealtime difficulties and dysphagia. This research should also identify the information needs of family carers and local support services and tailor awareness campaigns and strategies towards these. As discussed in chapter 9, one approach to this would be consolidating and clarifying care pathways for people with dementia. The need for streamlined referral processes and pathways was clear from the issues described in both phases of the study, and research that supports their development will benefit the care of all people with dementia. Furthermore, clearer routes to accessing AHPs will have wider health benefits for this cohort. Research that develops these pathways should also consider the impacts of delayed or missed referrals and access to services.

A key research priority should be the investigation of the factors that have the most impact on mealtime success and with the most significant consequences for the health and well-being of the person with dementia. If these factors can be identified, targeted, tailored interventions can be developed to ameliorate or eliminate the harm they cause. Further exploration of the longer-term effects of modified food and fluids is also necessary if SLTs wish to continue using them with this population. Future research must also consider how AHPs access and act upon research evidence. Research that develops the intervention and decision-making evidence base could also support the development of outcome measurements appropriate for this population and improve service delivery.

One factor essential to developing services is ensuring that all stakeholders are educated in the identification and first-line management of mealtime difficulties and dysphagia. Research targeting the development of effective and efficient training is vital. This research must consider how AHPs should tailor the components, timing, and delivery of their training. Most vitally, this research must generate data on the effectiveness of training by examining both long and short-term outcome measures in health, well-being, and quality of life. No research to date has clearly established the benefits of training for both the affected caseload and the health service. Theoretically, improved knowledge of dementia, mealtime difficulties and dysphagia, as well as improved knowledge and implementation of first-line management strategies, and relevant, timely referrals to the appropriate professionals, should result in reduced costs and strain on services. The development of this evidence would also support the development of a business case for managers to direct resources to its implementation. The current study provides a rationale for future research to consider these directions.

10.3 Limitations of the Research

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

For the survey study, 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 of participants 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. Consequently, the findings were mostly presented as a single group. Future research may wish to consider targeting SLTs in specific settings to mitigate this issue and to deliver a clearer understanding of the implication of setting on management.

Additionally, as respondents self-selected, there may have been response biases. For example, people who met the study criteria but had a negative view of SLT involvement in supporting with dementia may be less inclined to spend time completing a questionnaire or alternatively they might have been more likely to respond, viewing the survey as an opportunity to express the issues they have with their role. However, as the survey examined a broad range of issues and responses reflected both positive and negative views, it is likely that the results presented here validly reflect the realities of practice. Therefore, the researcher feels that the study has raised some crucial issues that future discussions and research on dementia care must consider.

For the interview study, as discussed in chapter 7, debate exists about sample size in qualitative research, and there are no definitive guidelines to guide the novice researcher. As such, the decision was taken to use Braun and Clarke’s (2013) sample size recommendation of 20+ interviews for a large project and 21 interviews were conducted. Despite meeting this criterion, it cannot be denied that this is a relatively small sample size and had a significantly larger sample been engaged, the research may have generated different themes. Furthermore, the current sample is unbalanced, with SLTs making up close to half of the sample. This imbalance may reflect recruitment challenges as fewer dietitians, OTs, and physiotherapists accepted the invitation to take part in the study, potentially as a result of the well-documented resource issues discussed here. On the other hand, the researcher is an SLT and dysphagia, a main component of mealtime difficulties, is a disorder predominantly managed by SLTs. Therefore, notwithstanding the current respondents seeing it as their role, some other AHPs may not have, and consequently, they did not consider themselves to have sufficient interest or insight to share on the topic.

Furthermore, given the nature of the research, there are generalisation limitations. Though the interviews are believed to be truly representative of this group of specialist AHPs views, and efforts were made to ensure a geographically wide sample, it is not possible to definitively declare that these findings are illustrative of the experiences of all AHPs in the Scottish NHS or beyond. The convergence of findings between the survey and the interviews suggests that many of these issues are indeed universal, but future research that takes account of variation across settings, boards, as well as stage and type of dementia would be beneficial. As suggested above, such research could build on the current findings by broadening the geographic scale of the interviews and considering service or health board case studies with multiple qualitative and quantitative data sources.

10.4 Conclusions

This two-phase study used an adapted explanatory sequential mixed methods design to unearth the practices and perspectives of allied health professionals who manage dementia-related mealtime difficulties and dysphagia. The research has exposed the complexities of managing these issues and has shown the quagmire of issues that AHPs face while supporting people with dementia. Many of the barriers and challenges to practice uncovered in this thesis expanded beyond the direct management of the disorders at hand and revealed policy level and service level issues that impede on practice and have the potential to negatively impact on people with dementia. This study has made the voices of passionate healthcare workers who support people with dementia apparent. These voices were clear in their wish for the quality of life of people with dementia. As such, the thesis has outlined directions for future research and growth and uncovered steps that can be taken to improve the services accessed by people with dementia.

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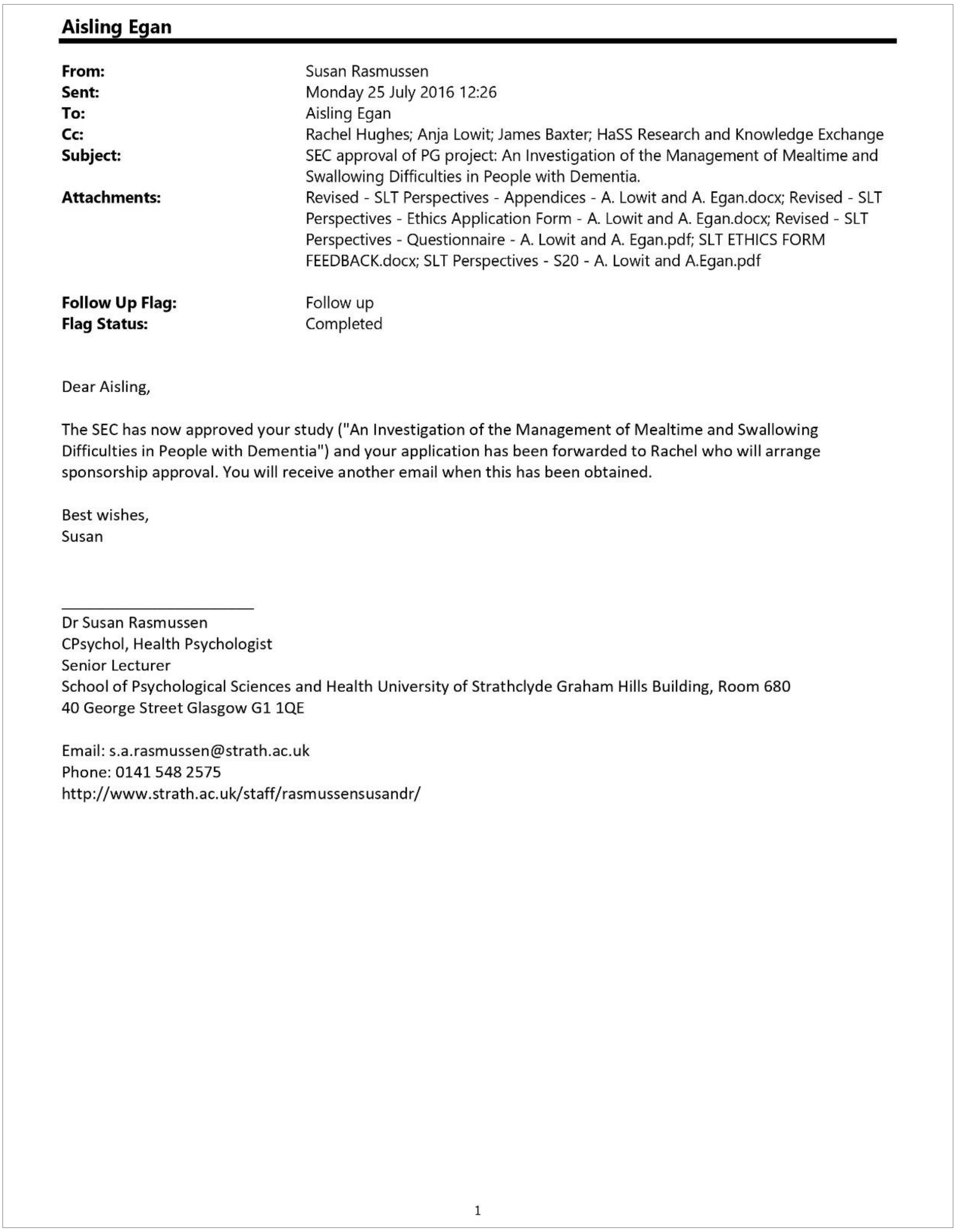
APPENDIX 1: ETHICAL APPROVAL QUESTIONNAIRE STUDY



Aisling Egan

From: Susan Rasmussen
Sent: Monday 25 July 2016 12:26
To: Aisling Egan
Cc: Rachel Hughes; Anja Lowit; James Baxter; HaSS Research and Knowledge Exchange
Subject: SEC approval of PG project: An Investigation of the Management of Mealtime and Swallowing Difficulties in People with Dementia.
Attachments: Revised - SLT Perspectives - Appendices - A. Lowit and A. Egan.docx; Revised - SLT Perspectives - Ethics Application Form - A. Lowit and A. Egan.docx; Revised - SLT Perspectives - Questionnaire - A. Lowit and A. Egan.pdf; SLT ETHICS FORM FEEDBACK.docx; SLT Perspectives - S20 - A. Lowit and A.Egan.pdf

Follow Up Flag: Follow up
Flag Status: Completed

Dear Aisling,

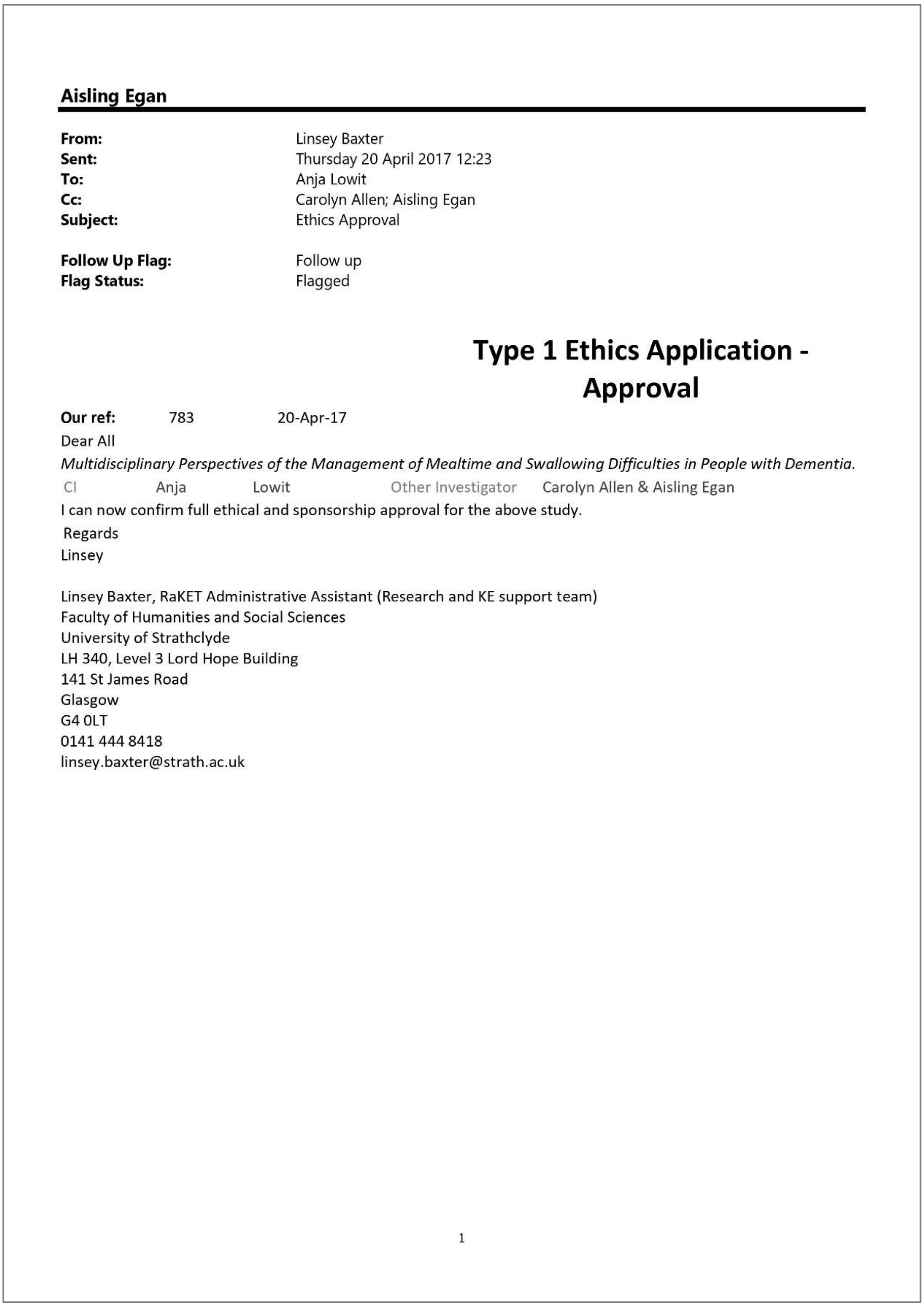
The SEC has now approved your study ("An Investigation of the Management of Mealtime and Swallowing Difficulties in People with Dementia") and your application has been forwarded to Rachel who will arrange sponsorship approval. You will receive another email when this has been obtained.

Best wishes,
Susan

Dr Susan Rasmussen
CPsychol, Health Psychologist
Senior Lecturer
School of Psychological Sciences and Health University of Strathclyde Graham Hills Building, Room 680
40 George Street Glasgow G1 1QE

Email: s.a.rasmussen@strath.ac.uk
Phone: 0141 548 2575
http://www.strath.ac.uk/staff/rasmussensusandr/

APPENDIX 2: ETHICAL APPROVAL INTERVIEW STUDY



Aisling Egan

From:	Linsey Baxter
Sent:	Thursday 20 April 2017 12:23
To:	Anja Lowit
Cc:	Carolyn Allen; Aisling Egan
Subject:	Ethics Approval
Follow Up Flag:	Follow up
Flag Status:	Flagged

Type 1 Ethics Application - Approval

Our ref: 783 20-Apr-17

Dear All

Multidisciplinary Perspectives of the Management of Mealtime and Swallowing Difficulties in People with Dementia.

CI Anja Lowit Other Investigator Carolyn Allen & Aisling Egan

I can now confirm full ethical and sponsorship approval for the above study.

Regards

Linsey

Linsey Baxter, RaKET Administrative Assistant (Research and KE support team)
Faculty of Humanities and Social Sciences
University of Strathclyde
LH 340, Level 3 Lord Hope Building
141 St James Road
Glasgow
G4 0LT
0141 444 8418
linsey.baxter@strath.ac.uk

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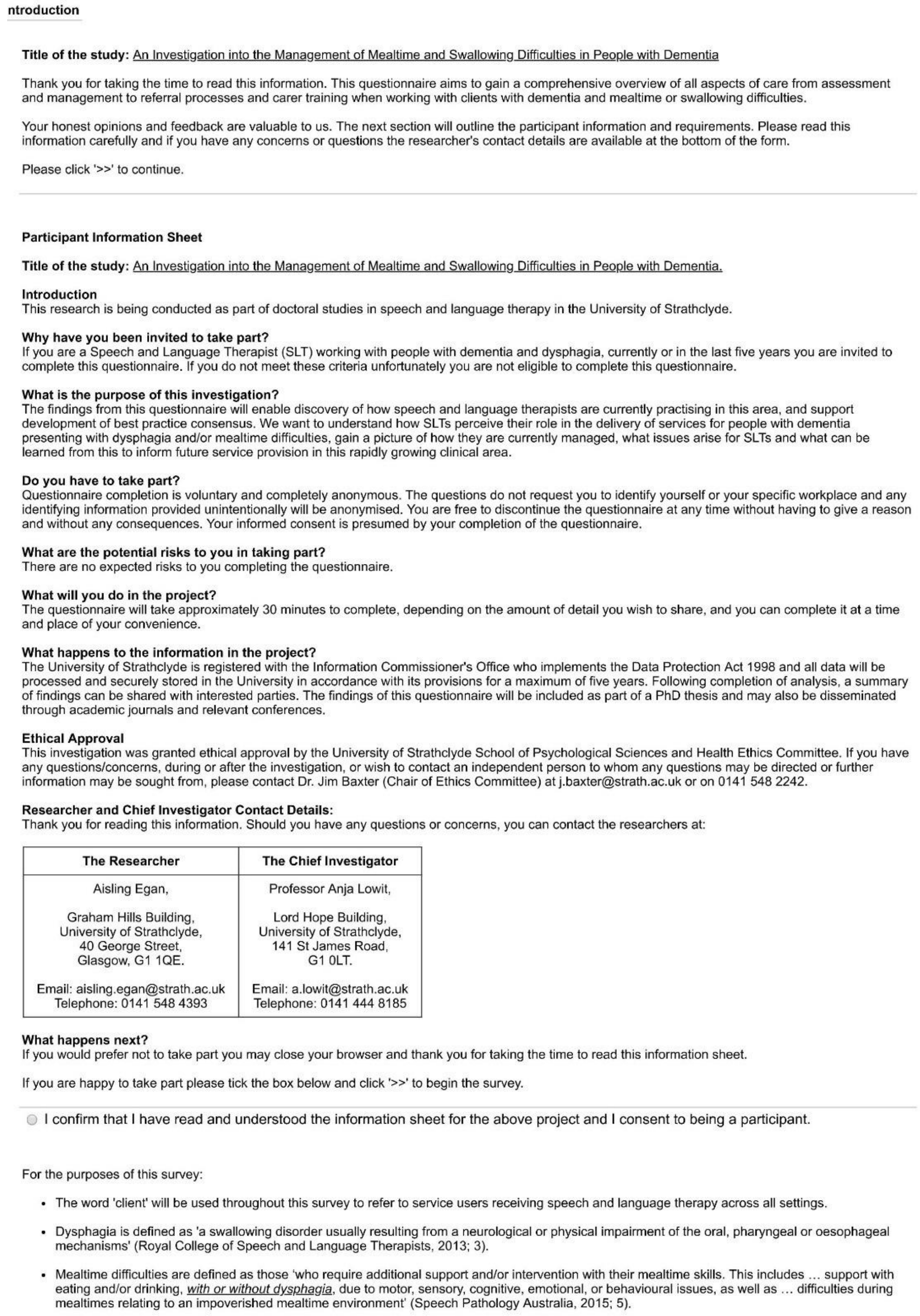
APPENDIX 3: QUESTIONNAIRE



ntroduction

Title of the study: An Investigation into the Management of Mealtime and Swallowing Difficulties in People with Dementia

Thank you for taking the time to read this information. This questionnaire aims to gain a comprehensive overview of all aspects of care from assessment and management to referral processes and carer training when working with clients with dementia and mealtime or swallowing difficulties.

