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# Helping people with dementia to eat well at home: An investigation to understand and enhance nutritional care

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# **UNIVERSITY OF PLYMOUTH**

## **HELPING PEOPLE WITH DEMENTIA TO EAT WELL AT HOME: AN INVESTIGATION TO UNDERSTAND AND ENHANCE NUTRITIONAL CARE**

by

**LOUISE MOLE**

A thesis submitted to the University of Plymouth in partial fulfilment for the  
degree of

**DOCTOR OF PHILOSOPHY**

School of Health Professions

**JULY 2021**

## Acknowledgements

---

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Writing the final Chapters of my thesis in 2020 and 2021 has been framed by some monumental life events – the first being starting a new role as a university lecturer, and the second being the COVID-19 pandemic. This had an impact upon my ability to write, primarily due to having less time available to do so. It is

due to the support of my family that I have been able to complete this piece of work, and their continued love and support that has kept me going. For listening to my ideas, reading drafts and motivating me when I needed it the most – thank you.

I feel privileged to have had this opportunity in my dietetic career to develop ideas that will hopefully improve the nutritional care (and quality of life) for people living at home with dementia. I have been able to meet many people involved in dementia care, and it has opened my eyes to the passion for care in this setting. The process has increased my determination to take the outputs of this thesis forward, and I feel a duty to do so for the many people who have taken the time to support me.

## Author's Declaration

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At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award without prior agreement of the Doctoral College Quality Sub-Committee.

This thesis has been proofread by a third party; no factual changes or additions or amendments to the argument were made as a result of this process. A copy of the thesis prior to proofreading will be made available to the examiners upon request.

Work submitted for this research degree at the University of Plymouth has not formed part of any other degree either at the University of Plymouth or at another establishment.

This study was financed with the aid of a studentship from the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South West Peninsula, now recommissioned as NIHR Applied Research Collaboration (ARC) South West Peninsula.

### Publications:

- Mole, L., Kent, B., Abbott, R., Wood, C. and Hickson, M. (2018) 'The nutritional care of people living with dementia at home: A scoping review', *Health Soc Care Community*, 26(4), pp. e485-e496. DOI: 10.1111/hsc.12540
- Mole, L., Hickson, M., Kent, B. and Abbott, R. (2019a) 'Family carers' experiences of nutritional care for people living with dementia at home: An interpretative phenomenological analysis', *Dementia*, pp. 231-246. DOI: 10.1177/1471301219872032
- Mole, L., Kent, B., Hickson, M. and Abbott, R. (2019b) 'It's what you do that makes a difference' An interpretative phenomenological analysis of health care professionals and homecare workers experiences of nutritional care for people living with dementia at home', *BMC Geriatrics*, 19(1), pp. 250. DOI: 10.1186/s12877-019-1270-4

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## Statement of candidate's contribution to co-authored papers

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There are three studies in this thesis which have been published. As detailed below, the substantial contribution to co-authored papers was made by the candidate. Chapters 3, 4 and 5 contain the manuscripts, and are presented in the format requested by the respective journal.

### Paper 1: Chapter 3

Mole, L., Kent, B., Abbott, R., Wood, C. and Hickson, M. (2018) 'The nutritional care of people living with dementia at home: A scoping review', *Health Soc Care Community*, 26(4), pp. e485-e496. DOI: 10.1111/hsc.12540

The first manuscript presented in this thesis was submitted to *Health and Social Care in the Community* and accepted in December 2017. The candidate developed the protocol, screened and selected articles (with the assistance of another PhD candidate, Chloe Wood), collected data from included papers, analysed the data, and wrote the manuscript with supervisory advice from Mary Hickson, Bridie Kent and Rebecca Abbott. Any discrepancies encountered during the screening stage were discussed with Rebecca Abbott. Morwenna Rogers and Joanna Triplett assisted with developing the literature search strategy.

### Paper 2: Chapter 4

Mole, L., Hickson, M., Kent, B. and Abbott, R. (2019a) 'Family carers' experiences of nutritional care for people living with dementia at home: An interpretative phenomenological analysis', *Dementia*, pp. 231-246. DOI: 10.1177/1471301219872032

The second manuscript presented in this thesis was submitted to *Dementia* and accepted in August 2019. The candidate developed the methodology, collected



and analysed the data, and wrote the manuscript with supervisory advice from Mary Hickson, Bridie Kent and Rebecca Abbott.

### Paper 3: Chapter 5

Mole, L., Kent, B., Hickson, M. and Abbott, R. (2019b) 'It's what you do that makes a difference' An interpretative phenomenological analysis of health care professionals and homecare workers experiences of nutritional care for people living with dementia at home', *BMC Geriatrics*, 19(1), pp. 250. DOI: 10.1186/s12877-019-1270-4

The third manuscript presented in this thesis was submitted to *BMC Geriatrics* and accepted in September 2019. The candidate developed the methodology, collected and analysed the data, and wrote the manuscript with supervisory advice from Mary Hickson, Bridie Kent and Rebecca Abbott.

## Abstract

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*Helping people with dementia to eat well at home: An investigation to understand and enhance nutritional care by Louise Mole*

In this thesis I developed a complex intervention to help people living at home with dementia to eat well, and improve nutritional care. This was achieved through four studies conducted using multiple methods.

A scoping review found 61 studies reported in 63 articles after searching six databases from inception to July 2016. Content analysis was used, and the overarching categories were: 'timely identification of nutritional risk and subsequent regular monitoring of nutritional status', 'multi-component tailored interventions', and the 'influence of the caregiving dyad on nutritional status'. Most studies were cross-sectional (n=24), cohort (n=15) or qualitative (n=9). Only three were randomised controlled trials. People living at home with dementia are identified as a vulnerable group (n=35); however, only four studies tested interventions to improve nutritional care.

In two qualitative studies, semi-structured interviews were used (alongside diaries and a vignette) to explore the experiences of the nutritional care of people living with dementia at home from the perspectives of family members, healthcare professionals and homecare workers. Eight family carers (mean age of 69.6 years) and seven healthcare professionals and homecare workers (mean time spent in profession = 8.9 years) were purposively recruited and interviewed between October 2017 and March 2018. An Interpretative phenomenological analysis approach was used. Three superordinate themes were identified for family carers: 'becoming carer and cook', 'changing role and relationships', and

‘emotional eating’. Four superordinate themes were identified for healthcare professionals and homecare workers: ‘responsibility to care’, ‘practice restrained by policy’, ‘in it together’, and ‘improving nutritional care’. Family carers, healthcare professionals and homecare workers feel that they do not have adequate knowledge to support someone if they are nutritionally compromised. They are conscious about ‘doing the right thing’ when it comes to providing nutritional care.

The acceptability and feasibility of three podcasts designed for homecare workers about providing nutritional care to someone with dementia were trialled. Six homecare workers took part between October and December 2019, attending a focus group, and completing a quiz. Normalisation process theory underpinned the thematic analysis of qualitative data. Knowledge improved from a score of 5.5 (median) before listening to 7.5 (median) after listening. Eight themes represented the views of the participants. Podcasts about nutritional care and dementia are acceptable to homecare workers, and knowledge of the nutritional concerns associated with dementia improved.

Family carers and people living at home with dementia should be supported when making appropriate food and drink choices, preventing the risk of malnutrition. It is anticipated that the findings of the studies included in this thesis, will encourage healthcare professionals and researchers to place more focus on the nutritional needs of people with dementia living at home. Further development is required for podcasts, and evaluation of their impact in terms of practice and clinical outcomes are required.

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## Glossary

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AD	Alzheimer's Disease
BMI	Body Mass Index
CLT	Cognitive Load Theory
CONSORT	Consolidated Standards of Reporting Trials
COREQ	Consolidated Criteria for Reporting Qualitative Research
CQC	Care Quality Commission
DHA	Docosahexaenoic acid
EPA	Eicosapentaenoic acid
ESPEN	European Society for Clinical Nutrition and Metabolism
GP	General Practitioner
IM	Intervention Mapping
IPA	Interpretative Phenomenological Analysis
MMSE	Mini Mental State Examination
MNA-SF	Mini Nutritional Assessment Short Form
MRC	Medical Research Council
MUST	Malnutrition University Screening Tool
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
NPT	Normalisation Process Theory
NSI	Nutrition Screening Initiative
ONS	Oral Nutritional Supplement
PPI	Patient and Public Involvement
QoL	Quality of Life
RCGP	Royal College of General Practitioners
RCT	Randomised Controlled Trial
RfPB	Research for Patient Benefit
SLT	Speech and Language Therapist
SSRI	Selective Serotonin Reuptake Inhibitors
TEATIME	Training for <b>EAT</b> ing and drinking In De <b>ME</b> ntia

# 1. Introduction

---

Dementia is a disease which affects brain function, and can adversely affect how well someone is able to meet their nutritional requirements. Most people living with dementia still live in their own homes, which can make providing support with nutritional care challenging. This thesis presents my work in developing a complex intervention to help people living at home with dementia to eat well, and improve nutritional care.