Your honest opinions and feedback are valuable to us. The next section will outline the participant information and requirements. Please read this information carefully and if you have any concerns or questions the researcher's contact details are available at the bottom of the form.

Please click '>>' to continue.

Participant Information Sheet

Title of the study: An Investigation into the Management of Mealtime and Swallowing Difficulties in People with Dementia.

Introduction
This research is being conducted as part of doctoral studies in speech and language therapy in the University of Strathclyde.

Why have you been invited to take part?
If you are a Speech and Language Therapist (SLT) working with people with dementia and dysphagia, currently or in the last five years you are invited to complete this questionnaire. If you do not meet these criteria unfortunately you are not eligible to complete this questionnaire.

What is the purpose of this investigation?
The findings from this questionnaire will enable discovery of how speech and language therapists are currently practising in this area, and support development of best practice consensus. We want to understand how SLTs perceive their role in the delivery of services for people with dementia presenting with dysphagia and/or mealtime difficulties, gain a picture of how they are currently managed, what issues arise for SLTs and what can be learned from this to inform future service provision in this rapidly growing clinical area.

Do you have to take part?
Questionnaire completion is voluntary and completely anonymous. The questions do not request you to identify yourself or your specific workplace and any identifying information provided unintentionally will be anonymised. You are free to discontinue the questionnaire at any time without having to give a reason and without any consequences. Your informed consent is presumed by your completion of the questionnaire.

What are the potential risks to you in taking part?
There are no expected risks to you completing the questionnaire.

What will you do in the project?
The questionnaire will take approximately 30 minutes to complete, depending on the amount of detail you wish to share, and you can complete it at a time and place of your convenience.

What happens to the information in the project?
The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998 and all data will be processed and securely stored in the University in accordance with its provisions for a maximum of five years. Following completion of analysis, a summary of findings can be shared with interested parties. The findings of this questionnaire will be included as part of a PhD thesis and may also be disseminated through academic journals and relevant conferences.

Ethical Approval
This investigation was granted ethical approval by the University of Strathclyde School of Psychological Sciences and Health Ethics Committee. If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact Dr. Jim Baxter (Chair of Ethics Committee) at j.baxter@strath.ac.uk or on 0141 548 2242.

Researcher and Chief Investigator Contact Details:
Thank you for reading this information. Should you have any questions or concerns, you can contact the researchers at:

The Researcher	**The Chief Investigator**
Aisling Egan, Graham Hills Building, University of Strathclyde, 40 George Street, Glasgow, G1 1QE. Email: aisling.egan@strath.ac.uk Telephone: 0141 548 4393	Professor Anja Lowit, Lord Hope Building, University of Strathclyde, 141 St James Road, G1 0LT. Email: a.lowit@strath.ac.uk Telephone: 0141 444 8185

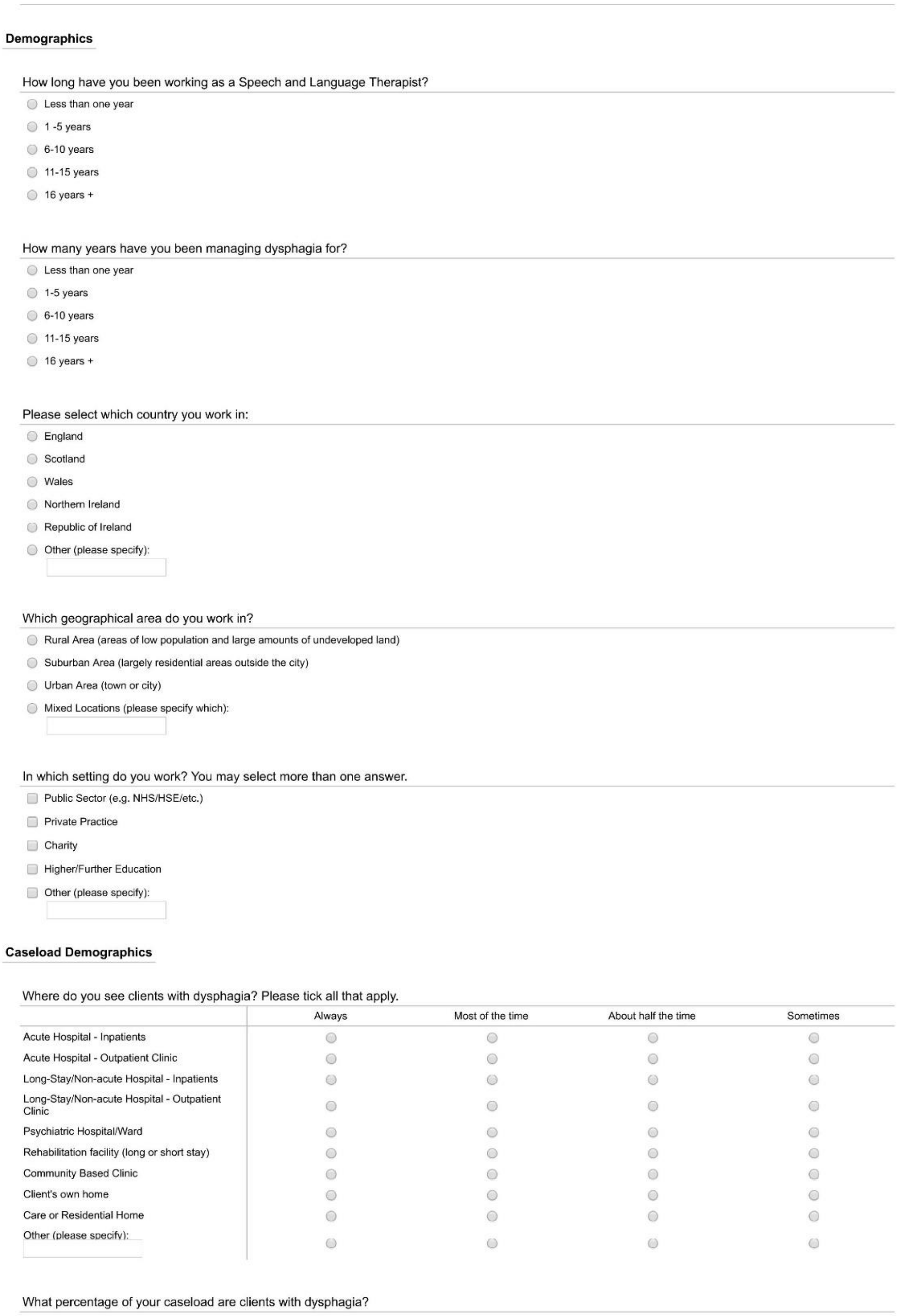
What happens next?
If you would prefer not to take part you may close your browser and thank you for taking the time to read this information sheet.

If you are happy to take part please tick the box below and click '>>' to begin the survey.

○ I confirm that I have read and understood the information sheet for the above project and I consent to being a participant.

For the purposes of this survey:

- The word 'client' will be used throughout this survey to refer to service users receiving speech and language therapy across all settings.
- Dysphagia is defined as '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, 2013; 3).
- Mealtime difficulties are defined as those 'who require additional support and/or intervention with their mealtime skills. This includes … support with eating and/or drinking, ***with or without dysphagia***, 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).



Demographics

How long have you been working as a Speech and Language Therapist?

○ Less than one year
○ 1 -5 years
○ 6-10 years
○ 11-15 years
○ 16 years +

How many years have you been managing dysphagia for?

○ Less than one year
○ 1-5 years
○ 6-10 years
○ 11-15 years
○ 16 years +

Please select which country you work in:

○ England
○ Scotland
○ Wales
○ Northern Ireland
○ Republic of Ireland
○ Other (please specify):

Which geographical area do you work in?

○ Rural Area (areas of low population and large amounts of undeveloped land)
○ Suburban Area (largely residential areas outside the city)
○ Urban Area (town or city)
○ Mixed Locations (please specify which):

In which setting do you work? You may select more than one answer.

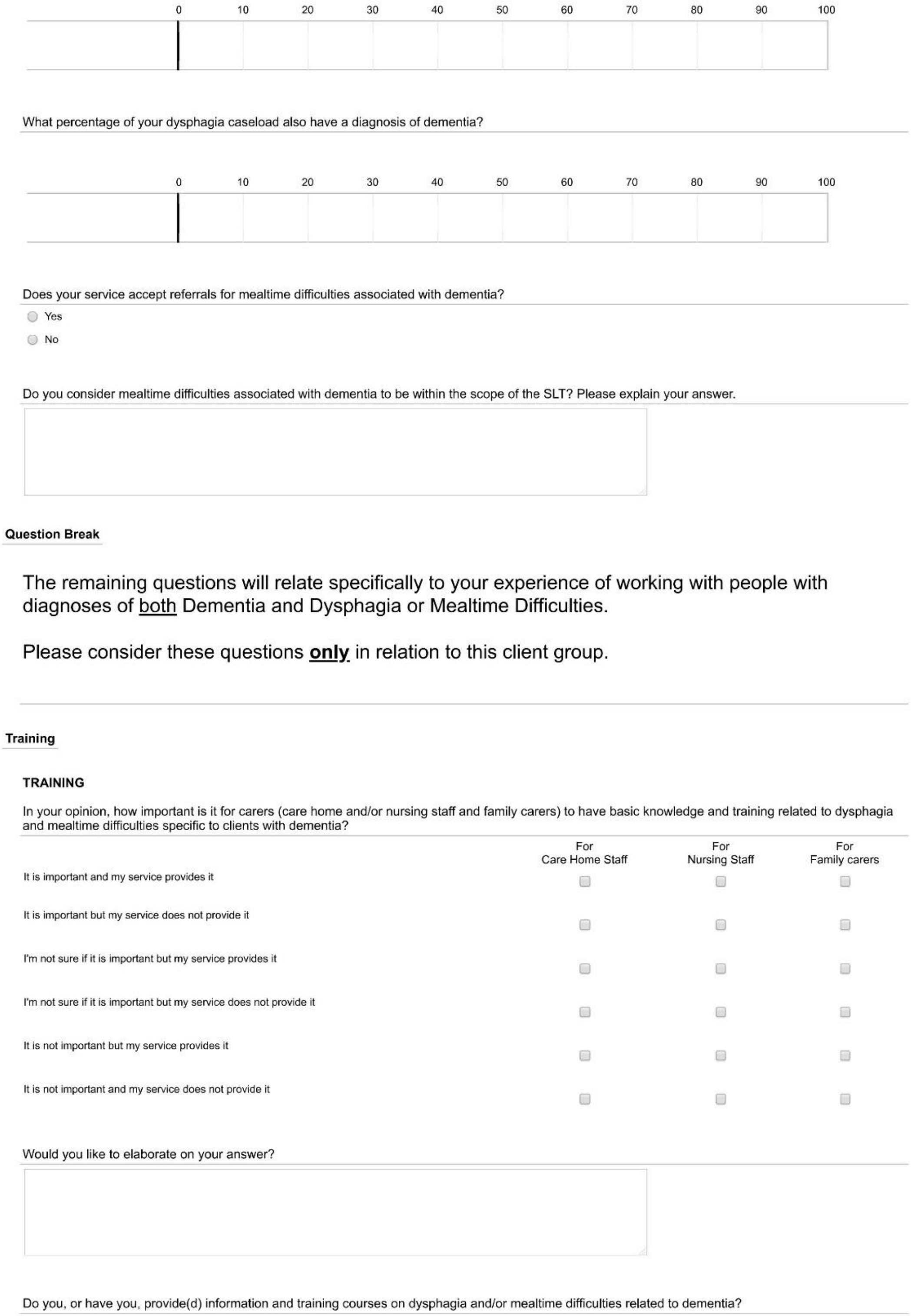
☐ Public Sector (e.g. NHS/HSE/etc.)
☐ Private Practice
☐ Charity
☐ Higher/Further Education
☐ Other (please specify):

Caseload Demographics

Where do you see clients with dysphagia? Please tick all that apply.

	Always	Most of the time	About half the time	Sometimes
Acute Hospital - Inpatients	○	○	○	○
Acute Hospital - Outpatient Clinic	○	○	○	○
Long-Stay/Non-acute Hospital - Inpatients	○	○	○	○
Long-Stay/Non-acute Hospital - Outpatient Clinic	○	○	○	○
Psychiatric Hospital/Ward	○	○	○	○
Rehabilitation facility (long or short stay)	○	○	○	○
Community Based Clinic	○	○	○	○
Client's own home	○	○	○	○
Care or Residential Home	○	○	○	○
Other (please specify):	○	○	○	○

What percentage of your caseload are clients with dysphagia?



0 10 20 30 40 50 60 70 80 90 100

What percentage of your dysphagia caseload also have a diagnosis of dementia?

0 10 20 30 40 50 60 70 80 90 100

Does your service accept referrals for mealtime difficulties associated with dementia?

○ Yes

○ No

Do you consider mealtime difficulties associated with dementia to be within the scope of the SLT? Please explain your answer.

Question Break

The remaining questions will relate specifically to your experience of working with people with diagnoses of <u>both</u> Dementia and Dysphagia or Mealtime Difficulties.

Please consider these questions **<u>only</u>** in relation to this client group.