## 1.1. Brief overview

An introduction to the background of dementia, including sub-types, diagnosis and current treatments is provided in Section 1.3. The challenges that someone living in their own home with dementia may encounter conclude this section. A background to the problem of malnutrition, including the prevalence, identification and management is outlined in Section 1.4, and the links between dementia and malnutrition are introduced in Section 1.5.

The role of nutrition in dementia, and the approaches currently used for therapeutic treatments are discussed in Section 1.6, concluding with an overview of dementia and malnutrition in the own home setting. A more detailed exploration of the literature regarding the nutritional care of people living at home with dementia is presented as a scoping review (see Chapter 3).

Family carers may manage the nutritional needs of family members living with dementia at home. The identification and management of symptoms that may affect nutritional status is often reliant upon the family carer. The experiences of family members who provide nutritional care to those with dementia is explored through a qualitative study (see Chapter 4).

Family carers, and those with dementia may need additional support, and healthcare professionals and homecare workers may be involved. The experiences of these workers in respect of treating and managing nutritional issues in people living at home with dementia, is explored in a second qualitative study (see Chapter 5).

There is a lack of evidence-based training regarding nutrition and dementia for homecare workers. A possible solution to this gap in knowledge is to provide training that aligns with the mobile working structure of homecare. A series of podcasts were developed and tested with homecare workers (see Chapter 6).

Chapter 7 presents a general discussion of the findings, the strengths and limitations of the studies, and reflections on the research process, as well as concluding remarks and future research priorities.

## 1.2. Definitions

The following statements qualify the principle terminology used in this thesis: *Malnutrition* can be defined as the state of being poorly nourished. It may be caused by a deficiency, or excess of energy, protein and other nutrients that results in adverse clinical outcomes (BAPEN, 2018a). For the purpose of this thesis, malnutrition will refer to the state of under-nutrition as this remains the common usage throughout the published literature.

*Nutritional (or dietary) intake* refers to food or nourishment, and the processes involved to provide this. It can be measured and used alongside physical (e.g. weight) and biological markers (e.g. serum cholesterol) to provide information about *nutritional status*. Assessing *nutritional status*, provides information on the effects of nutrition on health and disease (Elmadfa and Meyer, 2014). *Nutritional*

*care* refers to the support provided by others to help an individual maintain nutritional intake and improve nutritional status.

Domiciliary care workers provide non-medical support to people living at home, such as helping with personal hygiene, shopping, and food preparation. They are also referred to as *homecare workers*, which will be the terminology used in this thesis. *Healthcare professionals* refers to trained medical and allied health professionals, such as GPs, nurses, dietitians, occupational therapists and social workers.

*Podcasts* are media recordings that can be accessed online and then streamed or downloaded onto a smartphone or computer. Users can subscribe so that they are alerted when new episodes are available.

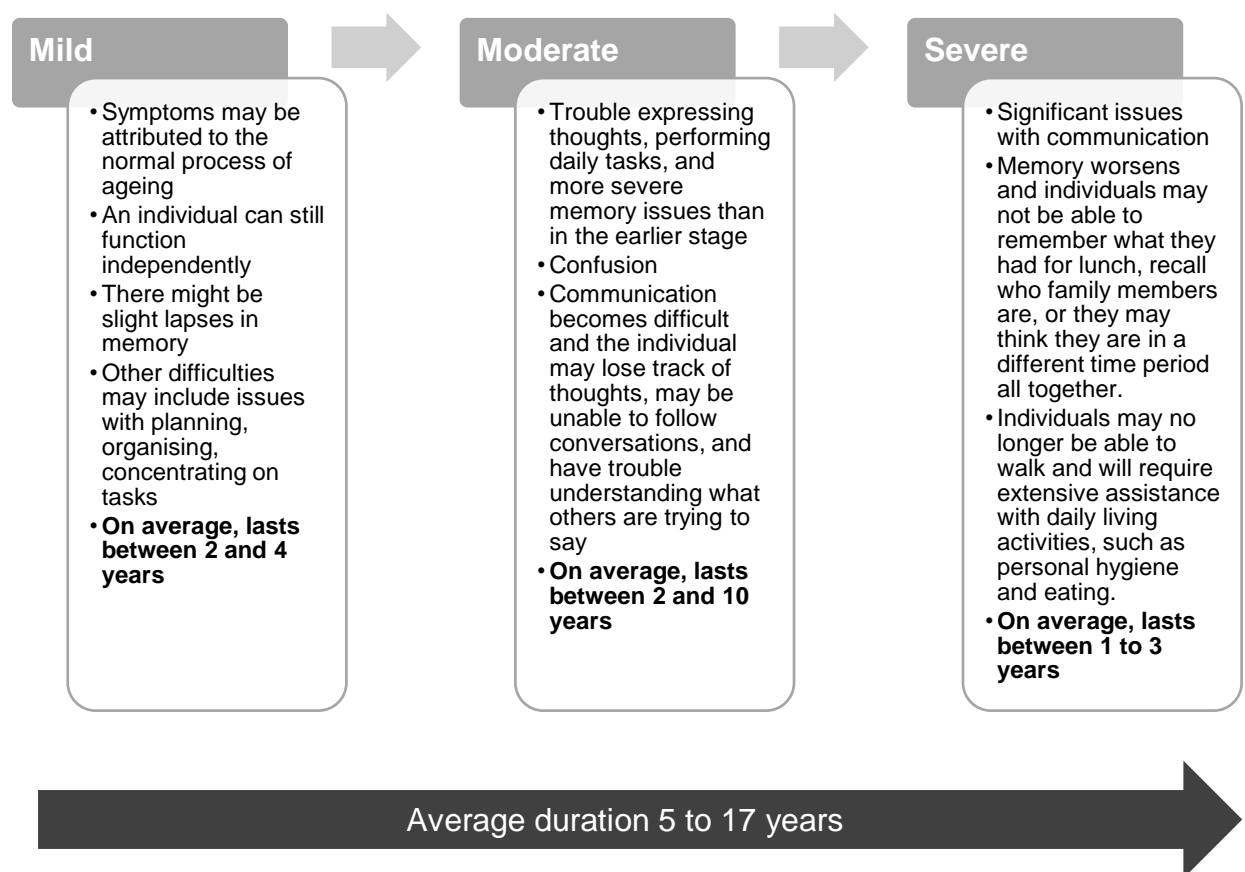
### 1.3. Dementia

Dementia is an incurable devastating disease, where brain function deteriorates leading to fading memory and unusual behaviour (Annear *et al.*, 2015; World Health Organisation, 2017). Its prevalence is reaching epidemic proportions, and is the greatest global challenge for health and social care in the 21st century (Kivimaki and Singh-Manoux, 2018). The increase in prevalence is explained, in part, by demographic ageing which is the main non-modifiable risk factor for dementia (Visser *et al.*, 2017). At least 850,000 people have the disease in the UK, and this is forecast to increase to over 1 million by 2025 (Prince *et al.*, 2014). Dementia changes the lives of those who have it and of those close to them. Memory problems, difficulties with language, and behaviour changes are the typical symptoms which affect how someone lives day-to-day (Robinson, Tang and Taylor, 2015). It makes people more dependant and vulnerable (Cunningham *et al.*, 2015). Family members that provide care can experience

stress, social isolation, poor physical and mental health, and financial hardship (Brodaty and Donkin, 2009; Karg *et al.*, 2018).

The symptoms of dementia tend to affect people at different stages throughout the disease. These stages are usually referred to as mild, moderate and severe dementia. Figure 1 shows the stages of decline and the average duration of each stage.

Figure 1 - Stages of dementia and average rate of decline (adapted from Dementia Care Central (2018))



### 1.3.1. Subtypes of dementia

There are thought to be over one hundred sub-types of dementia, but the main four, in order of prevalence are: Alzheimer's disease (AD), vascular dementia, dementia with Lewy bodies, and frontotemporal dementia (Alzheimer's Disease International, 2019; Cunningham *et al.*, 2015).

Alzheimer's disease is characterised by short-term memory loss, which can manifest as repetitive questioning (Cunningham *et al.*, 2015). It is typified by amyloid plaques and neurofibrillary tangles which constitute the two major neuropathological lesions found in the brain (Olesen, 1994). Vascular dementia is thought to occur as a result of cerebrovascular damage caused by large vessel atherosclerosis and small vessel arteriosclerosis (O'Brien and Thomas, 2015). The main symptoms experienced by those with vascular dementia, are trouble processing information and becoming easily distracted (Dichgans and Leys, 2017). It is common for Alzheimer's disease and vascular dementia to co-exist and this is referred to as mixed dementia (Custodio *et al.*, 2017). Dementia with Lewy bodies<sup>1</sup> is characterised by the accumulation of deposits of  $\alpha$ -synuclein protein on neurons (cells that transmit signals from the brain to other cells in the body), which is a similar pathology to Parkinson's disease (Outeiro *et al.*, 2019). Typical presentation includes episodes of inconsistent behaviour, incoherent speech, variable attention, and alterations in consciousness and visual hallucinations (McKeith *et al.*, 2017). Frontotemporal dementia refers to a group of neurocognitive syndromes that result in executive functioning impairment

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<sup>1</sup> Discovered by Fritz Jakob Heinrich Lewy (1885–1950) while studying the neuropathology of Parkinson's disease in 1912

(planning, organising and completing tasks), behavioural changes and a decrease in language proficiency (Young *et al.*, 2018).

### 1.3.2. Diagnosis and treatment of dementia

Dementia can be difficult to diagnose because the early symptoms resemble normal ageing (Custodio *et al.*, 2017). If an individual, or a family member suspects dementia, they are asked for a history of the symptoms that are affecting their everyday life, before completing a cognitive test. Biomarkers and structural imaging of the brain may also be examined as part of the diagnostic process (National Institute for Health and Care Excellence (NICE), 2018). There is increasing pressure on GPs to diagnose dementia as early as possible, to ensure that the patient is able to put in place an advance care plan whilst they have enough cognition to do so (Robinson, Tang and Taylor, 2015). The ethical considerations regarding early diagnosis are confounded by Fox *et al.* (2013) who propose that if a patient's health is not enhanced by early diagnosis then this should not be forced on them. The diagnosis of dementia mirrors the pathology – complex and not yet understood.

Disease-modifying therapies are yet to be discovered for dementia, so symptomatic and supportive treatments are used (Hugo and Ganguli, 2014). Acetylcholinesterase inhibitors can slow cognitive decline in Alzheimer's disease, and memantine may reduce behavioural and psychological symptoms of dementia (The National Institute for Health Care Excellence (NICE), 2014; Yiannopoulou and Papageorgiou, 2013). Combining these treatments may also have cognitive benefits for people with moderate to severe dementia (Howard *et al.*, 2012). Depression is a common occurrence in all types of dementias and at all disease stages, and is typically treated with serotonin reuptake inhibitors



(SSRIs) (Enache, Winblad and Aarsland, 2011). Use of antipsychotic medication to treat severe dementia symptoms such as hallucinations is controversial, and the risks of adverse effects often outweigh the benefits (Tampi *et al.*, 2016). Non-pharmacological supportive management strategies, such as music therapy, occupational activities (e.g. cooking), and physical exercise, have shown promising results when used to treat behaviour and psychological symptoms (de Oliveira *et al.*, 2015; Tible *et al.*, 2017). However, the wider effect of supportive strategies on outcomes such as preventing unnecessary hospital admissions, is not yet clear and warrants further research (Dawson *et al.*, 2015).

### 1.3.3. Living with dementia at home

Two-thirds of people with dementia are thought to be living at home, with an estimated 670,000 family and friends taking the role of primary carer (Prince *et al.*, 2014). This role includes meeting health, emotional and social needs, which become more complex and demanding as the dementia progresses, and can negatively impact the individual, their family, and their carers in many varied ways (Fauth and Gibbons, 2014). Caring for someone with dementia is stressful, and consequently may lead to depression or other mental health difficulties (Tremont, 2011). It is a struggle for family carers to find balance with their own lives (careers, or caring for children) and with caring responsibilities (Brodaty and Donkin, 2009). Perhaps the biggest struggle, however, is dealing with the sense of detachment and grief once the person with dementia forgets those around them (Blandin and Pepin, 2017; van Wijngaarden *et al.*, 2018).

There are different types of support currently available to those living at home with dementia and their families. The GP is usually seen first for clinical support, and they may refer to a specialist service such as a memory clinic for diagnosis.

Memory clinics also offer specialist psychogeriatric support from a team of healthcare professionals and can signpost to dementia charity organisations (Jolley and Moniz-Cook, 2009). These organisations offer community volunteer-led support groups for people living with dementia and their family members.

People with dementia and carers respond positively towards the informal nature of support groups, which allows bonds to be made with others experiencing the disease (Toms *et al.*, 2015). Memory cafes are a popular type of support group, which also offers respite for family carers, and offer interactive activities and an opportunity to talk with refreshments in a relaxed environment (Greenwood *et al.*, 2017). Despite these services being available, more than half of people living at home with dementia report feeling lonely and isolated (Alzheimer's Society, 2019). Loneliness is one of many factors that may affect appetite, and increases someone's risk of becoming malnourished (Eskelinen, Hartikainen and Nykänen, 2016; Ramic *et al.*, 2011).

#### 1.4. Malnutrition

There are an estimated 1.3 million adults over the age of 65 years in the UK who are malnourished (BAPEN, 2018a). Although people who are over-nourished or under-nourished can be referred to as malnourished, in this thesis I use the term to describe the latter condition. It is estimated that someone who is malnourished costs three to four times more to care for, compared to someone who is well-nourished (Elia, 2015).

Maintaining an individual's nutritional status includes preventing unintentional weight loss (fat and muscle), and meeting fluid and micronutrient requirements. The incidence of malnutrition in adults over the age of 65 is increasing, partly because we are living longer (Visser *et al.*, 2017). Increased prevalence of

diseases for which age is a risk factor, such as dementia, also contribute towards the increased risk of malnutrition.

Risk factors for malnutrition may be medical, sociological, psychological or environmental (Table 1).

Table 1 - Risk factors for malnutrition (adapted from Hickson, 2006)

Medical	Sociological	Psychological	Environmental
<ul style="list-style-type: none"> <li>• Poor appetite</li> <li>• Poor dentition</li> <li>• Dysphagia</li> <li>• Taste and smell disturbance</li> <li>• Gastrointestinal disorders</li> <li>• Endocrine disorders</li> <li>• Neurological disorders</li> <li>• Infections</li> <li>• Physical disability</li> <li>• Drug interactions</li> <li>• Cachexia caused by cancer</li> <li>• Polypharmacy</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of knowledge</li> <li>• Isolation/loneliness</li> <li>• Poverty</li> <li>• Inability to shop or prepare food</li> </ul>	<ul style="list-style-type: none"> <li>• Confusion</li> <li>• Depression</li> <li>• Bereavement</li> <li>• Anxiety</li> <li>• Dementia</li> </ul>	<ul style="list-style-type: none"> <li>• Food provision services</li> <li>• Time</li> <li>• Requiring help to eat</li> <li>• Appropriate cutlery and drinking vessels</li> <li>• Unable to meet religious or cultural dietary needs</li> </ul>

Malnutrition is a serious clinical condition, and can lead to life-changing health problems, and mortality. Someone who is malnourished may fall over more frequently, be vulnerable to infections, may not be able to move around as much as they need too, experience poor wound healing, and become confused (Leslie and Hankey, 2015; Neloska *et al.*, 2016; Neyens *et al.*, 2013; Soderstrom *et al.*, 2017).