Training

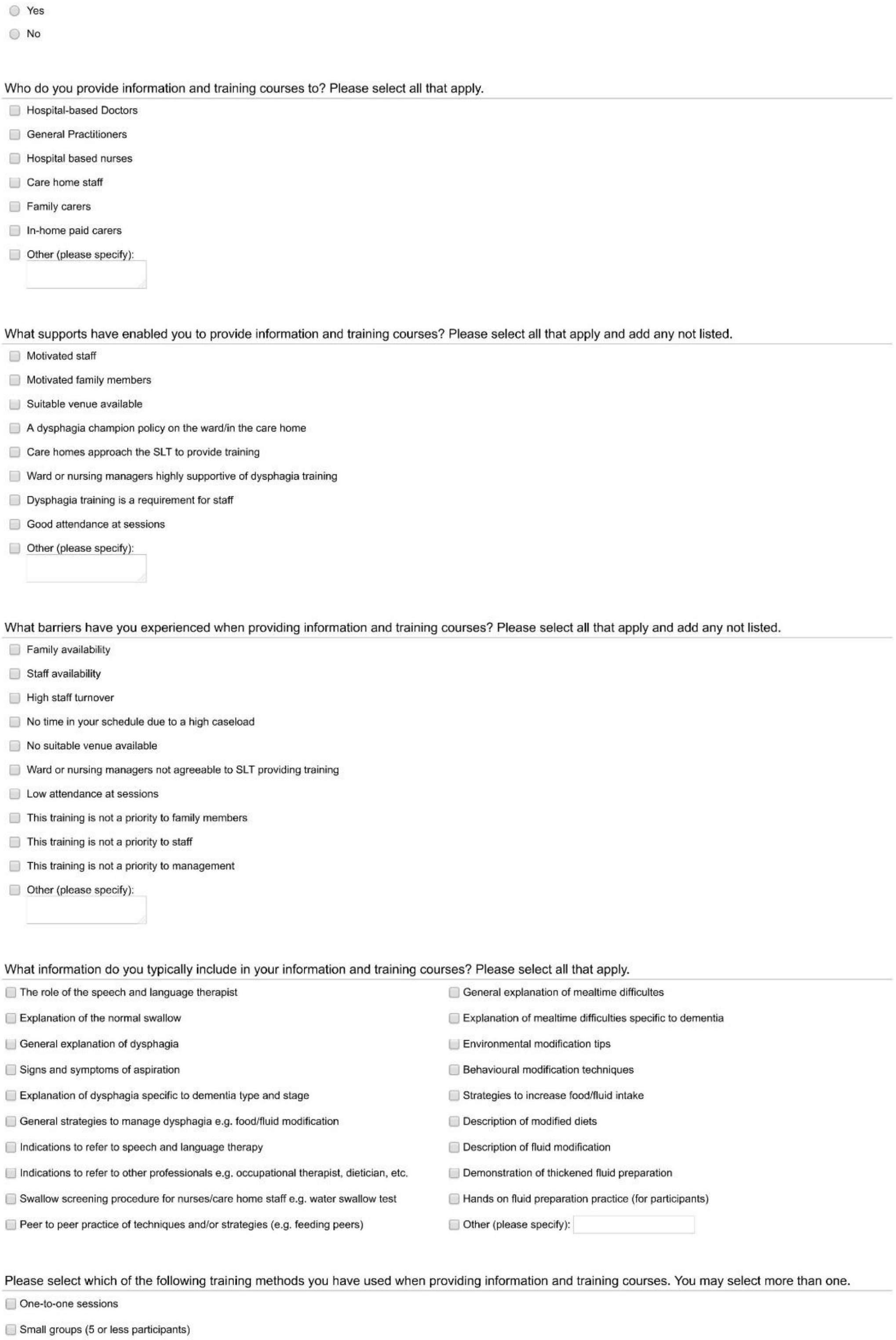
TRAINING

In your opinion, how important is it for carers (care home and/or nursing staff and family carers) to have basic knowledge and training related to dysphagia and mealtime difficulties specific to clients with dementia?

	For Care Home Staff	For Nursing Staff	For Family carers
It is important and my service provides it	☐	☐	☐
It is important but my service does not provide it	☐	☐	☐
I'm not sure if it is important but my service provides it	☐	☐	☐
I'm not sure if it is important but my service does not provide it	☐	☐	☐
It is not important but my service provides it	☐	☐	☐
It is not important and my service does not provide it	☐	☐	☐

Would you like to elaborate on your answer?

Do you, or have you, provide(d) information and training courses on dysphagia and/or mealtime difficulties related to dementia?



○ Yes

○ No

Who do you provide information and training courses to? Please select all that apply.

☐ Hospital-based Doctors

☐ General Practitioners

☐ Hospital based nurses

☐ Care home staff

☐ Family carers

☐ In-home paid carers

☐ Other (please specify):

What supports have enabled you to provide information and training courses? Please select all that apply and add any not listed.

☐ Motivated staff

☐ Motivated family members

☐ Suitable venue available

☐ A dysphagia champion policy on the ward/in the care home

☐ Care homes approach the SLT to provide training

☐ Ward or nursing managers highly supportive of dysphagia training

☐ Dysphagia training is a requirement for staff

☐ Good attendance at sessions

☐ Other (please specify):

What barriers have you experienced when providing information and training courses? Please select all that apply and add any not listed.

☐ Family availability

☐ Staff availability

☐ High staff turnover

☐ No time in your schedule due to a high caseload

☐ No suitable venue available

☐ Ward or nursing managers not agreeable to SLT providing training

☐ Low attendance at sessions

☐ This training is not a priority to family members

☐ This training is not a priority to staff

☐ This training is not a priority to management

☐ Other (please specify):

What information do you typically include in your information and training courses? Please select all that apply.

☐ The role of the speech and language therapist

☐ Explanation of the normal swallow

☐ General explanation of dysphagia

☐ Signs and symptoms of aspiration

☐ Explanation of dysphagia specific to dementia type and stage

☐ General strategies to manage dysphagia e.g. food/fluid modification

☐ Indications to refer to speech and language therapy

☐ Indications to refer to other professionals e.g. occupational therapist, dietician, etc.

☐ Swallow screening procedure for nurses/care home staff e.g. water swallow test

☐ Peer to peer practice of techniques and/or strategies (e.g. feeding peers)

☐ General explanation of mealtime difficultes

☐ Explanation of mealtime difficulties specific to dementia

☐ Environmental modification tips

☐ Behavioural modification techniques

☐ Strategies to increase food/fluid intake

☐ Description of modified diets

☐ Description of fluid modification

☐ Demonstration of thickened fluid preparation

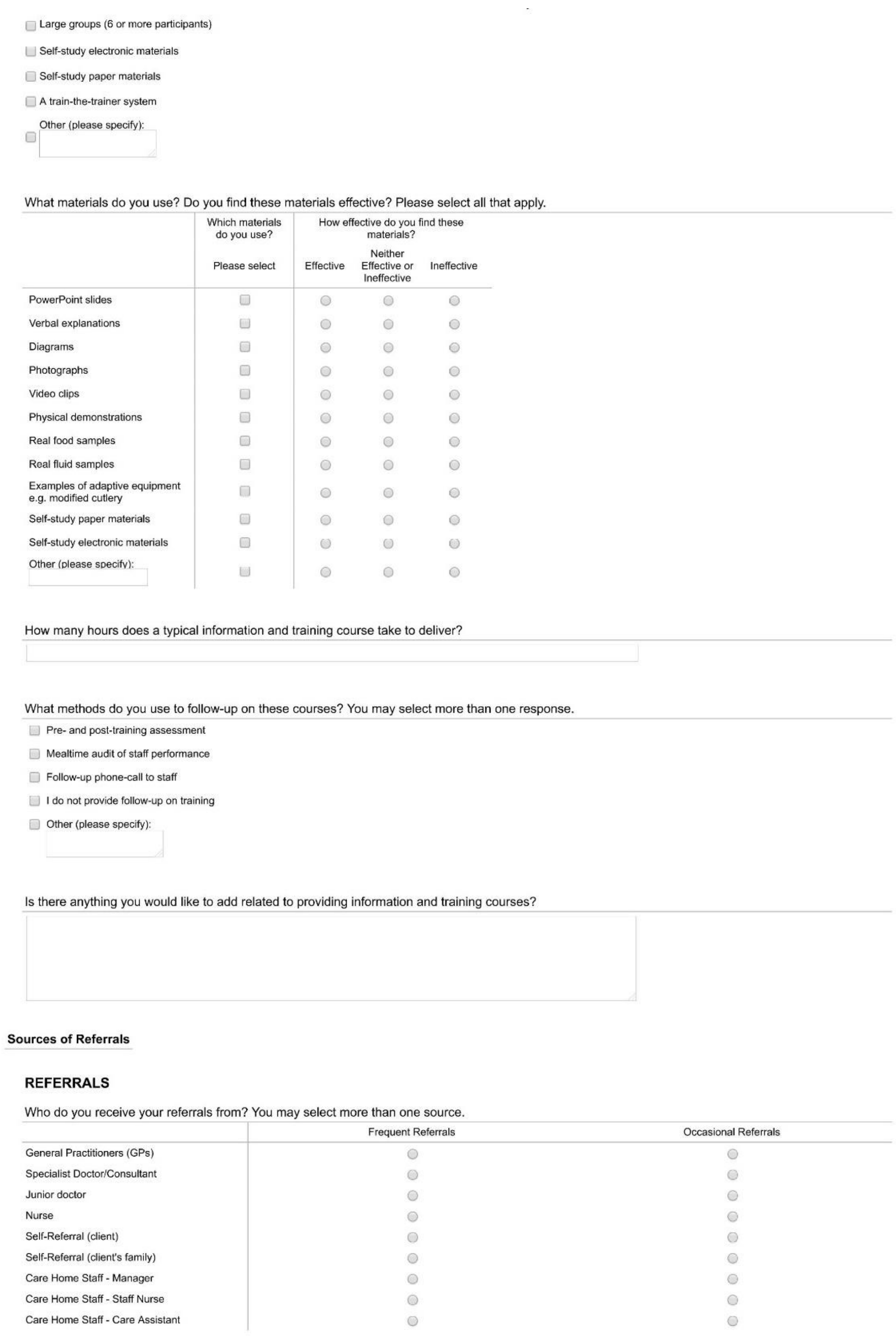
☐ Hands on fluid preparation practice (for participants)

☐ Other (please specify):

Please select which of the following training methods you have used when providing information and training courses. You may select more than one.

☐ One-to-one sessions

☐ Small groups (5 or less participants)



☐ Large groups (6 or more participants)

☐ Self-study electronic materials

☐ Self-study paper materials

☐ A train-the-trainer system

☐ Other (please specify):

What materials do you use? Do you find these materials effective? Please select all that apply.

	Which materials do you use?	How effective do you find these materials?		
	Please select	Effective	Neither Effective or Ineffective	Ineffective
PowerPoint slides	☐	○	○	○
Verbal explanations	☐	○	○	○
Diagrams	☐	○	○	○
Photographs	☐	○	○	○
Video clips	☐	○	○	○
Physical demonstrations	☐	○	○	○
Real food samples	☐	○	○	○
Real fluid samples	☐	○	○	○
Examples of adaptive equipment e.g. modified cutlery	☐	○	○	○
Self-study paper materials	☐	○	○	○
Self-study electronic materials	☐	○	○	○
Other (please specify):	☐	○	○	○

How many hours does a typical information and training course take to deliver?

What methods do you use to follow-up on these courses? You may select more than one response.

☐ Pre- and post-training assessment

☐ Mealtime audit of staff performance

☐ Follow-up phone-call to staff

☐ I do not provide follow-up on training

☐ Other (please specify):

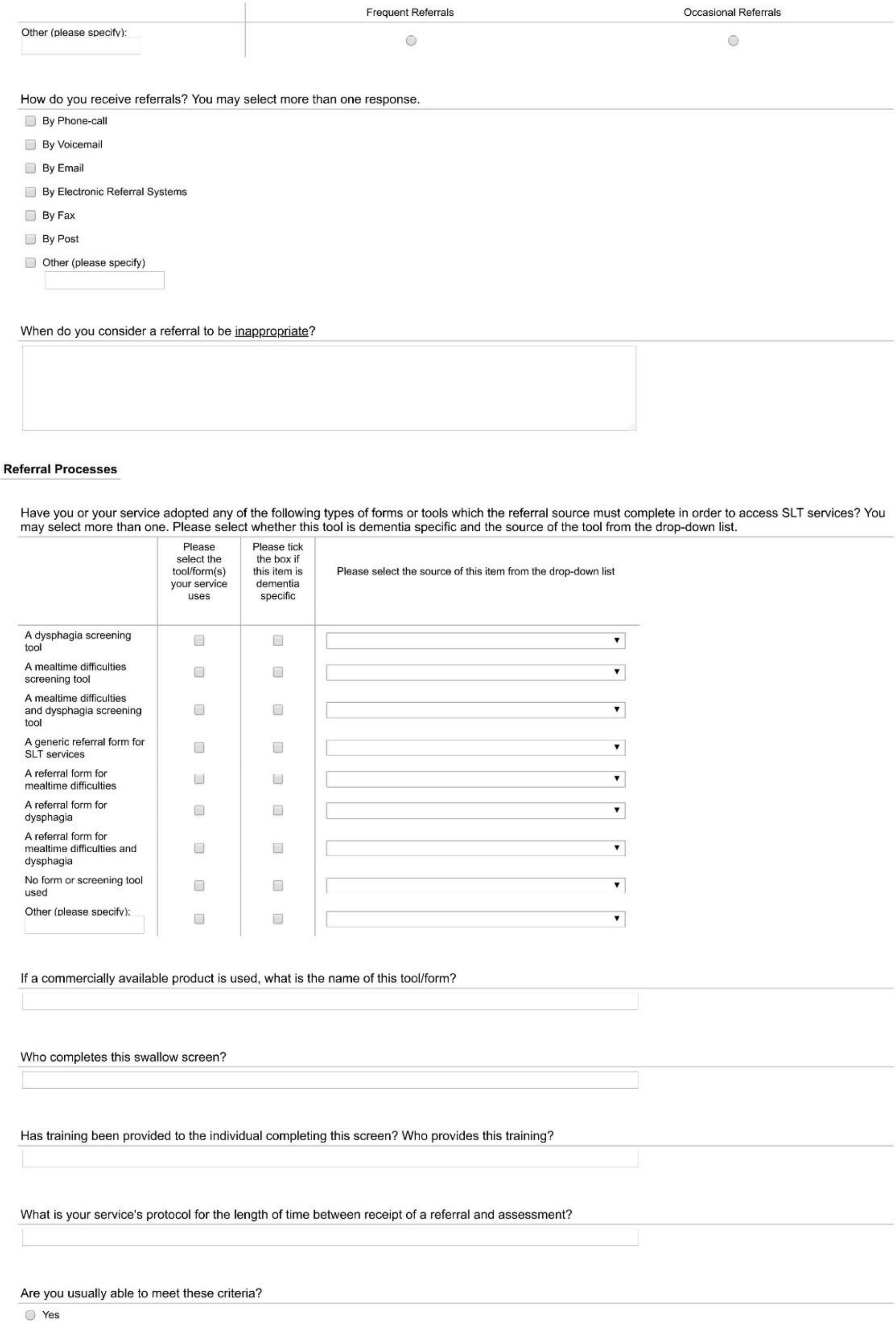
Is there anything you would like to add related to providing information and training courses?

Sources of Referrals

REFERRALS

Who do you receive your referrals from? You may select more than one source.

	Frequent Referrals	Occasional Referrals
General Practitioners (GPs)	○	○
Specialist Doctor/Consultant	○	○
Junior doctor	○	○
Nurse	○	○
Self-Referral (client)	○	○
Self-Referral (client's family)	○	○
Care Home Staff - Manager	○	○
Care Home Staff - Staff Nurse	○	○
Care Home Staff - Care Assistant	○	○



	Frequent Referrals	Occasional Referrals
Other (please specify):	○	○

How do you receive referrals? You may select more than one response.

☐ By Phone-call
☐ By Voicemail
☐ By Email
☐ By Electronic Referral Systems
☐ By Fax
☐ By Post
☐ Other (please specify)

When do you consider a referral to be <u>inappropriate</u>?

Referral Processes

Have you or your service adopted any of the following types of forms or tools which the referral source must complete in order to access SLT services? You may select more than one. Please select whether this tool is dementia specific and the source of the tool from the drop-down list.

	Please select the tool/form(s) your service uses	Please tick the box if this item is dementia specific	Please select the source of this item from the drop-down list
A dysphagia screening tool	☐	☐	▼
A mealtime difficulties screening tool	☐	☐	▼
A mealtime difficulties and dysphagia screening tool	☐	☐	▼
A generic referral form for SLT services	☐	☐	▼
A referral form for mealtime difficulties	☐	☐	▼
A referral form for dysphagia	☐	☐	▼
A referral form for mealtime difficulties and dysphagia	☐	☐	▼
No form or screening tool used	☐	☐	▼
Other (please specify):	☐	☐	▼

If a commercially available product is used, what is the name of this tool/form?

Who completes this swallow screen?

Has training been provided to the individual completing this screen? Who provides this training?

What is your service's protocol for the length of time between receipt of a referral and assessment?

Are you usually able to meet these criteria?

○ Yes

○ No

○ I don't know

Are there any additional comments you would like to make relating to referral processes?

☐

Assessment

ASSESSMENT

When assessing clients with dementia and dysphagia/mealtime difficulties please specify what you consider important to include and/or observe for in the assessment. Please drag and drop items into the box, the order is not important.