Malnutrition comes at a cost to a person's health and quality of life, but also the economy. In England, £19.6 billion was spent on malnutrition-related hospital stays, moves to nursing homes, and GP visits and prescriptions between 2011

and 2012 (Elia, 2015). The issue is most prevalent in the community where one in ten adults over the age of 65 are malnourished or at risk of malnutrition (European Nutrition for Health Alliance, 2006).

#### 1.4.1. Identifying and managing malnutrition in the community

It is important to find out whether someone may be at risk of malnutrition so that they can receive appropriate support, particularly if they are living at home (Phillips *et al.*, 2010). European and UK guidelines recommend that people are screened for malnutrition when they come into contact with healthcare services and if there is a clinical concern (Cederholm *et al.*, 2017; NICE, 2017). The Malnutrition Universal Screening Tool (MUST) or Mini Nutritional Assessment Short Form (MNA-SF) are the most widely used screening tools in Europe (Elia and Russell, 2009; Kaiser *et al.*, 2009). Validation of tools specific for use in the community is lacking (Power *et al.*, 2018).

Healthcare professionals may feel that it takes too long to screen someone for malnutrition risk, and question the need to do it in the first place (Harris *et al.*, 2019). To address the resistance to screening, simpler tools have been developed for use by volunteers, family members and healthcare professionals, such as the 'Nutrition Wheel' (Wessex Academic Health Science Network, 2019). This tool provides an opportunity to start a conversation about someone's nutritional status, and if concerns are raised a formal malnutrition screening tool can then be used. This is particularly important for older adults, as weight loss may be a sign of dementia before a diagnosis (Grundman, 2005).

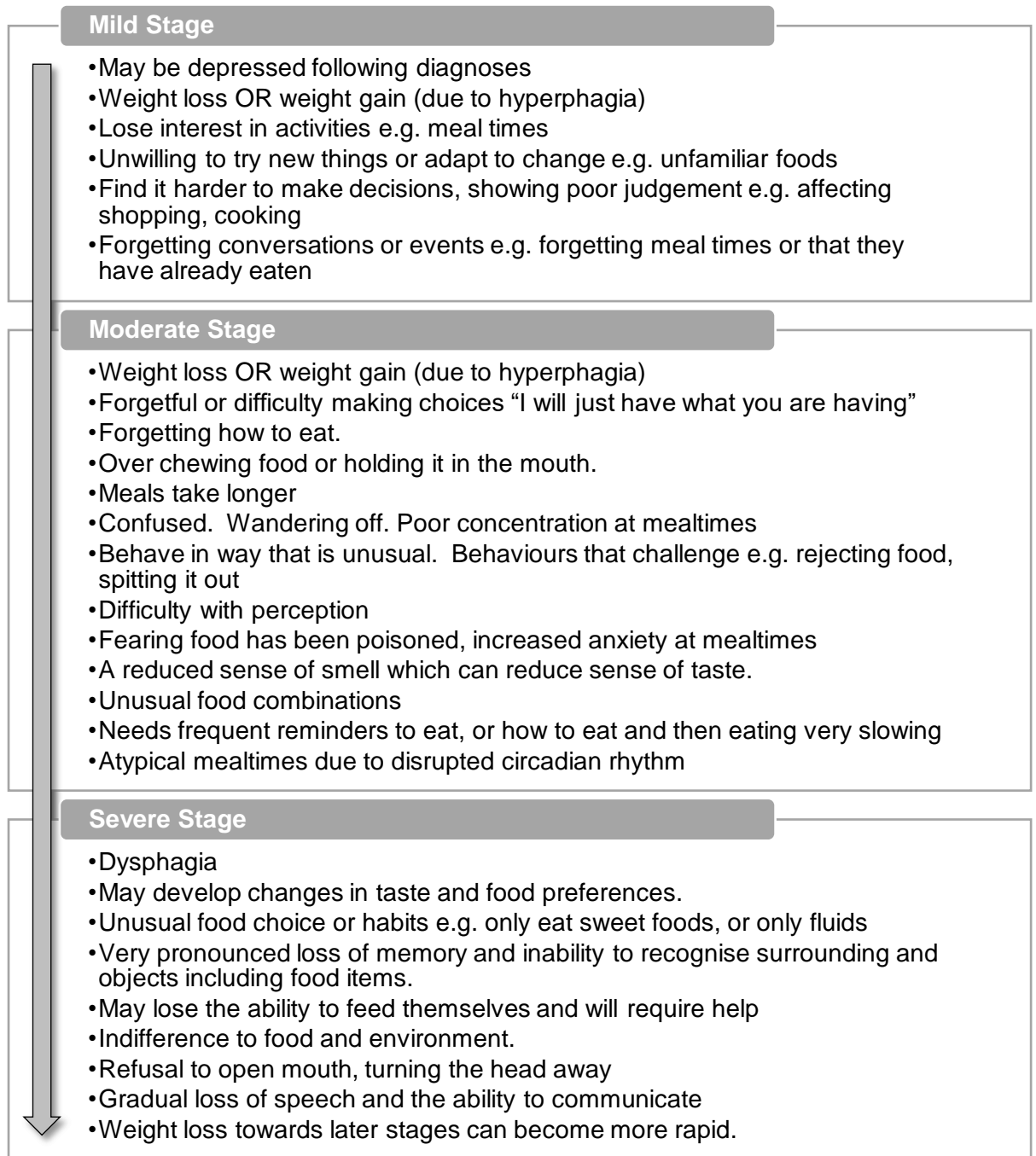
Despite the focus on adherence to using malnutrition screening tools, they should not replace intuition that someone may be at risk of malnutrition (BAPEN, 2018b).

### 1.5. Dementia and malnutrition

The nutritional needs of someone with dementia should be considered at all stages. The main symptoms that can affect nutritional status include: memory decline, loss of motor skills, how someone relates visual information to the space around them, taste changes, changes in appetite, swallowing problems, involuntary muscle movements, and restless behaviours (e.g. pacing). Weight loss can also occur as a result of hyper metabolism and inflammatory processes associated with the disease (Cerejeira, Lagarto and Mukaetova-Ladinska, 2012; Dauncey, 2014).

The symptoms that may affect the ability of someone with dementia to eat and drink enough will vary throughout the course of the disease (Figure 2). People with Alzheimer's disease have been observed to develop appetite changes at an early stage of the disease, progressing to changes in eating habits and food preference at a moderate stage, and swallowing disturbances in the later stages (Kai *et al.*, 2015). Although these findings were for people with Alzheimer's disease in a hospital setting in Japan, they are commonly reported symptoms in all sub-types and settings (Cipriani *et al.*, 2016; Sandilyan, 2011; van der Linde *et al.*, 2014). Other studies have found changes in eating behaviour more prevalent in frontotemporal dementia than in Alzheimer's disease (Ikeda *et al.*, 2002).

Figure 2 - Symptoms of dementia over the course of the disease



Some people will experience side effects from medications whether these have been prescribed for the symptoms of the dementia or other conditions. For example, cholinesterase inhibitors are often prescribed to slow the cognitive decline associated with dementia, but they result in weight loss. A risk-benefit analysis into the use of cholinesterase inhibitors found the beneficial effects to be

short-lived, with weight loss as a negative clinically significant side-effect (Buckley and Salpeter, 2015).

As well as the symptoms of dementia, and side effects of medications, caregiver burden can contribute towards malnutrition risk (Bilotta *et al.*, 2010; Gillette-Guyonnet *et al.*, 2000). Family carers lack education and support to help them understand dementia, its impact on nutrition and to know how to provide the right care at each stage (Whitlatch and Orsulic-Jeras, 2018). Studies involving the provision of educational interventions for people in the early stages of dementia and their carers, have shown short-term benefits to relationship quality and improved communication (Moon and Adams, 2012; Orsulic-Jeras *et al.*, 2016). Whether these interventions yield benefits longer-term is yet to be explored.

#### 1.6. The role of nutrition in dementia care

There is no consensus on how the nutritional requirements of someone with dementia may change at different stages of the disease. The European Society for Clinical Nutrition and Metabolism (ESPEN) has published guidance regarding the goals of nutritional treatment for this patient group, which will depend on a number of individual factors (Volkert *et al.*, 2015). These include: the presence of other diseases that may increase metabolic stress or require dietary consideration (e.g. diabetes); body mass index (BMI); activity levels; physical ability to prepare and eat food; and living circumstances (e.g. alone). Enteral feeding (tube feeding) is not routinely indicated for older patients with eating difficulties and dementia, as it does not extend life, and could negatively affect the quality of life for the individual and carer (Ticinesi *et al.*, 2016). The effects that individual nutrients have on brain function have been explored in laboratory settings, and some studies have examined these effects in humans.

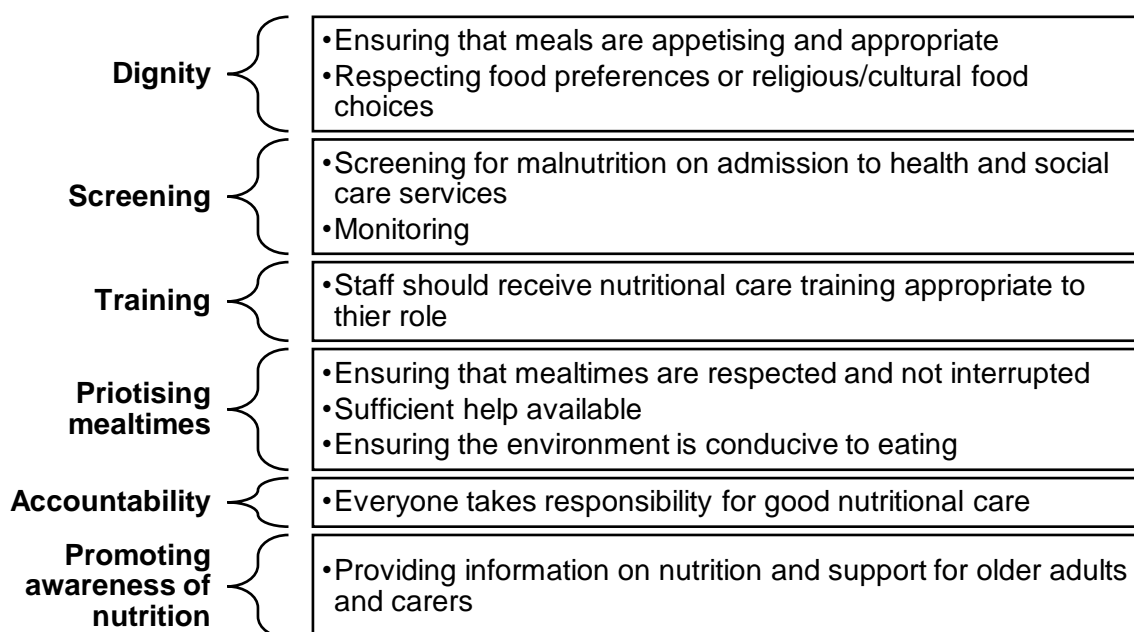
Nutrigenomic research is exploring the impact of diet on reducing  $\epsilon 4$  allele levels, and murine studies indicate that high-fat diets and links to the progression of Alzheimer's disease warrant further exploration (Lane-Donovan and Herz, 2016). The presence of the  $\epsilon 4$  allele of Apolipoprotein E (a cholesterol carrier that supports lipid transport and injury repair in the brain), has been found to genetically determine an increased risk of Alzheimer's disease (Liu *et al.*, 2013). Specialised oral nutritional supplements (ONS) including docosahexaenoic acid (DHA), eicosapentaenoic acid (EPA), uridine (as uridine monophosphate), and choline have been shown to improve brain functional connectivity (over a 24 week period) (Scheltens *et al.*, 2012). Longer duration studies are required, and the supplements focus on improving brain function only (i.e. they are not nutritionally complete).

The optimal way to help someone manage the symptoms of dementia will vary depending on the care setting. Systematic reviews have focused on randomised controlled trials (RCT's) carried out across all care settings (residential homes, ward environments and own homes), but include minimal analysis of studies in the own home setting (Abdelhamid *et al.*, 2016; Bunn *et al.*, 2016a), leaving a significant gap in our collective knowledge. These reviews examined the efficacy of direct (e.g. prescribing ONS) and indirect (e.g. playing soothing music during mealtimes) interventions to improve, maintain or facilitate food and drink intake, and improve nutritional status in people with dementia. It is known from studies in dementia care units that enhanced input from dietitians (closer monitoring of residents on an as-needed-care basis), and menu changes can result in residents' weight gain or maintenance (Keller *et al.*, 2003). However, this type of intervention cannot be easily implemented in a patient's own home.



Carers may benefit from increased support from primary healthcare professionals, to help them understand the nutritional needs and consequences associated with dementia in those living at home (Alzheimer's Society, 2012). Providing support about nutrition and dementia to caregivers could reduce feelings of burden, increase knowledge and improve nutritional outcomes for everyone involved. To further reduce the burden experienced by family caregivers, homecare support may be used, and can help someone with dementia maintain an adequate nutritional status whilst living at home. Best practice guidelines have been published to support managers of homecare agencies (Skills for Care, 2014). Despite this, there is limited literature that evaluates the nutritional care that these agencies provide, or captures the views and experiences of homecare workers. Family members and homecare workers play a key role in managing the nutritional status of older adults who live at home (if trained and supported to do so), and this is transferable to people living at home with dementia (Marshall *et al.*, 2017). Practical, achievable strategies (see *Figure 3*) that focus on food and eating environments to increase the amount people with dementia eat and drink, whilst minimising carer burden (and cost) should be a consideration for nutritional care interventions (Jansen *et al.*, 2014).

Figure 3 - Factors that contribute to providing good nutritional care adapted from Social Care Institute for Excellence (SCIE) (2009)



#### 1.6.1. Dementia and malnutrition at home

Malnutrition and dementia are closely intertwined; each issue can exacerbate the other and lead to an ever worsening clinical condition.

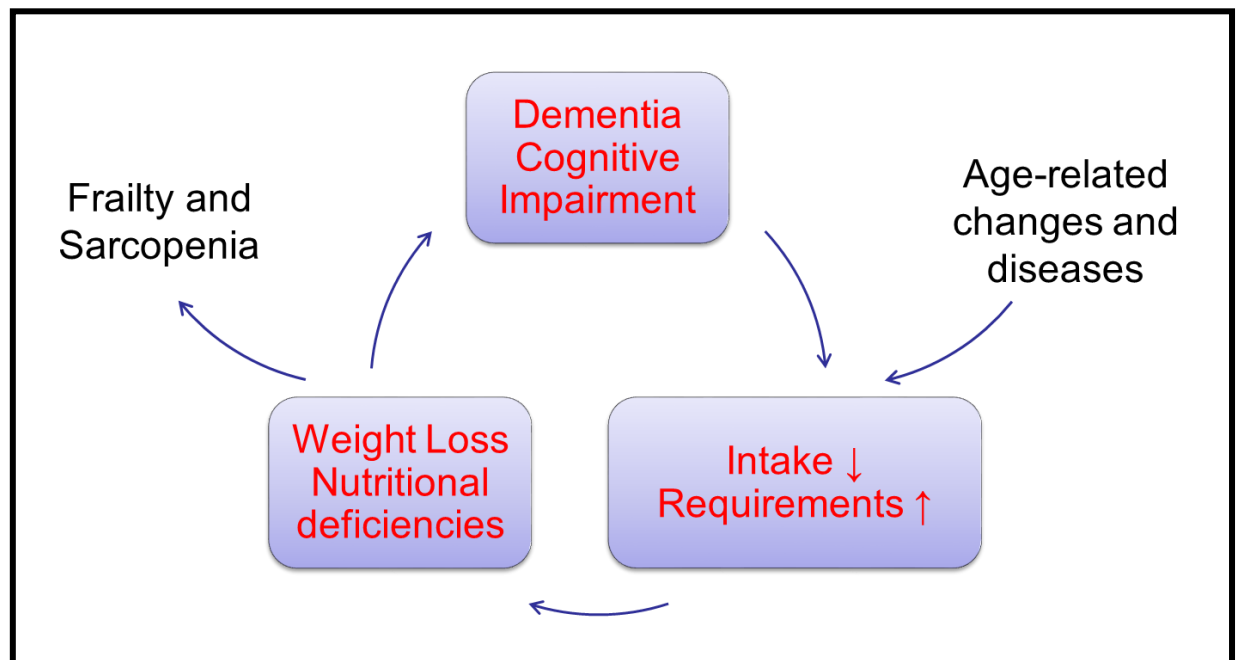
Dementia can affect someone's ability to plan, prepare and eat meals at home and consequently put them at greater risk of malnutrition. They may forget to eat, not store food properly, be unable to use cooking devices or follow a recipe and struggle to plan a food shopping trip (Evans, Price and Meyer, 2016), all of which may result in lower or unbalanced food intake.