Items

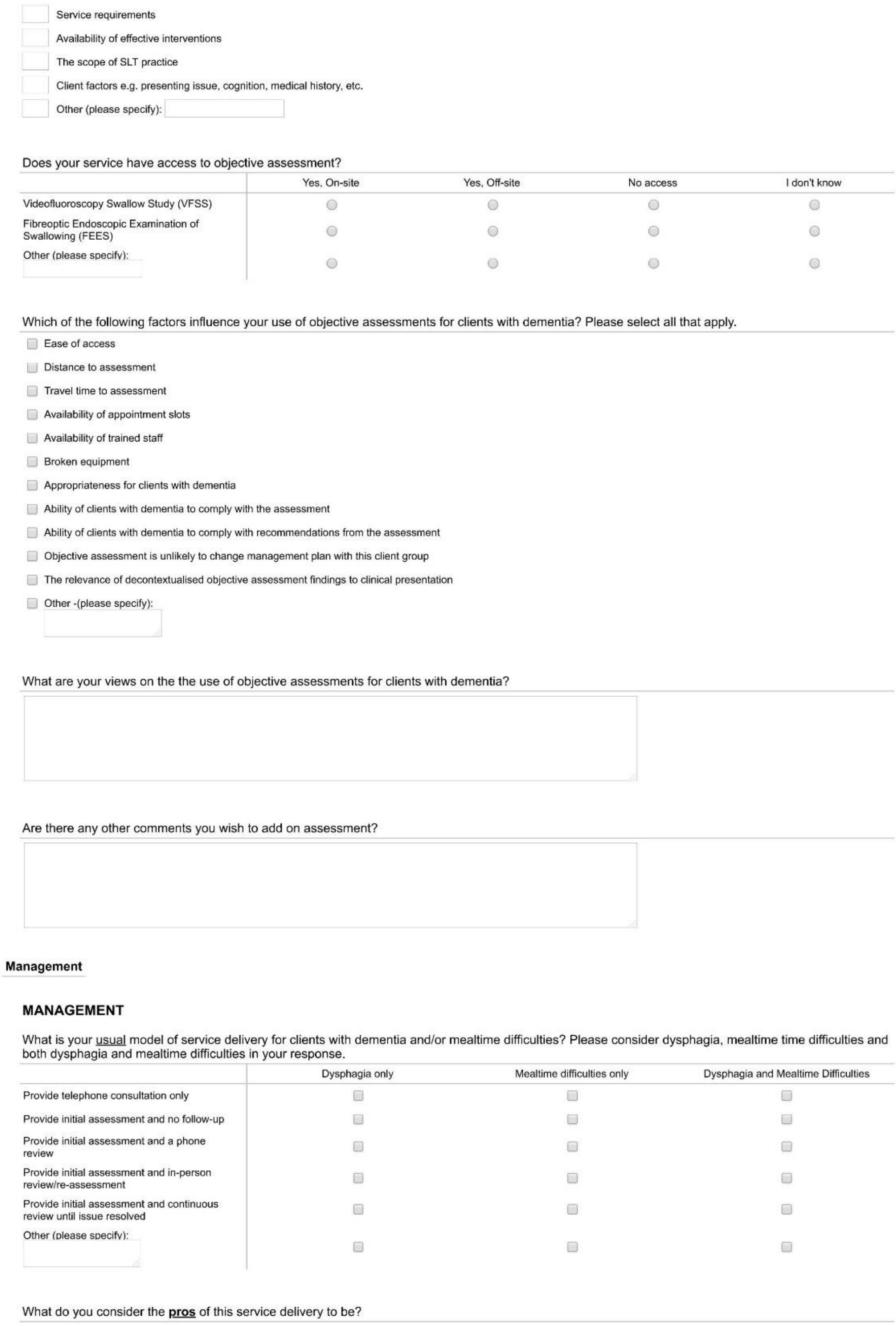
- Medical history
- History of complaint
- List of current medications
- Cognition
- Orientation to person, place and time
- Level of Alertness
- Language assessment
- Ability to follow commands
- Communication assessment
- Assessment of voice
- Assessment of speech
- Oromotor exam
- Dentition
- Sensation
- Gag reflex
- Volitional cough
- Volitional swallow
- Trials of fluid of various consistencies
- Trials of food of various consistencies
- Lip seal
- Efficacy of lingual movements
- Mastication
- Bolus formation
- Oral Residue
- Cervical auscultation
- Hyolaryngeal palpation
- Vocal quality
- Pulse Oximetry
- Cognitive-behavioural issues e.g. food pouching
- Awareness and anticipation of meals
- A mealtime observation
- Client preferences (e.g. food preferences, seating preferences, choice of carer, etc.)
- Self-feeding ability
- Client's positioning
- Utensils used
- Placemat/crockery used
- Carer's style of feeding support
- The mealtime environment e.g. light, noise, etc.
- Other (please specify): ☐

Items usually included

What is your rationale for including the selected items in your assessments? Please rank from the most likely (1) to least likely (7).

☐ Clinical experience

☐ Available evidence



☐ Service requirements
☐ Availability of effective interventions
☐ The scope of SLT practice
☐ Client factors e.g. presenting issue, cognition, medical history, etc.
☐ Other (please specify):

Does your service have access to objective assessment?

	Yes, On-site	Yes, Off-site	No access	I don't know
Videofluoroscopy Swallow Study (VFSS)	○	○	○	○
Fibreoptic Endoscopic Examination of Swallowing (FEES)	○	○	○	○
Other (please specify):	○	○	○	○

Which of the following factors influence your use of objective assessments for clients with dementia? Please select all that apply.

☐ Ease of access
☐ Distance to assessment
☐ Travel time to assessment
☐ Availability of appointment slots
☐ Availability of trained staff
☐ Broken equipment
☐ Appropriateness for clients with dementia
☐ Ability of clients with dementia to comply with the assessment
☐ Ability of clients with dementia to comply with recommendations from the assessment
☐ Objective assessment is unlikely to change management plan with this client group
☐ The relevance of decontextualised objective assessment findings to clinical presentation
☐ Other -(please specify):

What are your views on the the use of objective assessments for clients with dementia?

Are there any other comments you wish to add on assessment?

Management

MANAGEMENT

What is your usual model of service delivery for clients with dementia and/or mealtime difficulties? Please consider dysphagia, mealtime time difficulties and both dysphagia and mealtime difficulties in your response.

	Dysphagia only	Mealtime difficulties only	Dysphagia and Mealtime Difficulties
Provide telephone consultation only	☐	☐	☐
Provide initial assessment and no follow-up	☐	☐	☐
Provide initial assessment and a phone review	☐	☐	☐
Provide initial assessment and in-person review/re-assessment	☐	☐	☐
Provide initial assessment and continuous review until issue resolved	☐	☐	☐
Other (please specify):	☐	☐	☐

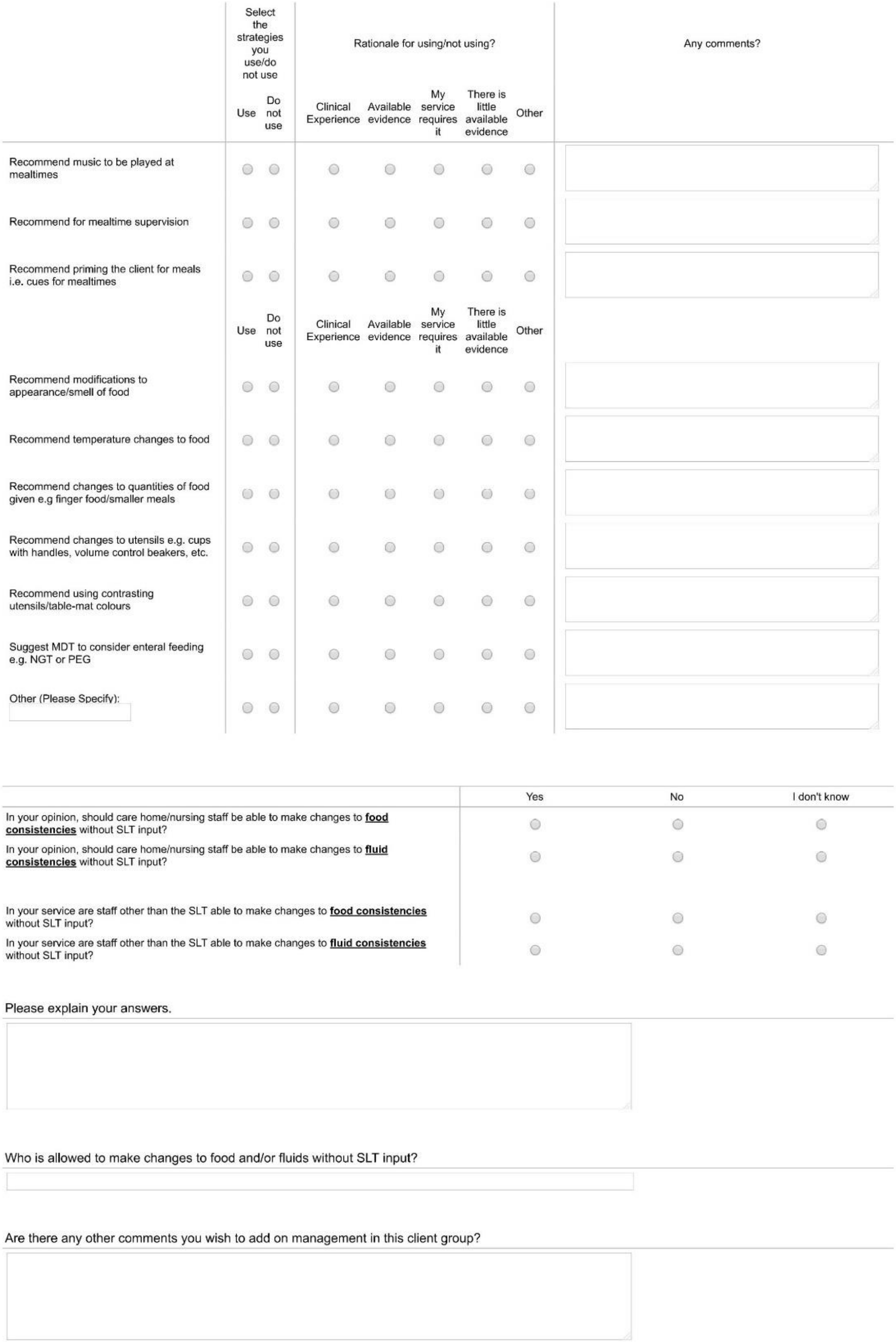
What do you consider the **pros** of this service delivery to be?

What do you consider the **cons** of this service delivery to be?

What would your preferred service delivery be and what would be the benefits of this?

From the management strategies below please identify which ones you use/do not use with clients with dementia and/or mealtime difficulties. What is your primary rationale for including/excluding the strategy?

	Select the strategies you use/do not use		Rationale for using/not using?					Any comments?
	Use	Do not use	Clinical Experience	Available evidence	My service requires it	There is little available evidence	Other	
Give advice to caregivers and families on strategies for management	○	○	○	○	○	○	○	
Provide consultation to nursing staff on strategies for management	○	○	○	○	○	○	○	
Provide consultation to care home staff on strategies for management	○	○	○	○	○	○	○	
Onward referral to other professionals (e.g. dietician, occupational therapist, doctor, etc.)	○	○	○	○	○	○	○	
Recommend food consistency changes	○	○	○	○	○	○	○	
Recommend fluid consistency changes	○	○	○	○	○	○	○	
Recommend postural change and monitoring	○	○	○	○	○	○	○	
Recommend compensatory strategies e.g. head turn, chin tuck, etc.	○	○	○	○	○	○	○	
	Use	Do not use	Clinical Experience	Available evidence	My service requires it	There is little available evidence	Other	
Recommend rehabilitation exercises e.g. masako, mendelsohn's manouevre	○	○	○	○	○	○	○	
Recommend environmental changes e.g. where client is seated for meals, who they sit with, etc.	○	○	○	○	○	○	○	
Recommend changes to lighting	○	○	○	○	○	○	○	
Recommend changes to noise levels	○	○	○	○	○	○	○	
Recommend reducing distractions	○	○	○	○	○	○	○	



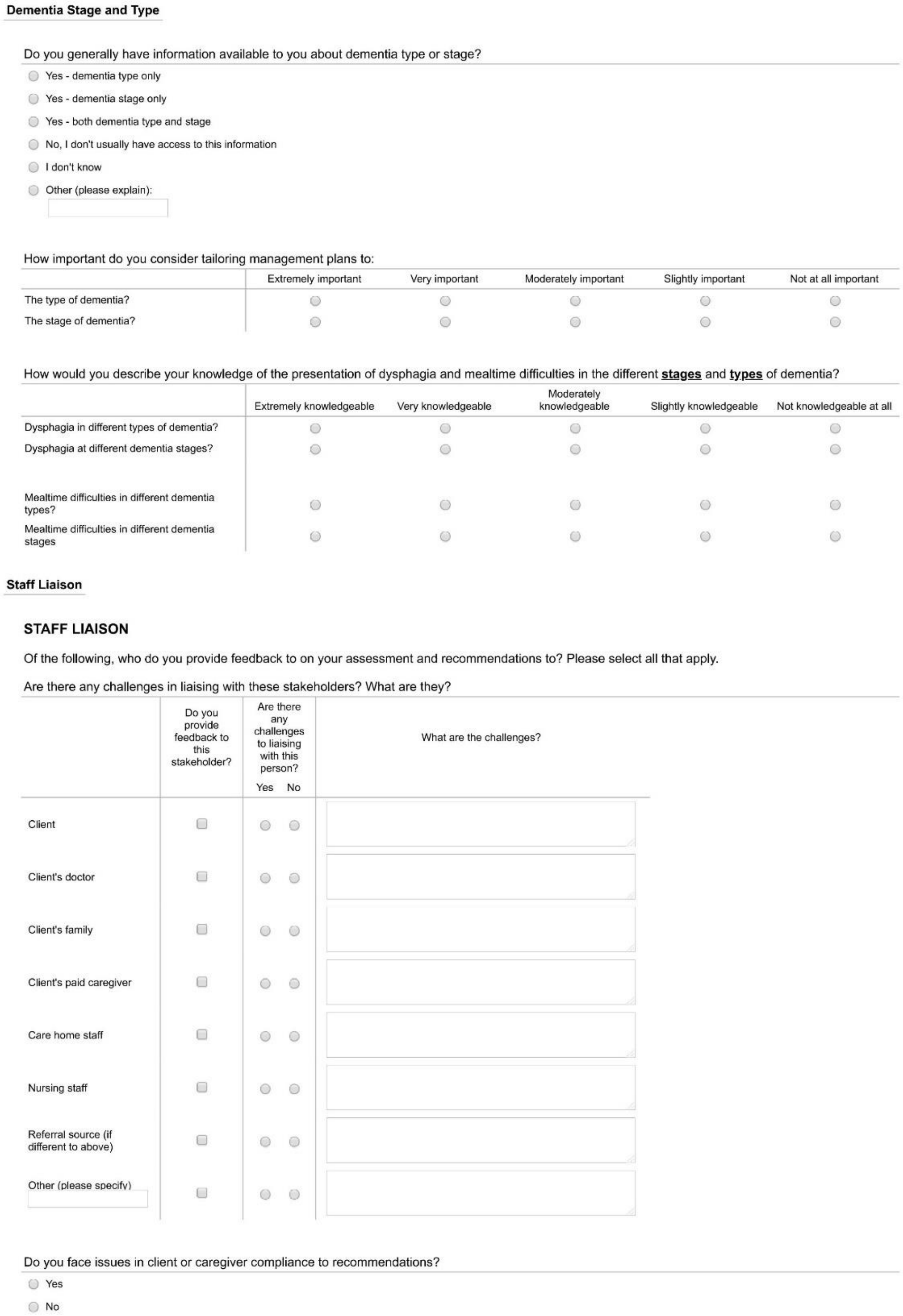
	Select the strategies you use/do not use		Rationale for using/not using?					Any comments?
	Use	Do not use	Clinical Experience	Available evidence	My service requires it	There is little available evidence	Other	
Recommend music to be played at mealtimes	○	○	○	○	○	○	○	
Recommend for mealtime supervision	○	○	○	○	○	○	○	
Recommend priming the client for meals i.e. cues for mealtimes	○	○	○	○	○	○	○	
	Use	Do not use	Clinical Experience	Available evidence	My service requires it	There is little available evidence	Other	
Recommend modifications to appearance/smell of food	○	○	○	○	○	○	○	
Recommend temperature changes to food	○	○	○	○	○	○	○	
Recommend changes to quantities of food given e.g finger food/smaller meals	○	○	○	○	○	○	○	
Recommend changes to utensils e.g. cups with handles, volume control beakers, etc.	○	○	○	○	○	○	○	
Recommend using contrasting utensils/table-mat colours	○	○	○	○	○	○	○	
Suggest MDT to consider enteral feeding e.g. NGT or PEG	○	○	○	○	○	○	○	
Other (Please Specify):	○	○	○	○	○	○	○	

	Yes	No	I don't know
In your opinion, should care home/nursing staff be able to make changes to **food consistencies** without SLT input?	○	○	○
In your opinion, should care home/nursing staff be able to make changes to **fluid consistencies** without SLT input?	○	○	○
In your service are staff other than the SLT able to make changes to **food consistencies** without SLT input?	○	○	○
In your service are staff other than the SLT able to make changes to **fluid consistencies** without SLT input?	○	○	○

Please explain your answers.

Who is allowed to make changes to food and/or fluids without SLT input?

Are there any other comments you wish to add on management in this client group?



Dementia Stage and Type

Do you generally have information available to you about dementia type or stage?

- ○ Yes - dementia type only
- ○ Yes - dementia stage only
- ○ Yes - both dementia type and stage
- ○ No, I don't usually have access to this information
- ○ I don't know
- ○ Other (please explain):

How important do you consider tailoring management plans to:

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
The type of dementia?	○	○	○	○	○
The stage of dementia?	○	○	○	○	○

How would you describe your knowledge of the presentation of dysphagia and mealtime difficulties in the different **stages** and **types** of dementia?