Dehydration increases the risk of many health issues including confusion and delirium, poor skin integrity and gastrointestinal problems (Popkin, D'Anci and Rosenberg, 2010). Similarly, a decline in cognitive status has been found to be linked to an increased risk of dehydration in older adults in care homes (Hooper *et al.*, 2016), and this is likely to be the case for those living at home as well. People with dementia may not drink as much as their body requires to function

properly. They may forget to drink, or not feel thirsty, which is common for older adults (Kenney and Chiu, 2001). If they live at home alone or without a full-time carer, these difficulties may not be counteracted by a carer reminding them to drink or providing regular drinks. Thus, the risk of dehydration and the associated problems will rise.

Dementia can lead to an increased risk of malnutrition. However, malnutrition is also associated with increased risk of cognitive decline (Garcia-Ptacek *et al.*, 2014; Qizilbash *et al.*, 2015). A retrospective cohort study involving two million people over two decades, found an inverse association between the incidence of dementia and BMI (Qizilbash *et al.*, 2015). People who were underweight during their middle years of life, were at greater risk of developing dementia than their normal weight counterparts, and the risk further reduced for those with higher BMIs. It has been suggested that the mechanisms underlying this association are due to body composition changes when weight-loss occurs which negatively confounds the relationship between weight and dementia risk (Pegueroles *et al.*, 2018). Dementia leads to decreased nutritional intake and deterioration of nutritional status, which itself contributes to acceleration of the disease, as Figure 4 illustrates.

Figure 4 - The 'dementia – malnutrition' cycle (adapted from Volkert *et al.* (2015))



### 1.7. Summary

This Chapter has provided an overview of the problem of malnutrition and dementia. It has been shown how malnutrition can be identified, the factors involved in the development of malnutrition and the reasons why its prevention is so important. The symptoms of dementia, current treatment, and how it can affect someone living at home have been presented. Finally, the important link between dementia and malnutrition risk has been shown, and how this is a particular problem for people living at home.

The increasing financial and psychosocial cost of dementia warrants an increase in investment in research across the entire dementia care spectrum, from prevention to end of life. Social care organisations who provide support for people with dementia living in their own homes, are under scrutiny to ensure that they are providing safe and adequate care. The James Lind Alliance in conjunction with the Alzheimer's Society, have set priorities for research in

dementia (Alzheimer's Society, 2013). This thesis aligns with the sixth priority: 'finding the most effective ways to encourage people with dementia to eat, drink and maintain nutritional intake'. The over-arching aim was to develop and test the feasibility of a complex intervention to improve the nutritional care of people living with dementia at home.

The research questions this thesis will answer are:

- i. What is known about managing the nutritional status of people with dementia living at home from the perspectives of people with dementia, those of their carers, and of other healthcare professionals involved in nutritional care?
- ii. How can the nutritional care provided by primary healthcare professionals and family carers of people living at home with dementia be improved?
- iii. What type of intervention (incorporating the improvements identified in ii)) will potentially lead to improved nutritional care for people with dementia living in their own home?
- iv. Is such intervention feasible for implementation in a complex primary healthcare system?

I have undertaken four studies which follow a complex intervention framework (Medical Research Council, 2006) forming the basis of this thesis. The first study (Chapter 3) is a scoping review of the literature to identify existing work and gaps in this area. This informed the subsequent studies (Chapter 4 and 5) which capture the experiences of those involved in providing nutritional care to people with dementia at home.

In order to address the problem of malnutrition in people living with dementia at home, I developed three, 30 minute podcasts for homecare workers, containing information on nutritional care and dementia. The following topics are addressed: malnutrition and the symptoms of dementia that can affect nutritional status; important nutrients and identifying someone who may be at risk of malnutrition; and how to adapt someone's surroundings and meals to help prevent malnutrition. This is a novel idea that has no documented precedent.

This intervention (set of podcasts) was developed and tested with a small group of homecare workers to assess their feasibility and acceptability (Chapter 6).

How and whether my studies answered the proposed research questions are brought together into a discussion in Chapter 7. The strengths and limitations of the studies and reflections on the research process are also described. The thesis finishes with implications for practice and recommendations for future research.

## 2. Methodologies

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### 2.1. Chapter overview

The research for this doctoral thesis is comprised of four studies that investigate what is known about managing the nutritional status of people living with dementia at home, how it can be improved, and whether an intervention aimed at homecare workers is feasible. This Chapter describes the research strategy and outlines the contribution of each study to the overall aims outlined in the Introduction. The rationale for the methods used in each study is discussed. Three of the studies described in this thesis have been published elsewhere, and are presented in Chapters 3, 4 and 5 in the style requested by the respective journals. Method details are presented in these Chapters, as well as in Chapter 6, which describes the final study. A brief summary of outcomes from each study is included in this Chapter to demonstrate the rationale for the next phase of research.

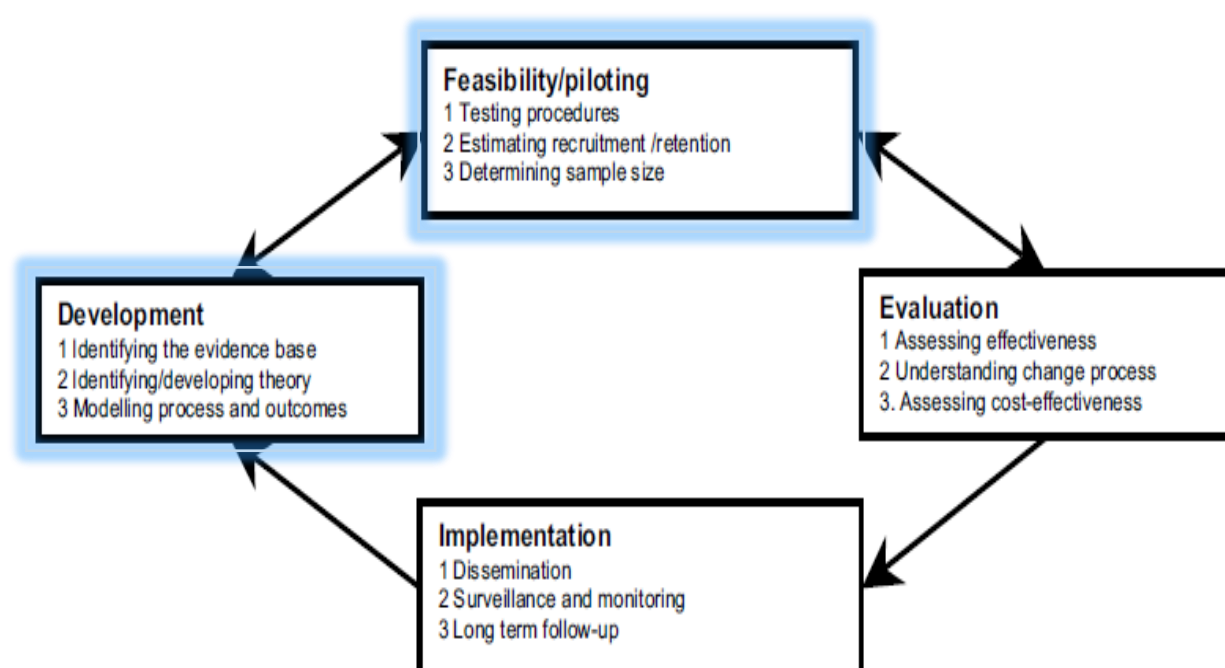
### 2.2. The framework for developing complex interventions

Supporting the nutritional needs of someone with dementia in the primary care setting is multifaceted, involving many healthcare professionals and social determinants. Given these complexities, the Medical Research Council (MRC) framework for developing and evaluating complex interventions (Medical Research Council, 2008) has been used to structure this research project. This framework provides a programmatic approach to solving problems that exist in a complex healthcare environment, where extrinsic and intrinsic factors may need to be addressed in interventions (Richards and Hallberg, 2015). Extrinsic factors that could affect the nutritional care of people living with dementia at home include: the availability of support services, the presence of family members who

help with care, and carer knowledge of nutritional care for people living with dementia. Intrinsic factors include: the stage of dementia and associated symptoms that could affect nutritional intake, such as memory loss and behaviour changes.

When developing a complex intervention, it is important to understand how the mediators (causal mechanisms) and moderators (characteristics of studies, populations, and settings) of the intervention will interact to produce individual outcomes. The studies presented in this thesis align with the two initial framework phases highlighted in Figure 5; development and feasibility/piloting. This has enabled a deeper understanding of the needs of people living with dementia at home and nutritional care, and an appropriate design of an intervention that can address these needs. The evaluation and implementation phases are planned for this work, but beyond the scope of this thesis.

Figure 5 – MRC complex intervention development and evaluation process (adapted from Craig et al (2008))





Within the development phase, I used a systematic reviewing method to establish the evidence regarding the nutritional care of people living with dementia at home (see Chapter 3). Next I identified and developed the theory through qualitative methods to discover the views and experiences of those involved in providing nutritional care to people living with dementia at home (see Chapter 4 and Chapter 5). The outcomes of such steps in the development phase informed the design of an intervention aimed at homecare workers who provide nutritional care to people with dementia living at home (see Chapter 6). In the second phase, the intervention was trialled with a group of homecare workers to assess acceptability and feasibility, as part of the feasibility phase of the MRC complex intervention process (see Chapter 6). This allowed some intervention procedures to be tested, such as the production and method of distribution of the intervention to homecare workers. The challenges associated with participant recruitment and retention were realised and discussed in Chapter 7, including the work required prior to a larger pilot study.

### 2.3. Stakeholder involvement

The involvement of stakeholders is important in the development of complex interventions, in order to fully understand the problem and help find realistic solutions that make a difference (Brett *et al.*, 2014; O'Cathain *et al.*, 2019). There are a number of people involved in caring for people living at home with dementia who are likely to have an interest in an intervention aimed at improving nutritional status. The James Lind Alliance and Alzheimer's Society developed research priorities created by patients, carers and clinicians involved with dementia care (section 1.7) (Alzheimer's Society, 2013). These priorities formed the starting point for my research and I decided to involve stakeholders from the outset. In

the early stages, discussions with family carers and volunteers at local memory cafes and carer support groups helped identify the priorities for nutritional care for people living with dementia. I attended three groups from June to August 2016 (Age UK dementia drop-in, a local dementia support information evening, and Alzheimer's UK memory cafe), each well attended with at least 30 people with dementia, carers and volunteers. I was given the opportunity to present my research ideas to the entire group before then sitting with smaller groups for informal discussions during tea breaks and planned group activities (e.g. quizzes and bingo). The focus of these discussions was to explore the attendees' experiences of eating and drinking since the diagnosis of dementia. Experiences were unique to individuals and their carers, and these included noticing an increasing preference for sweet foods (and concern for this), loss of appetite and loss of interest in mealtimes. They supported the decision to focus the intervention within the home setting. A family carer, community dietitian and GP were involved in ratifying the outputs from the scoping review (Chapter 3). A local Alzheimer's Society steering group, which included staff members of the Alzheimer's Society and people living with dementia, were consulted when developing the protocol for the qualitative studies (Chapters 4 and 5). They provided valuable feedback on the design of the participant information sheets and interview question prompts. The content of the podcasts was co-produced with a training manager of a local homecare agency, and with a variety of healthcare professionals who work with people living with dementia. Many of these individuals also featured in the podcasts. A group of homecare workers were involved in testing the feasibility of the podcasts, and provided feedback during a focus group. Finally, a junior doctor, dietitian, and research professional also provided feedback after listening to the podcasts. Stakeholder input has

been invaluable throughout, as I recognised that I have limited experience of caring for someone with dementia in a professional or personal capacity. It was important for me to produce an intervention that met the needs of those that would use it, and be benefited by it. Building rapport with stakeholders enabled the exchange of knowledge and ideas; one of the fundamental aspects of patient and public involvement (PPI) (Gibson, Welsman and Britten, 2017).

#### 2.4. Scoping review

Scoping reviews are useful for gaining a comprehensive overview of the research field of interest. Furthermore, scoping reviews help in mapping the nature and extent of research activities and provide a rigorous and transparent methodology (Levac, Colquhoun and O'Brien, 2010). They are an emerging method of identifying research gaps in the literature, and are considered a more viable option than a systematic review when the research question is broad (Daudt, van Mossel and Scott, 2013).

The Arksey and O'Malley (2005) framework is frequently used in scoping reviews, providing structure and methodological rigour (Pham *et al.*, 2014). The framework includes identifying the research question, searching for relevant studies, selecting studies, charting the data, and collating, summarising and reporting the results, and consultation with stakeholders to validate findings and facilitate opportunities for knowledge transfer and exchange. This framework is deemed suitable for the inclusion of a range of study types to answer a range of questions related to a broad topic. I used this framework to prepare a scoping review protocol that defined the inclusion and exclusion criteria, search strategy and data extraction template. The protocol was made available in the public domain, by hosting it on ResearchGate:

<https://www.researchgate.net/publication/308168581> The nutritional care of people living with dementia at home a protocol for a scoping study

#### 2.4.1. Objectives

The objectives of the scoping review were to examine how the nutritional status of people living at home with dementia is managed, the difficulties associated with doing this, and the involvement of carers and other healthcare professionals.

Preliminary searches returned no evidence of existing scoping studies in this field of study. At the time of the preliminary search (June, 2016), two review protocols were listed on the Prospero Register and Cochrane Database of Systematic Reviews:

- [https://www.crd.york.ac.uk/prospero/display\\_record.php?ID=CRD42014014546](https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42014014546)
- <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD011542/full>

The first focused on conducting an umbrella review of current systematic reviews of Randomised Controlled Trials (RCTs), intending to investigate nutritional interventions for individuals over the age of 80 years living with dementia (however excluded mild cognitive impairment, which could be an indicator for dementia and have nutritional consequences) (Burckhardt *et al.*, 2014). The second planned to explore the effects of environmental or behavioural modifications on food and fluid intake and nutritional status in people with dementia across all care settings, and was concerned with patient-related outcomes only (i.e. excludes impact of RCT interventions on carers or other stakeholders) (Herke *et al.*, 2018).

Since publication of my scoping review, the Cochrane review exploring the effects of environmental or behavioural modifications on food and fluid intake and nutritional status in people with dementia has now been completed. The authors concluded that no specific environmental or behavioural modifications for improving food and fluid intake in people with dementia were identified, due to the limited amount and poor quality of evidence found (Herke *et al.*, 2018). The umbrella systematic review of RCT studies has not been completed.

The aims of the protocols helped refine the research question for the scoping review. The intention was not to focus on RCTs in isolation, but explore a wider field of enquiry. The subsequent intervention was, therefore, developed from a broad view of the literature.

#### 2.4.2. Inclusion and exclusion criteria

A scoping study method encourages finding and analysing a breadth of literature, and the following were included:

- any interventions (using any research approach) aimed at maintaining or improving the nutritional status of individuals (no age restriction, male and females) with dementia or mild cognitive decline, who live at home alone, or with formal and/or informal carers;
- any literature where carer or patient knowledge of nutrition and dementia and awareness of available support has been explored;
- any literature exploring the nutritional consequences of dementia.

Any literature conducted in nursing or residential care homes, or an acute setting were excluded; however, studies conducted with patients using day-centres or short-term respite care were included. This was because the person with dementia was likely to still live in their own home, and may have respite care (to

give family members a break from caring duties) for a few hours or a few weeks at undefined periods (Neville *et al.*, 2015).

There were no restrictions imposed on the outcomes of studies and both quantitative (e.g. body weight, blood markers, and hand grip strength) and qualitative (e.g. themes, concepts, case-studies, perceptions and experiences) findings were included. Further details of specific methods can be found in Chapter 3. The scoping review identified gaps in the literature, which informed the next two studies which explored the views and experiences of those involved in providing nutritional care to people living with dementia at home.