	Extremely knowledgeable	Very knowledgeable	Moderately knowledgeable	Slightly knowledgeable	Not knowledgeable at all
Dysphagia in different types of dementia?	○	○	○	○	○
Dysphagia at different dementia stages?	○	○	○	○	○
Mealtime difficulties in different dementia types?	○	○	○	○	○
Mealtime difficulties in different dementia stages	○	○	○	○	○

Staff Liaison

STAFF LIAISON

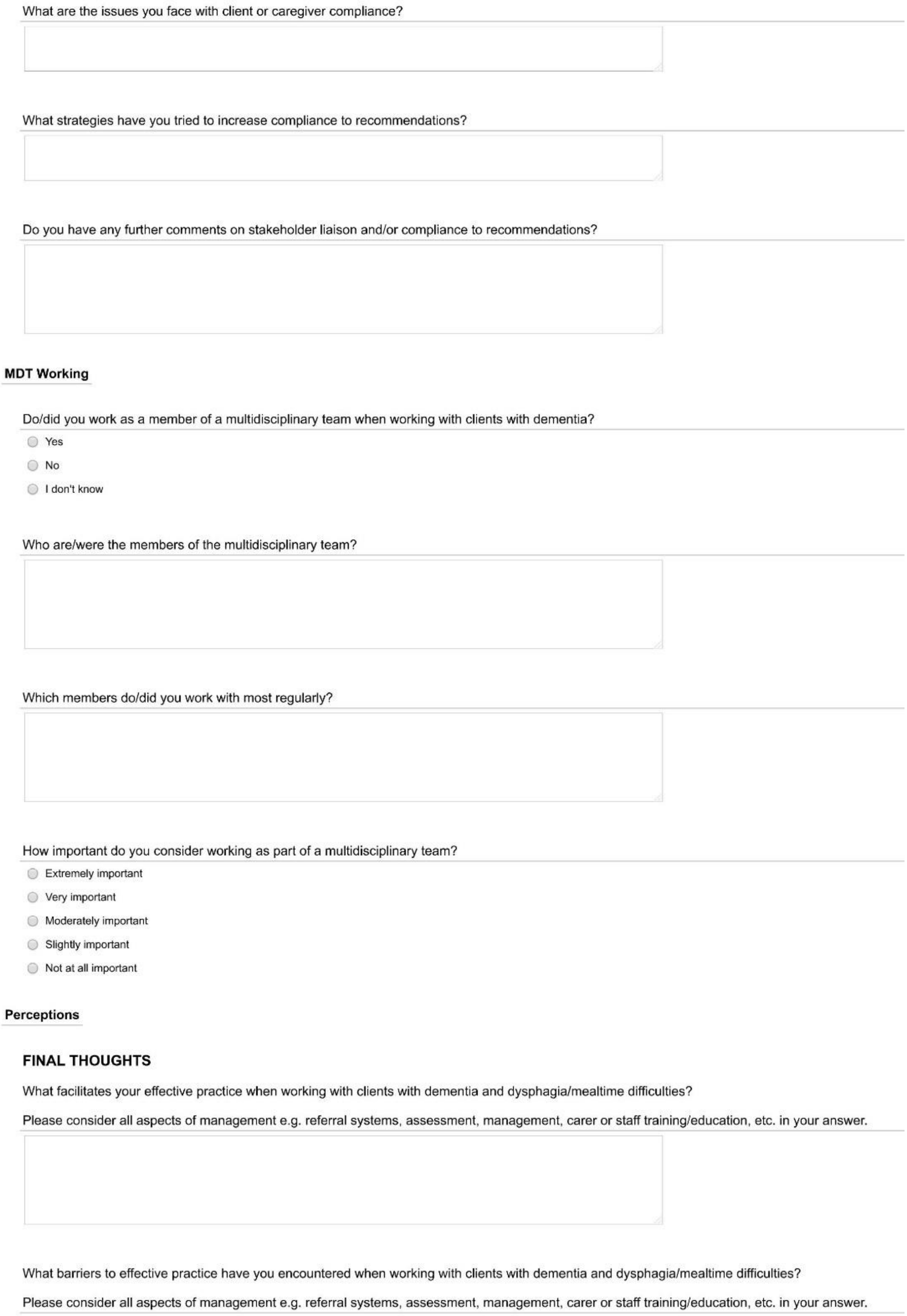
Of the following, who do you provide feedback to on your assessment and recommendations to? Please select all that apply.

Are there any challenges in liaising with these stakeholders? What are they?

	Do you provide feedback to this stakeholder?	Are there any challenges to liaising with this person? Yes	No	What are the challenges?
Client	☐	○	○	
Client's doctor	☐	○	○	
Client's family	☐	○	○	
Client's paid caregiver	☐	○	○	
Care home staff	☐	○	○	
Nursing staff	☐	○	○	
Referral source (if different to above)	☐	○	○	
Other (please specify)	☐	○	○	

Do you face issues in client or caregiver compliance to recommendations?

- ○ Yes
- ○ No



What are the issues you face with client or caregiver compliance?

What strategies have you tried to increase compliance to recommendations?

Do you have any further comments on stakeholder liaison and/or compliance to recommendations?

MDT Working

Do/did you work as a member of a multidisciplinary team when working with clients with dementia?

○ Yes
○ No
○ I don't know

Who are/were the members of the multidisciplinary team?

Which members do/did you work with most regularly?

How important do you consider working as part of a multidisciplinary team?

○ Extremely important
○ Very important
○ Moderately important
○ Slightly important
○ Not at all important

Perceptions

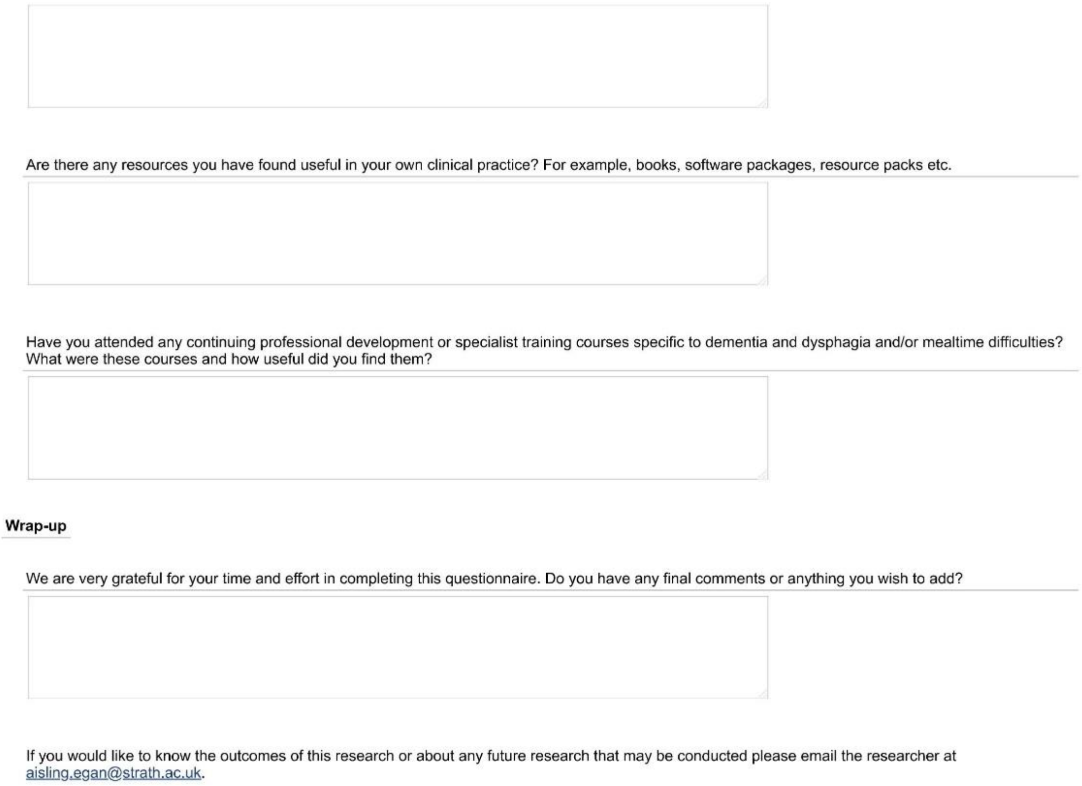
FINAL THOUGHTS

What facilitates your effective practice when working with clients with dementia and dysphagia/mealtime difficulties?

Please consider all aspects of management e.g. referral systems, assessment, management, carer or staff training/education, etc. in your answer.

What barriers to effective practice have you encountered when working with clients with dementia and dysphagia/mealtime difficulties?

Please consider all aspects of management e.g. referral systems, assessment, management, carer or staff training/education, etc. in your answer.



Are there any resources you have found useful in your own clinical practice? For example, books, software packages, resource packs etc.

Have you attended any continuing professional development or specialist training courses specific to dementia and dysphagia and/or mealtime difficulties? What were these courses and how useful did you find them?

Wrap-up

We are very grateful for your time and effort in completing this questionnaire. Do you have any final comments or anything you wish to add?

If you would like to know the outcomes of this research or about any future research that may be conducted please email the researcher at aisling.egan@strath.ac.uk.

APPENDIX 4: TESTS OF ASSOCIATION HYPOTHESES

Knowledge of dysphagia and mealtime difficulties and the importance of tailoring management	H_0: No relationship exists between knowledge of dysphagia in dementia types and perceived importance of tailoring management to dementia type in the population H_1: There is a relationship between knowledge of dysphagia in dementia types and perceived importance of tailoring management to dementia type in the population
	H_0: No relationship exists between knowledge of mealtime difficulties in dementia types and perceived importance of tailoring management to dementia type in the population H_1: There is a relationship between knowledge of mealtime difficulties in dementia types and perceived importance of tailoring management to dementia type in the population
	H_0: No relationship exists between knowledge of dysphagia in dementia stage and perceived importance of tailoring management to dementia stage in the population H_1: There is a relationship between knowledge of dysphagia in dementia stage and perceived importance of tailoring management to dementia stage in the population
	H_0: No relationship exists between knowledge of mealtime difficulties in dementia stages and perceived importance of tailoring management to dementia stage in the population H_1: There is a relationship between knowledge of mealtime difficulties in dementia stages and perceived importance of tailoring management to dementia stage in the population
Knowledge of dysphagia and	H_0: No relationship exists between knowledge of dysphagia in dementia types and knowledge of mealtime difficulties in dementia types in the population

mealtime difficulties	H_1: There is a relationship between knowledge of dysphagia in dementia types and knowledge of mealtime difficulties in dementia types in the population
	H_0: No relationship exists between knowledge of dysphagia in dementia stage and knowledge of mealtime difficulties in dementia stages in the population H_1: There is a relationship between knowledge of dysphagia in dementia stage and knowledge of mealtime difficulties in dementia stages in the population
	H_0: No relationship exists between knowledge of dysphagia in dementia stages and knowledge of dysphagia in dementia types in the population H_1: There is a relationship between knowledge of dysphagia in dementia stages and knowledge of dysphagia in dementia types in the population
	H_0: No relationship exists between knowledge of mealtime difficulties in dementia stages and knowledge of mealtime difficulties in dementia types in the population H_1: There is a relationship between knowledge of mealtime difficulties in dementia stages and knowledge of mealtime difficulties in dementia types in the population
Place of work	H_0: No relationship exists between place of work and knowledge of dysphagia in dementia types in the population H_1: There is a relationship between place of work and knowledge of dysphagia in dementia types in dementia in the population
	H_0: No relationship exists between place of work and knowledge of dysphagia in dementia stages in the population

	H_1: There is a relationship between place of work and knowledge of dysphagia in dementia stages in dementia in the population
	H_0: No relationship exists between place of work and knowledge of mealtime difficulties in dementia types in the population H_1: There is a relationship between place of work and knowledge of mealtime difficulties in dementia types in dementia in the population
	H_0: No relationship exists between place of work and knowledge of dysphagia in dementia stages in the population H_1: There is a relationship between place of work and knowledge of dysphagia in dementia stages in dementia in the population
	H_0: No relationship exists between place of work and importance of tailoring management to dementia type in the population H_1: There is a relationship between place of work and importance of tailoring management to dementia type in dementia in the population
	H_0: No relationship exists between place of work and importance of tailoring management to dementia stages in the population H_1: There is a relationship between place of work and importance of tailoring management to dementia stages in dementia in the population
Country of Work	H_0: No relationship exists between Country worked in and knowledge of dysphagia in dementia type in the population H_1: There is a relationship between Country worked in and knowledge of dysphagia in dementia type in the population

	H_0: No relationship exists between country worked in and knowledge of dysphagia in dementia stages in the population H_1: There is a relationship between country worked in and knowledge of dysphagia in dementia stages in the population
	H_0: No relationship exists between Country worked in and knowledge of mealtime difficulties in dementia type in the population H_1: There is a relationship between Country worked in and knowledge of mealtime difficulties in dementia type in the population
	H_0: No relationship exists between country worked in and knowledge of mealtime difficulties in dementia stages in the population H_1: There is a relationship between country worked in and knowledge of mealtime difficulties in dementia stages in the population
	H_0: No relationship exists between country worked in and perceived importance of tailoring management to dementia type in the population H_1: There is a relationship between country worked in and perceived importance of tailoring management to dementia type in the population
	H_0: No relationship exists between country worked in and perceived importance of tailoring management to dementia stage in the population H_1: There is a relationship between country worked in and perceived importance of tailoring management to dementia stage in the population

Years of Experience	H_0: No relationship exists between years of experience working as an SLT and knowledge of dysphagia in dementia type in the population H_1: There is a relationship between years of experience working as an SLT and knowledge of dysphagia in dementia type in the population
	H_0: No relationship exists between years of experience working as an SLT and knowledge of dysphagia in dementia stages in the population H_1: There is a relationship between years of experience working as an SLT and knowledge of dysphagia in dementia stages in the population
	H_0: No relationship exists between years of experience working as an SLT and knowledge of mealtime difficulties in dementia type in the population H_1: There is a relationship between years of experience working as an SLT and knowledge of mealtime difficulties in dementia type in the population
	H_0: No relationship exists between years of experience working as an SLT and knowledge of mealtime difficulties in dementia stages in the population H_1: There is a relationship between years of experience working as an SLT and knowledge of mealtime difficulties in dementia stages in the population
	H_0: No relationship exists between years of experience working as an SLT and importance of tailoring management to dementia stages in the population

	H_1: There is a relationship between years of experience working as an SLT and importance of tailoring management to dementia stages in dementia in the population
	H_0: No relationship exists between years of experience working as an SLT and importance of tailoring management to dementia stages in the population H_1: There is a relationship between years of experience working as an SLT and importance of tailoring management to dementia stages in dementia in the population

APPENDIX 5: TESTS OF ASSOCIATION RESULTS

Factor 1	**Factor 2**	**χ^2 or Fisher's Exact**	**Φc**	**Significance (two-tailed)**
Knowledge of dysphagia in dementia types	Importance of tailoring management to dementia type	$\chi^2(4) = 21.34$	$\Phi c = .30$	**p = < .001**
Knowledge of mealtime difficulties in dementia types	Importance of tailoring management to dementia type	$\chi^2(4) = 18.39$	$\phi c = .27$	**p = .001**
Knowledge of dysphagia in dementia stages	Importance of tailoring management to dementia stage	Fisher's Exact		**p = .006**
Knowledge of mealtime difficulties in dementia stages	Importance of tailoring management to dementia stage	Fisher's Exact		p = .281
Knowledge of dysphagia in dementia types	Knowledge of mealtime difficulties in dementia types	$\chi 2(4) = 150.20$	Φc = .78	**p = .000**
Knowledge of dysphagia in dementia stages	Knowledge of mealtime difficulties in dementia stages	Fisher's Exact		**p = .000**
Knowledge of dysphagia in dementia stages	Knowledge of dysphagia in dementia types	Fisher's Exact		**p = .000**
Knowledge of mealtime difficulties in dementia stages	Knowledge of mealtime difficulties in dementia types	$\chi^2(4) = 55.52$	$\phi c = .55$	**p = .000**

Factor 1	**Factor 2**	**χ^2 or Fisher's Exact**	**Φc**	**Significance (two-tailed)**
Place of work	Knowledge of dysphagia in dementia types	$\chi^2(4) = 3.05$	$\phi c = .11$	$p = .550$
Place of work	mealtime difficulties in dementia types	$\chi^2(4) = 7.98$	$\phi c = .18$	$p = .092$
Place of work	knowledge of dysphagia in dementia stages	Fisher's Exact		$p = .935$
Place of work	mealtime difficulties in dementia stages	Fisher's Exact		$p = .528$
Place of work	Importance of tailoring management to dementia stage	Fisher's Exact		$p = .268$
Place of work	Importance of tailoring management to dementia type	$\chi^2(4) = 14.73$,	$\phi c = .25$	**$p = .005$**
Country of work	Importance of tailoring management to dementia stage	Fisher's Exact		$p = .681$
Country of work	Importance of tailoring management to dementia type	$\chi^2(2) = 2.30$	$\phi c = .14$	$p = .317$
Country of work	Knowledge of dysphagia in dementia stages	$\chi^2(2) = .36$	$\phi c = .05$	$p = .833$

Factor 1	**Factor 2**	**χ^2 or Fisher's Exact**	**Φc**	**Significance (two-tailed)**
Country of work	Knowledge of dysphagia in dementia types	$\chi^2(2) = 1.25$	$\phi c = .10$	$p = .536$
Country of work	Knowledge of mealtime difficulties in dementia stages	$\chi^2(2) = 1.01$,	$\phi c = .10$	$p = .603$
Country of work	Knowledge of mealtime difficulties in dementia types	$\chi^2(2) = 7.88$	$\phi c = .25$	**$p = .019$**
SLTs' years of experience	Importance of tailoring management to dementia stages	Fisher's Exact		$p = .156$
SLTs' years of experience	Importance of tailoring management to dementia type	$\chi^2(4) = 3.78$	$\phi c = .12$	$p = .437$
SLTs' years of experience	Knowledge of dysphagia in dementia stages	Fisher's Exact		$p = .743$
SLTs' years of experience	Knowledge of dysphagia in dementia types	$\chi^2(4) = 10.37$	$\phi c = .20$	**$p = .035$**
SLTs' years of experience	Knowledge of mealtime difficulties in dementia stages	Fisher's Exact		$p = .897$

Factor 1	**Factor 2**	**χ^2 or Fisher's Exact**	**Φc**	**Significance (two-tailed)**
SLTs' years of experience	Knowledge of mealtime difficulties in dementia types	$\chi^2(4) = 6.99$	$\phi c = .17$	$p = .136$

APPENDIX 6: INTERVIEW SCHEDULE

Rapport building

1. Thanks for taking the time to meet with me today. My name is Aisling Egan; I'm a PhD student in the University of Strathclyde. I am doing some research about how multidisciplinary team members and carers provide support to people with dementia when they have problems swallowing and around the mealtime. I would like to ask you some questions about your background, your experience supporting people with dementia, how you view your professional role, any issues you face, and any concerns you would like to raise. I hope to use this information to help speech and language therapists, other professionals, and carers to understand the issues better and to come up with new ways to help. The interview should take around an hour, and will be recorded. Does that all sound OK to you? Do you have any questions?

Background Information / Perception of Own Role

1. Type of professional and length of time in that career: how long have you been working as *your profession?*
    a. Can you tell me about your work experience?
        i. What setting do you usually work in?
2. What is the main scope of your current work?
    a. Is this particular to your service?
3. Is your clinical caseload predominantly with dementia or a mixed caseload?
    a. How long have you been working with people with dementia?

    b. Can you tell me a bit about your experience working with people with dementia?

4. What do you consider *your profession's* priority role (or roles) is in management or care of the elderly?
    a. Is that the same or different to elderly with dementia?
    b. E.g. is falls prevention, continuing mobilisation more of a priority etc.
5. Can you tell me how you view the role of *your profession* in managing mealtime or swallowing difficulties with people with dementia?
    a. Are there any strategies or programmes you implement that are specific to people with dementia
        i. Can you tell me about it?
    b. Can you tell me a bit about your management of ___ specific to dementia:
        i. SLTs: dysphagia, food refusal, behavioural feeding issues, etc.
        ii. Dietitians: food refusal, malnutrition, dehydration, etc.
        iii. Occupational Therapists: visual agnosia, cognitive-behavioural issues at mealtimes, utensils, etc.
        iv. Physiotherapists: positioning, postural changes
    c. What do you feel are the limitations of your role at mealtimes?
    d. Are there areas you feel that you could have more of a role or offer more input?
    e. Are there any aspects of your role that you view as beyond your scope/training or more suited to another professional?

        f. Do you find that there are any problems or issues in implementing your recommendations in different Settings?
            i. E.g., care home vs family home etc.
            ii. What kind of issues are there?
            iii. How do you manage/overcome these?

Roles of the MDT

1. In your opinion, who should be involved in a team supporting people with dementia?
    a. Prompt: suggest professionals, family, carers
    b. Is that the same team you are currently working with?
2. What do you consider the roles of these team members to be?
    a. SLT/OT/PT/dietitian/medical team/carers/family/other
3. Where do you think these roles overlap?
    a. Potential areas for joint working
    b. Interdisciplinary working
4. Are there any things that you work on that you think should be *your profession's* sole role?
    a. What are they?
    b. Why?
    c. Prompt around areas for potential interdisciplinary working
5. SLT ONLY: There can be some ethical issues around food/fluid recommendations in dementia,

   a. how do you consider the role of the SLT in decisions around tube feeding/comfort feeding?
   b. Does your service have a comfort feeding protocol? What’s involved?
      i. Do you see the need for a protocol?
   c. How do you manage situations where a person with dementia may be refusing thickened fluids or modified diets?
      i. Consent vs assent
      ii. Decision-making: individual/family/care home/Medical team

6. SLT ONLY: What directions would you consider for growth of the SLT role in dementia management?

Provision of training

1. What kind of trainings do you provide to carers or families?
   a. Who do you train? E.g. families, care home staff, nursing staff, other?
   b. Do you usually provide training as one on one/in groups/formally/case by case basis?
2. Is any of the training you provide specific to dementia?
3. Do you provide any training relevant to mealtimes or swallowing problems?
4. Provision of training
   a. Do you provide any joint training? With who? What? How have they worked?
   b. Have you experienced any barriers in providing training?
   c. What supports to providing training have you come across?

        d. What outcomes would you hope to see for your service after training
            i. E.g. increase/reduction in referrals, more appropriate referrals, carers able to independently manage some issues

Receipt of Training/Education

1. Have you received any dementia specific training?
    a. Where was this training provided? Who carried it out?
    b. What was the training about?
    c. How do you find this has influenced your practice?

Working practices/policies around referrals and liaison with care staff/nursing homes

If established that the professional works in care homes and supports mealtime issues:

1. What's your usual practice when working with care homes?
2. How do you receive referrals, what criteria do you look for?
3. What is your follow-up like?
4. Have you had any issues with follow-up of recommendations?
5. What do you think caring or nursing staff should be able to independently manage?

Policy and Implementing new Evidence/Guidance

1. What, if any, impact do the release of policies/changes to legislation have on your service?
    a. E.g. National dementia strategy, Promoting Excellence, etc.
2. How are policy changes implemented in your service?

    a. How are decisions made around implementing changes?

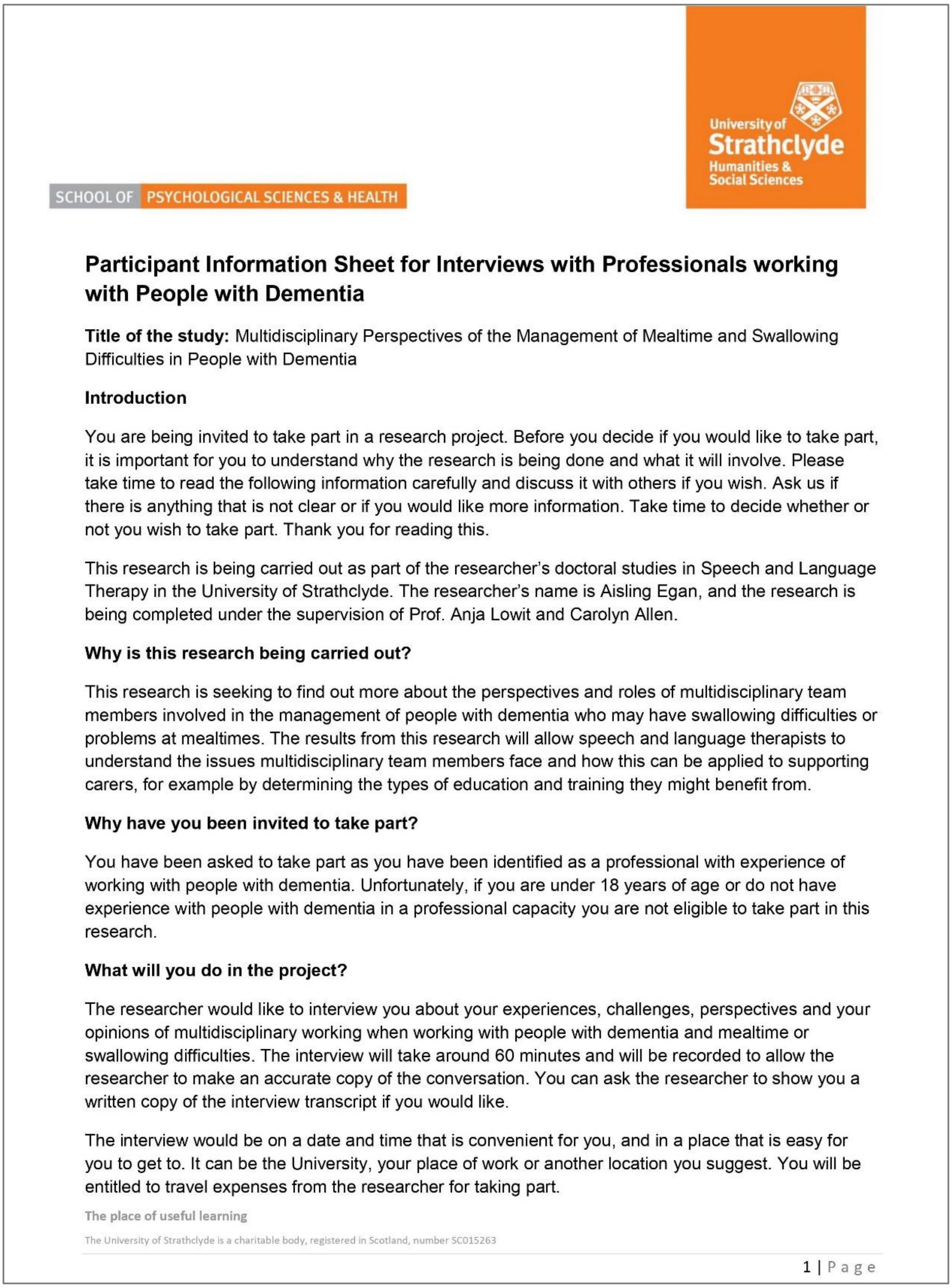
Partnerships with external bodies

1. Do you have links with any other sectors that support your work/programmes?
    a. Who? Prompts: charities, government bodies, NHS services
    b. How do you support each other in your work?
    c. How do these relationships influence your work?

Wrap-up

1. In your opinion, what do you feel is the biggest need/gap in service?
    a. E.g. more training? More information? Changes to the environment? Increased staffing levels? Etc.
2. Is there any policy or service that your team offers that you feel has made a big difference in care?
    a. Anything your service does/policy your service has that you think all services should be implementing?
    b. What is it? What do you feel it has contributed? Difficult to implement
3. What is one thing you wish people knew about your role supporting people with dementia?
4. Is there anything else you would like to tell me about?

APPENDIX 7: PARTICIPANT INFORMATION SHEET AND CONSENT FORM – INTERVIEW STUDY



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Participant Information Sheet for Interviews with Professionals working with People with Dementia

Title of the study: Multidisciplinary Perspectives of the Management of Mealtime and Swallowing Difficulties in People with Dementia

Introduction

You are being invited to take part in a research project. Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

This research is being carried out as part of the researcher's doctoral studies in Speech and Language Therapy in the University of Strathclyde. The researcher's name is Aisling Egan, and the research is being completed under the supervision of Prof. Anja Lowit and Carolyn Allen.

Why is this research being carried out?

This research is seeking to find out more about the perspectives and roles of multidisciplinary team members involved in the management of people with dementia who may have swallowing difficulties or problems at mealtimes. The results from this research will allow speech and language therapists to understand the issues multidisciplinary team members face and how this can be applied to supporting carers, for example by determining the types of education and training they might benefit from.

Why have you been invited to take part?

You have been asked to take part as you have been identified as a professional with experience of working with people with dementia. Unfortunately, if you are under 18 years of age or do not have experience with people with dementia in a professional capacity you are not eligible to take part in this research.

What will you do in the project?

The researcher would like to interview you about your experiences, challenges, perspectives and your opinions of multidisciplinary working when working with people with dementia and mealtime or swallowing difficulties. The interview will take around 60 minutes and will be recorded to allow the researcher to make an accurate copy of the conversation. You can ask the researcher to show you a written copy of the interview transcript if you would like.

The interview would be on a date and time that is convenient for you, and in a place that is easy for you to get to. It can be the University, your place of work or another location you suggest. You will be entitled to travel expenses from the researcher for taking part.

The place of useful learning

The University of Strathclyde is a charitable body, registered in Scotland, number SC015263

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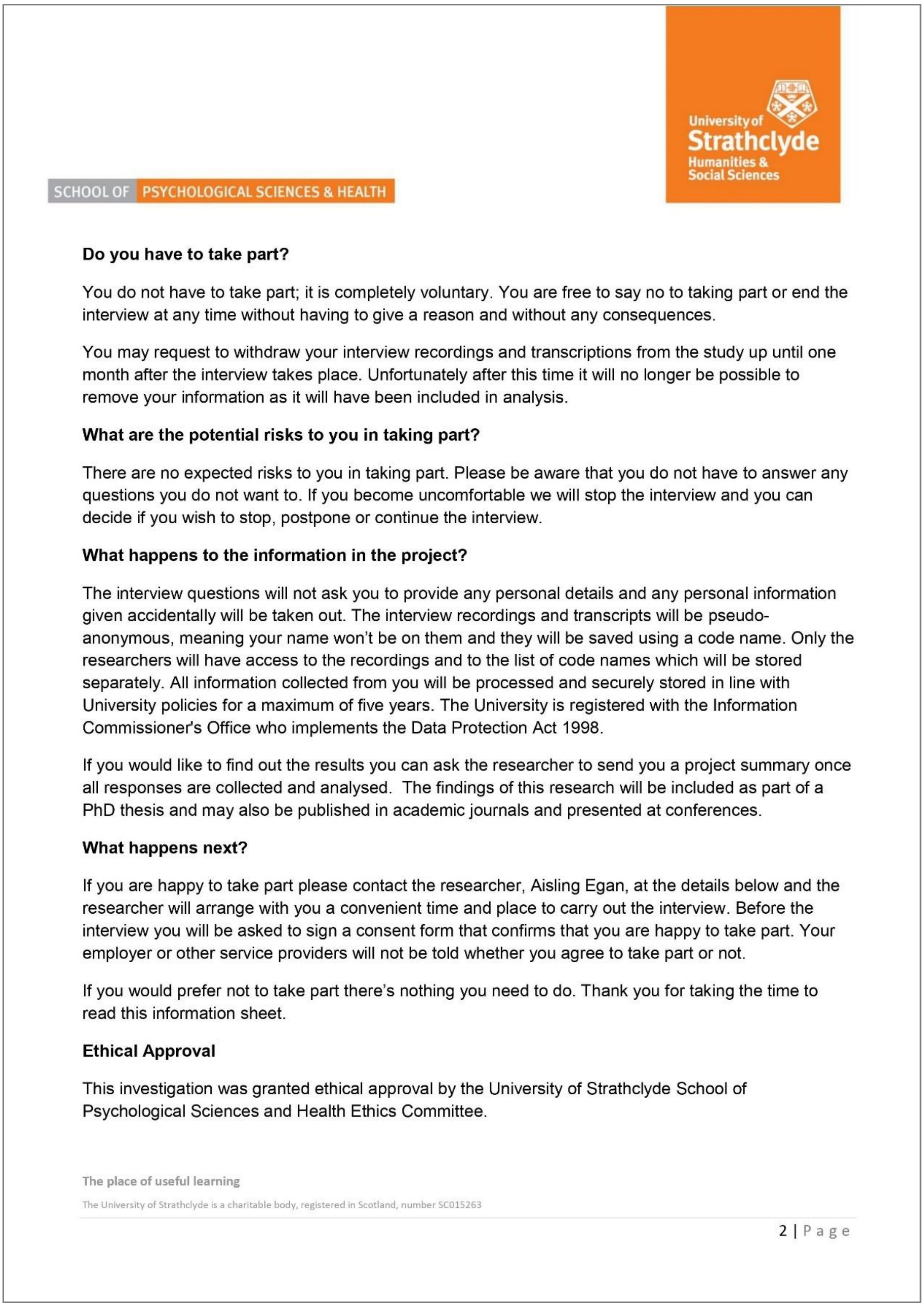

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Do you have to take part?

You do not have to take part; it is completely voluntary. You are free to say no to taking part or end the interview at any time without having to give a reason and without any consequences.

You may request to withdraw your interview recordings and transcriptions from the study up until one month after the interview takes place. Unfortunately after this time it will no longer be possible to remove your information as it will have been included in analysis.

What are the potential risks to you in taking part?

There are no expected risks to you in taking part. Please be aware that you do not have to answer any questions you do not want to. If you become uncomfortable we will stop the interview and you can decide if you wish to stop, postpone or continue the interview.

What happens to the information in the project?

The interview questions will not ask you to provide any personal details and any personal information given accidentally will be taken out. The interview recordings and transcripts will be pseudo-anonymous, meaning your name won't be on them and they will be saved using a code name. Only the researchers will have access to the recordings and to the list of code names which will be stored separately. All information collected from you will be processed and securely stored in line with University policies for a maximum of five years. The University is registered with the Information Commissioner's Office who implements the Data Protection Act 1998.

If you would like to find out the results you can ask the researcher to send you a project summary once all responses are collected and analysed. The findings of this research will be included as part of a PhD thesis and may also be published in academic journals and presented at conferences.

What happens next?

If you are happy to take part please contact the researcher, Aisling Egan, at the details below and the researcher will arrange with you a convenient time and place to carry out the interview. Before the interview you will be asked to sign a consent form that confirms that you are happy to take part. Your employer or other service providers will not be told whether you agree to take part or not.

If you would prefer not to take part there's nothing you need to do. Thank you for taking the time to read this information sheet.

Ethical Approval

This investigation was granted ethical approval by the University of Strathclyde School of Psychological Sciences and Health Ethics Committee.

The place of useful learning

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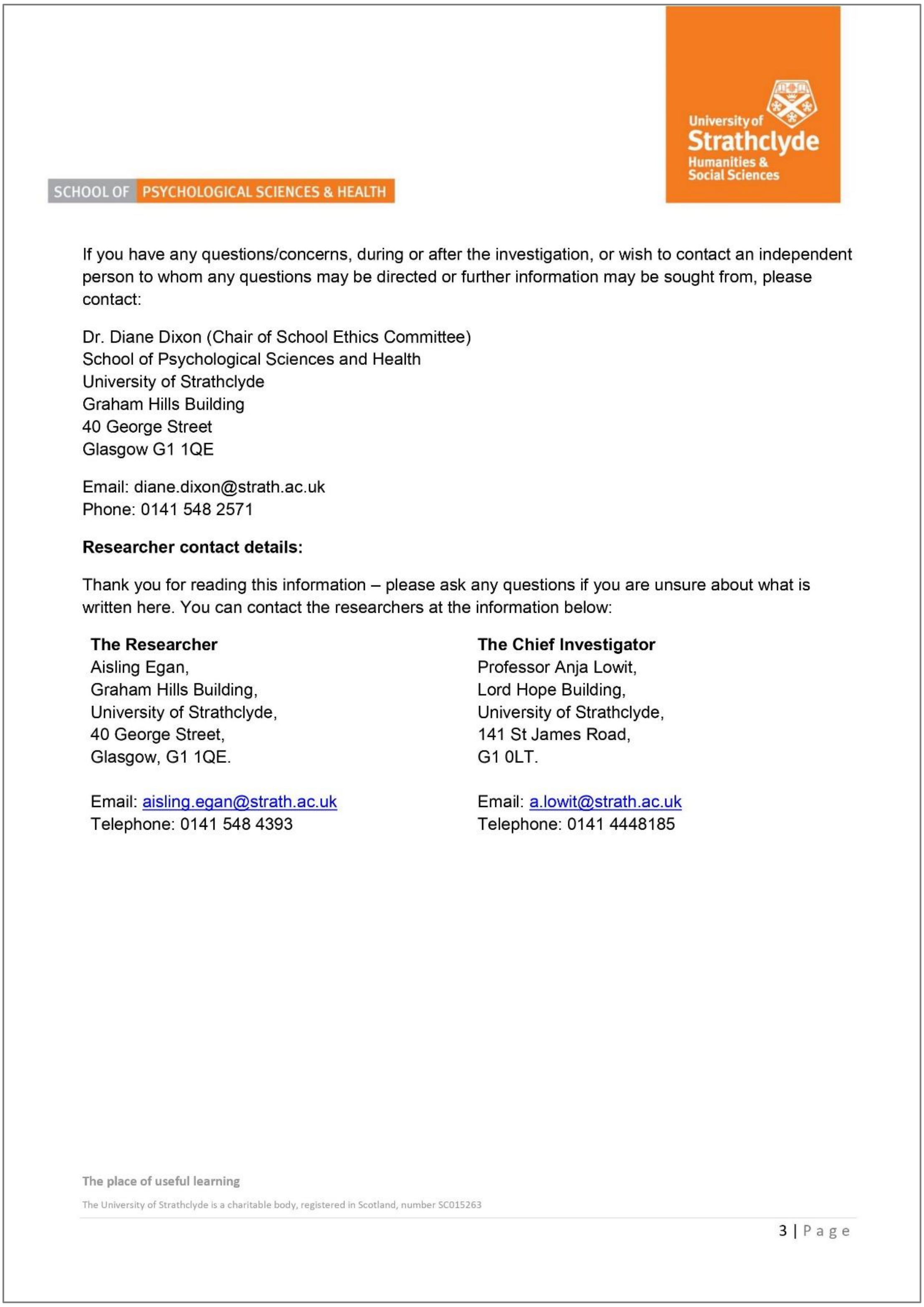


If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Dr. Diane Dixon (Chair of School Ethics Committee)
School of Psychological Sciences and Health
University of Strathclyde
Graham Hills Building
40 George Street
Glasgow G1 1QE

Email: diane.dixon@strath.ac.uk
Phone: 0141 548 2571

Researcher contact details:

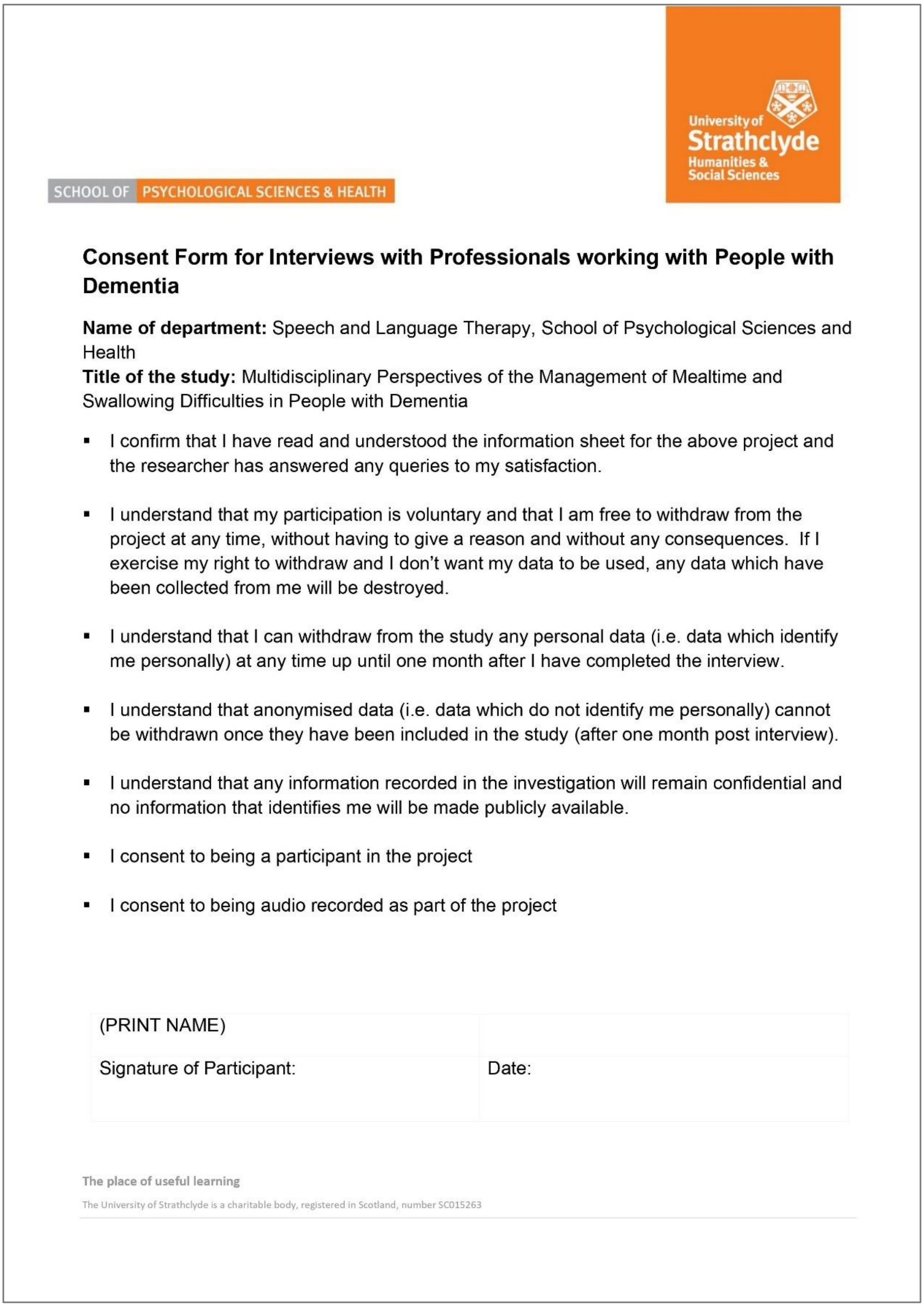
Thank you for reading this information – please ask any questions if you are unsure about what is written here. You can contact the researchers at the information below:

The Researcher
Aisling Egan,
Graham Hills Building,
University of Strathclyde,
40 George Street,
Glasgow, G1 1QE.

Email: aisling.egan@strath.ac.uk
Telephone: 0141 548 4393

The Chief Investigator
Professor Anja Lowit,
Lord Hope Building,
University of Strathclyde,
141 St James Road,
G1 0LT.

Email: a.lowit@strath.ac.uk
Telephone: 0141 4448185



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Humanities & Social Sciences

SCHOOL OF PSYCHOLOGICAL SCIENCES & HEALTH

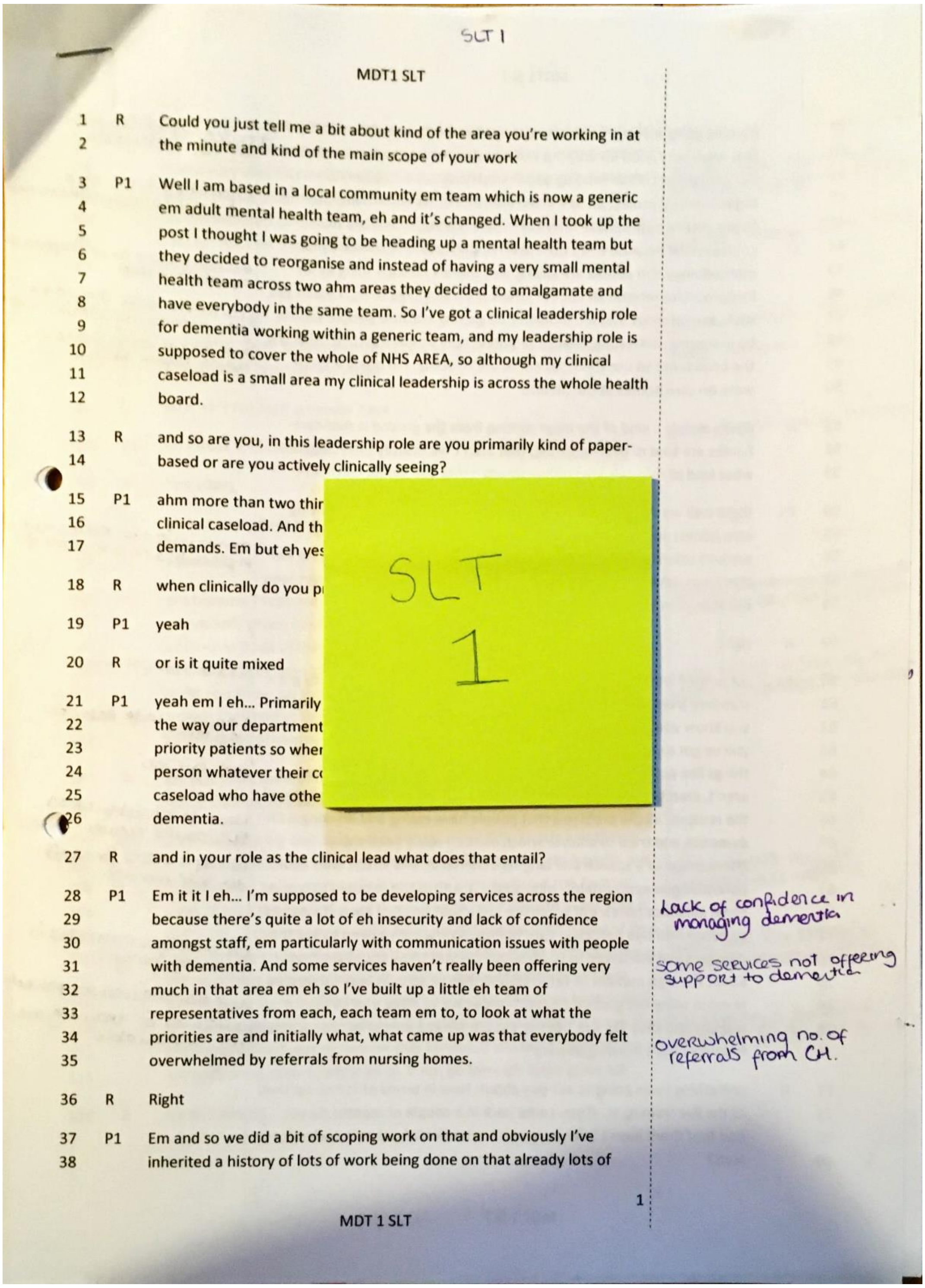
Consent Form for Interviews with Professionals working with People with Dementia

Name of department: Speech and Language Therapy, School of Psychological Sciences and Health
Title of the study: Multidisciplinary Perspectives of the Management of Mealtime and Swallowing Difficulties in People with Dementia

- I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any consequences. If I exercise my right to withdraw and I don't want my data to be used, any data which have been collected from me will be destroyed.
- I understand that I can withdraw from the study any personal data (i.e. data which identify me personally) at any time up until one month after I have completed the interview.
- I understand that anonymised data (i.e. data which do not identify me personally) cannot be withdrawn once they have been included in the study (after one month post interview).
- I understand that any information recorded in the investigation will remain confidential and no information that identifies me will be made publicly available.
- I consent to being a participant in the project
- I consent to being audio recorded as part of the project

(PRINT NAME)	
Signature of Participant:	Date:

APPENDIX 8: TRANSCRIPT EXTRACT WITH INITIAL CODES



SLT 1

MDT1 SLT

R Could you just tell me a bit about kind of the area you're working in at the minute and kind of the main scope of your work

P1 Well I am based in a local community em team which is now a generic em adult mental health team, eh and it's changed. When I took up the post I thought I was going to be heading up a mental health team but they decided to reorganise and instead of having a very small mental health team across two ahm areas they decided to amalgamate and have everybody in the same team. So I've got a clinical leadership role for dementia working within a generic team, and my leadership role is supposed to cover the whole of NHS AREA, so although my clinical caseload is a small area my clinical leadership is across the whole health board.

R and so are you, in this leadership role are you primarily kind of paper-based or are you actively clinically seeing?

P1 ahm more than two thir
clinical caseload. And th
demands. Em but eh yes

R when clinically do you p

P1 yeah

R or is it quite mixed

P1 yeah em I eh... Primarily
the way our department
priority patients so wher
person whatever their c
caseload who have othe
dementia.

SLT
1

R and in your role as the clinical lead what does that entail?

P1 Em it it I eh... I'm supposed to be developing services across the region because there's quite a lot of eh insecurity and lack of confidence amongst staff, em particularly with communication issues with people with dementia. And some services haven't really been offering very much in that area em eh so I've built up a little eh team of representatives from each, each team em to, to look at what the priorities are and initially what, what came up was that everybody felt overwhelmed by referrals from nursing homes.

Lack of confidence in managing dementia

some services not offering support to dementia

overwhelming no. of referrals from CH.

R Right

P1 Em and so we did a bit of scoping work on that and obviously I've inherited a history of lots of work being done on that already lots of

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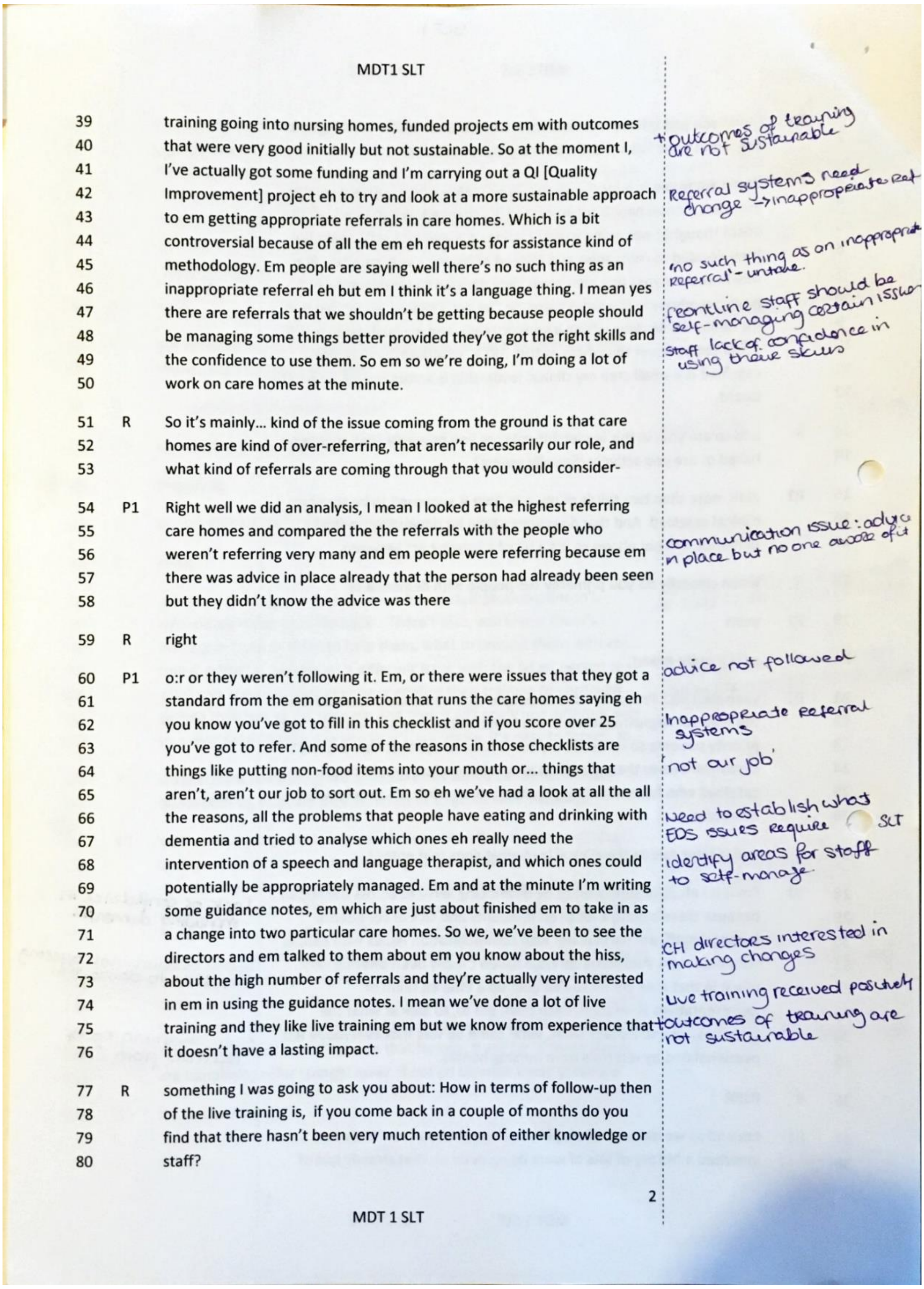
MDT 1 SLT



training going into nursing homes, funded projects em with outcomes that were very good initially but not sustainable. So at the moment I, I've actually got some funding and I'm carrying out a QI [Quality Improvement] project eh to try and look at a more sustainable approach to em getting appropriate referrals in care homes. Which is a bit controversial because of all the em eh requests for assistance kind of methodology. Em people are saying well there's no such thing as an inappropriate referral eh but em I think it's a language thing. I mean yes there are referrals that we shouldn't be getting because people should be managing some things better provided they've got the right skills and the confidence to use them. So em so we're doing, I'm doing a lot of work on care homes at the minute.

+ outcomes of training are not sustainable

Referral systems need change → inappropriate Ref

'no such thing as an inappropri referral' - untrue.

frontline staff should be self-managing certain issue

staff lack of confidence in using their skills

R So it's mainly… kind of the issue coming from the ground is that care homes are kind of over-referring, that aren't necessarily our role, and what kind of referrals are coming through that you would consider-

P1 Right well we did an analysis, I mean I looked at the highest referring care homes and compared the the referrals with the people who weren't referring very many and em people were referring because em there was advice in place already that the person had already been seen but they didn't know the advice was there

communication issue: advic in place but no one aware of it

R right

P1 o:r or they weren't following it. Em, or there were issues that they got a standard from the em organisation that runs the care homes saying eh you know you've got to fill in this checklist and if you score over 25 you've got to refer. And some of the reasons in those checklists are things like putting non-food items into your mouth or… things that aren't, aren't our job to sort out. Em so eh we've had a look at all the all the reasons, all the problems that people have eating and drinking with dementia and tried to analyse which ones eh really need the intervention of a speech and language therapist, and which ones could potentially be appropriately managed. Em and at the minute I'm writing some guidance notes, em which are just about finished em to take in as a change into two particular care homes. So we, we've been to see the directors and em talked to them about em you know about the hiss, about the high number of referrals and they're actually very interested in em in using the guidance notes. I mean we've done a lot of live training and they like live training em but we know from experience that it doesn't have a lasting impact.

advice not followed

Inappropriate Referral systems

'not our job'

Need to establish what EDS issues require SLT

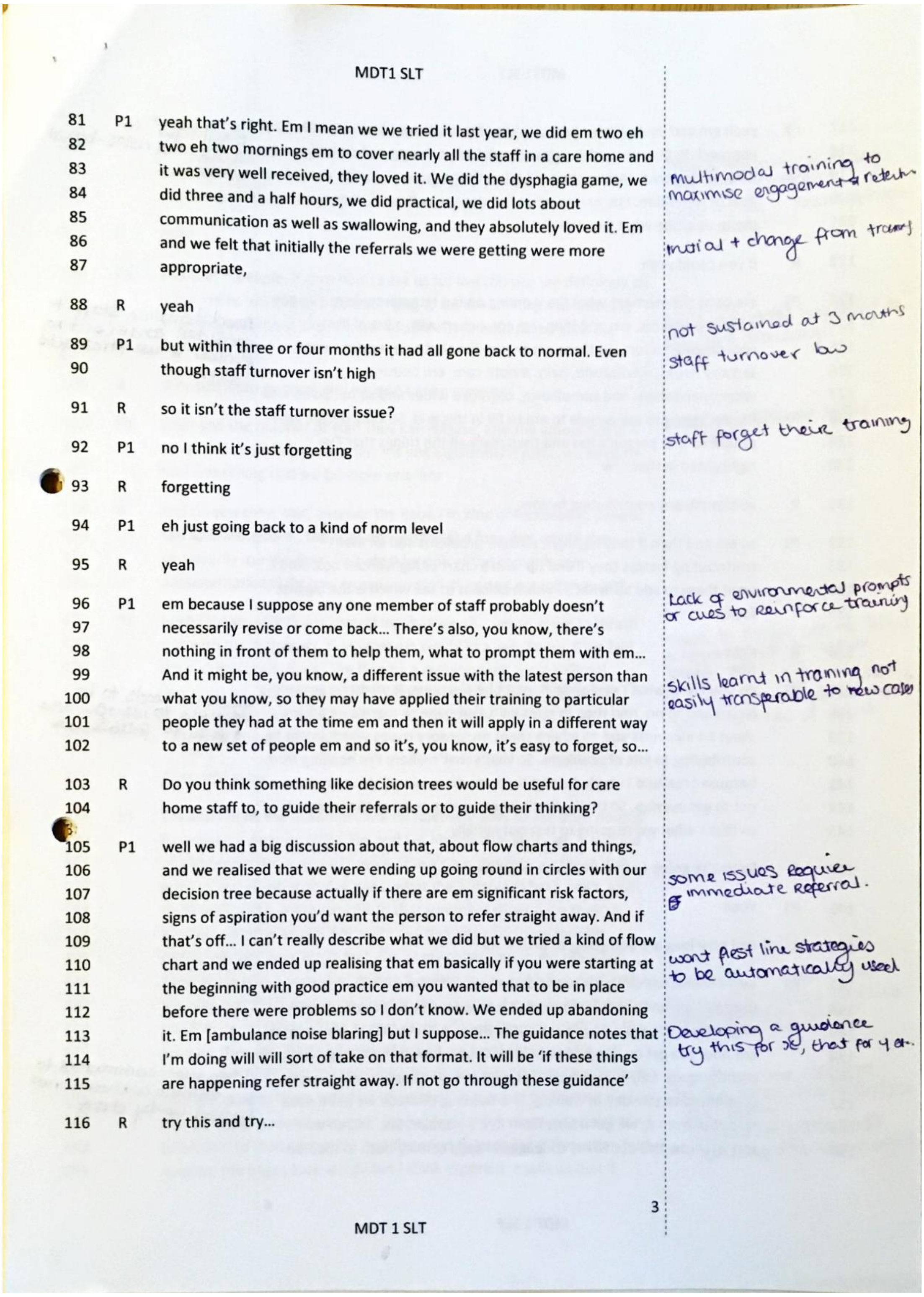
identify areas for staff to self-manage

CH directors interested in making changes

Live training received positively

+ outcomes of training are not sustainable

R something I was going to ask you about: How in terms of follow-up then of the live training is, if you come back in a couple of months do you find that there hasn't been very much retention of either knowledge or staff?



P1 yeah that's right. Em I mean we we tried it last year, we did em two eh two eh two mornings em to cover nearly all the staff in a care home and it was very well received, they loved it. We did the dysphagia game, we did three and a half hours, we did practical, we did lots about communication as well as swallowing, and they absolutely loved it. Em and we felt that initially the referrals we were getting were more appropriate,

multimodal training to maximise engagement & retentn

initial + change from training

R yeah

P1 but within three or four months it had all gone back to normal. Even though staff turnover isn't high

not sustained at 3 months

staff turnover low

R so it isn't the staff turnover issue?

P1 no I think it's just forgetting

staff forget their training

R forgetting

P1 eh just going back to a kind of norm level

R yeah

P1 em because I suppose any one member of staff probably doesn't necessarily revise or come back… There's also, you know, there's nothing in front of them to help them, what to prompt them with em… And it might be, you know, a different issue with the latest person than what you know, so they may have applied their training to particular people they had at the time em and then it will apply in a different way to a new set of people em and so it's, you know, it's easy to forget, so…

Lack of environmental prompts or cues to reinforce training

skills learnt in training not easily transferable to new cases

R Do you think something like decision trees would be useful for care home staff to, to guide their referrals or to guide their thinking?

P1 well we had a big discussion about that, about flow charts and things, and we realised that we were ending up going round in circles with our decision tree because actually if there are em significant risk factors, signs of aspiration you'd want the person to refer straight away. And if that's off… I can't really describe what we did but we tried a kind of flow chart and we ended up realising that em basically if you were starting at the beginning with good practice em you wanted that to be in place before there were problems so I don't know. We ended up abandoning it. Em [ambulance noise blaring] but I suppose… The guidance notes that I'm doing will will sort of take on that format. It will be 'if these things are happening refer straight away. If not go through these guidance'

some issues require immediate referral.

want first line strategies to be automatically used

Developing a guidance try this for x, that for y etc.

R try this and try…

APPENDIX 9: THEME DEVELOPMENT

Theme	**Subtheme**	**Code Cluster**	**Refined Code**
Professional Roles	Awareness of Roles	AHP role perception	SLT role
			OT role
			PT role
			DT role
		Role blurring	Hard to define
			An overlap in roles
			Incorrect advice/outside scope
			Working in own scope
			See a need, meet the need
			Cross-cover colleagues
		Knowing the role	People don't know (roles)
			Misperception of role
			MDT understanding of AHP
			Public awareness of roles
		Losing referrals	Need for signposting
			A way to go/slow to change
			No recognition of need (for AHP input)
		Advance care planning*	Manage expectations
			Other conditions have clearer paths

Theme	**Subtheme**	**Code Cluster**	**Refined Code**
		The SLTs role	SLT misunderstood as EOL only
			Thickener-focused
			Over focus on dysphagia
			Focus on communication
	Out of the (MDT) Loop	MDT access	‘ideal world’ MDT
			Access to teams
			Knowing team members
			Challenges info-sharing across teams
			Time for MDT meetings
			Fight to access teams
		Impact of location	Multi-site working
			Proximity leads to liaison
			Single site working
			Isolation
			Decision-making as teams/individuals
			SLT not used as much as they could
Decision-making is Individual	It’s not one size fits all	Person-first	Uniqueness of people
			Background > dementia
			No typical dementia
		Diagnosis	Impact of diagnosis - usefulness

Theme	**Subtheme**	**Code Cluster**	**Refined Code**
			Impact of diagnosis – not useful
		Intervention	Dementia = indirect intervention
			Intervene with carers
			Unpredictable intervention pathway
		Outcome measurement	Outcome measurement is challenging
			‘good’ outcomes vary
			Mealtime difficulties and discharge
	Quality of life is individual	Environment influence	Social aspects of meals
			Meal delivery
			Environment’s impact on enjoyment
			Mealtime segregation
		Food as pleasure	Food and pleasure
			Eating = last pleasure
		Impact on Family	Family leniency with food
			Stress of meal changes
		Balance	Balance negative consequences with quality of life
			Balancing risk with quality of life

Theme	**Subtheme**	**Code Cluster**	**Refined Code**
		Personal perspective	Own view influences approach
			Seeing someone ‘kept alive’
			‘not what I would want’
	Risk	Risk language	Positive risk-taking (OT/PT)
			Facilitating risk
			‘at risk’
			Malnutrition risk (DT)
			Aspiration risk (SLT)
		Consequences	Cure worse than the cause
			Comfort is not comfort
		Perceptions	Understanding risk
			The real risk
			Priorities
			Acceptable risk
		Influences	Personally acceptable to AHP
			Carers wary of risk
			Structures are risk averse
			Risk vs caution
		Formal processes	Risk feeding decisions – hard
			Ownership of risk

Theme	**Subtheme**	**Code Cluster**	**Refined Code**
			Roles in risk decision-making
			Risk protocols – useful
			Clinical decision > protocol
	Advance Care Planning	Dementia	Comparison to care in other conditions
			Earlier conversation in other conditions
		Disease course	Unpredictable course
			To families: unknown disease course
			Future seems unknown
			What to plan for is uncertain
			Manage expectations
		Timing	Early discussions = scaremongering
			People ‘don’t want to know’
			People do want clarity on future
			No way to identify who wants to know
			Earlier discussions needed

Theme	**Subtheme**	**Code Cluster**	**Refined Code**
			Point of diagnosis too soon
			Cognitive change makes early planning essential
		Planning breakdown	Conversations not happening
			Lack of in-depth discussion
			No discussion = leaving people in the dark
			Not knowing = can’t plan
			No knowledge of course = don’t know who to access
			Limited future planning limits future care
		ACP Awareness	Families don’t recognise EOL
			Awareness raising too generic
			Advance planning virtually unknown
		Roles and legalities	Advance planning conflated with POA
			Who should initiate ACP discussions

Theme	**Subtheme**	**Code Cluster**	**Refined Code**
			ACP binding
		Limitations	ACP not advanced to apply to mealtime difficulties
			ACP for dysphagia has unique needs
			Cannot predict reaction to dysphagia
			Food refusal not a known EOL response
The Realities	Over-stretched Resources	Service Impact	Limited time resource
			Limited presence*
			Understaffed - AHPs
			Resource issues impact teamwork
			Reduced collaboration d/t resource
			Blurred role boundaries
			Lack capacity to expand services
			Can’t offer preferred services
			Tsunamis, floodgates, firefighting
		Nursing colleagues	Understaffed – Nursing and HCAs

Theme	**Subtheme**	**Code Cluster**	**Refined Code**
			Not using ‘common-sense’
			First-line strategies – not carried out
			First-line strategies – core role
		Personal Impact	Disheartening
			Overwhelmed
		Working around*	Management innovation
			Individualised care
		Training	Train auxiliaries to reduce load
			No time to train
			Training not sustainable
			No training impacts referrals
			Training provision as non-essential
		System breakdown	Onward referral unclear
			Care pathways non-existent
			Service breakdowns
	Workarounds	Non-standard approach	Solution-focused approach
			Management innovation
			Individualised care

Theme	**Subtheme**	**Code Cluster**	**Refined Code**
			Adaptable intervention
		Use what's available	Indirect Ix - Use families
			Families present at meals
			Circumvent cognitive breakdowns
			Use cognitive change to support strategies
		System constraints	Can't adapt environments
			Open visiting is a boon
			Perception of other environments having fewer constraints
			Health and safety gone mad
		Role blurring	See a need, meet the need
			Cross-cover colleagues
	Culture Change	Meal practices	Seeing unsafe feeding practice
			Task-based approach
			No interaction
		Mealtime as an experience	Social opportunity
			Meal environment*
			Task-based approach
		The 'how' of culture change	Approach change carefully
			Easy to get people offside

Theme	Subtheme	Code Cluster	Refined Code
			Empowering staff supports change
			Knowledge does not equate to change
		Change the system	Systems disempower staff
			Created helplessness?
			Systems resistant to change
			Pace of change (slow)
		Out of the (MDT) loop*	Multi-site working limits opportunities to model change