## 2.5. Qualitative studies

The scoping review highlighted that there are few studies that have captured the lived experiences of family carers concerning the management of the nutritional needs of those being cared for. The scoping review also highlighted that the physical and emotional complexities of the caregiving relationship, or 'dyad', could affect the nutritional status of the person with dementia and that of the carer. The review also showed that there is a paucity of studies examining the views and experiences of domiciliary carers, and other healthcare professionals who may interact with people living with dementia at home (GPs, community social workers, community dietitians, and dementia key workers). These three areas warranted further investigation, and were the focus of the next phase of research described in Chapters 4 and 5.

The aim of this phase was to explore the experience and perception of nutritional care by people who care for those living at home with dementia. The research question that framed the approach was:

*“How do family carers, domiciliary carers and healthcare professionals make sense of providing nutritional care to those living with dementia at home?”*

The objectives were:

- to capture the lived experiences of family carers of people living at home with dementia, relating to the provision of nutritional care;
- to capture the lived experiences and perceptions, relating to nutritional care, of a range of primary healthcare professionals and homecare workers, who support people living at home with dementia and family members;
- to identify the main issues based on the Interpretative Phenomenological Analysis (IPA) of data arising from the experiences and perceptions of the family carer, domiciliary carer and healthcare professional in respect of the nutritional care of people living with dementia at home;
- to highlight areas for future research relating to nutritional care based on participants' experiences;
- to inform the development of an intervention aimed at improving the nutritional care of people living with dementia at home.

#### 2.5.1. Qualitative approach

I chose IPA for these studies, because I wanted to focus on the lived experience of providing nutritional care to someone living at home with dementia (the phenomenon). IPA allows participants to offer their own perspectives of a phenomenon, and for the researcher to explore the meaning, feelings and concerns behind these perspectives (Larkin, Watts and Clifton, 2006). IPA allowed me to shift my focus from the general topic of nutritional care for those

living at home with dementia (which would suit a different qualitative method such as thematic analysis) to instead, *the people* that are providing the nutritional care.

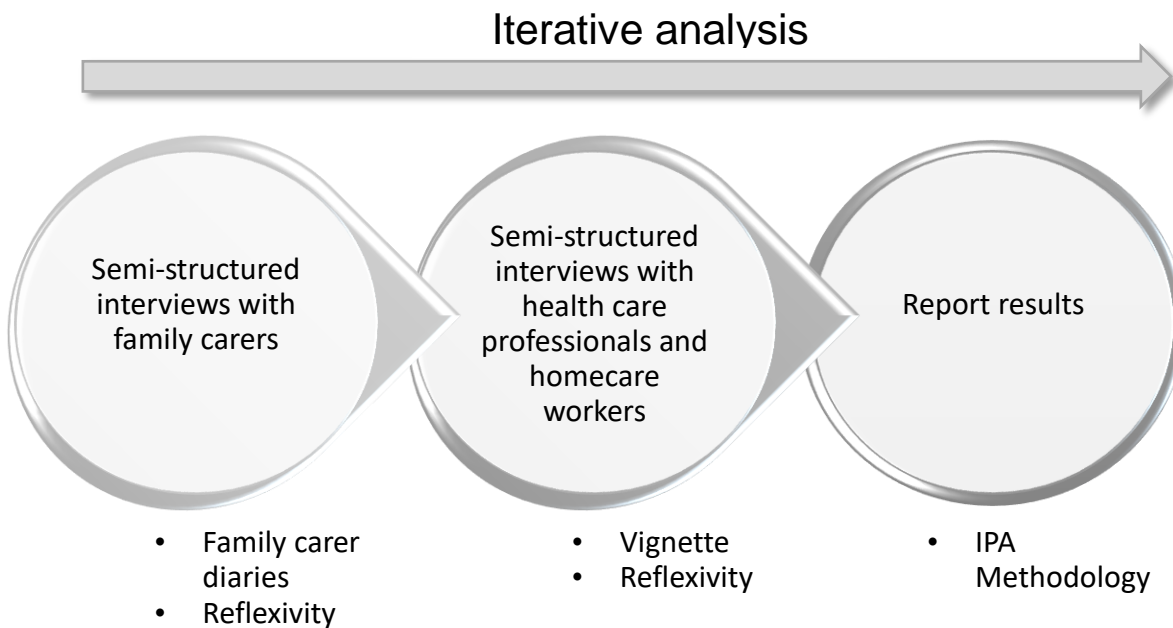
An IPA methodology involves a double hermeneutic approach, in that the researcher is making sense of the participant, who is making sense of their experience, and this is acknowledged in the analysis and interpretation of data. Researcher reflexivity was, therefore, an important component of knowledge generation in this study (Hopkins, 2004). I kept a reflexive diary during the collection and analysis of qualitative data. The diary allowed me to explore my interpretations of the participant accounts, and how I personally made sense of them. I was able to reflect upon my clinical and research experience as part of the sense-making process.

The experiences of family carers was my initial area of interest, after finding a lack of information on this aspect in the scoping review. The findings from these semi-structured interviews with family carers and their participant diaries were used to develop a vignette, which was incorporated into the semi-structured interviews with homecare workers and healthcare professionals.

*Figure 6* shows the order of this study.



Figure 6 –\_Diagram showing order of qualitative studies to answer the research question: ‘How do family carers, domiciliary carers and healthcare professionals make sense of providing nutritional care to those living with dementia at home?’



#### 2.5.2. Qualitative interviews with family carers

This phase of the study involved conducting semi-structured interviews with family carers who provided nutritional care (i.e. food shopping, cooking meals, providing mealtime assistance, monitoring weight) to a family member living with dementia at home. There are an estimated 700,000 informal carers caring for the 850,000 people in the UK living with dementia (Lewis *et al.*, 2014). Around half of carers are caring for someone in the same household (more likely to be female and caring for their spouse), and half care for someone living elsewhere (such as children caring for a parent) (Carers UK, 2019). It was important, therefore, to explore the perspectives of family members providing nutritional care to another family member regardless of whether they lived together. This resulted in a variety of familial relationships being explored. The amount and type of care family members provide will vary greatly, but it is known that practical

help such as preparing meals, or shopping is the most reported care activity in the UK (Carers UK, 2019). The nutritional status of someone living with dementia can, therefore, be affected by family carer's choices regarding which foods to buy and cook.

A third of adult carers in the UK spend more than 100 hours a week caring for their relative, and the majority report that caring responsibilities result in them feeling tired (Adult Social Care Statistics Team, 2019). I was aware that by inviting this group to take part in an interview study, would add further demands on their time. It was intended that keeping a diary would help them capture information that they may otherwise forget when carrying out the demands of their caring role.

Participants were asked to complete a record of their experiences prior to interview using unstructured (i.e. not chronologically dependant) diary entries (either handwritten or computer-typed). This qualitative mixed methods approach, allowed a deeper understanding of the caring experiences encountered by family carers regarding nutritional care, some actively reflected their diary entries to respond during the interviews.

Previous studies interviewing carers of people with dementia have asked participants to keep diaries (Clarke, 1999; Välimäki, Vehviläinen-Julkunen and Pietilä, 2007). They provide a subjective account of the thoughts and feelings associated with caregiving. The value of diary completion versus oral recollection of experiences, reveals a greater understanding of the challenges faced by carers of people living with dementia, and would be useful in the clinical setting as well as in research (Jayalath, Ashaye and Kvavilashvili, 2016). Participants who have caring duties, should not be expected to keep a diary for longer than two weeks,

as it is suggested that they may become bored or tired of making entries (Jacelon and Imperio, 2005). There are disadvantages to using a diary method, including the time burden placed upon already busy carers, and the reliance upon participants having the appropriate literacy or technological skills. However, combining interviews with a diary method is an under-utilised research approach, and could provide a greater level of depth, as well as providing confidence to participants when sharing their experiences with the researcher.

A semi-structured interview design provides opportunities for the interviewee and interviewer to discuss topics in more detail as the interview unfolds, yet ensures that pre-defined topic areas are covered throughout the course of the interview (Hancock, Ockleford and Windridge, 2007). A semi-structured interview approach also has limitations, and the merits of using this as a qualitative data collection method relies upon the interviewer having the appropriate skills to manage the interview situation so that data collected truly reflect the opinions and feelings of the interviewee, whilst keeping them at ease (Hancock, Ockleford and Windridge, 2007).

The IPA methodology advises that the first interview is transcribed and analysed before conducting subsequent interviews (Smith, Flowers and Larkin, 2009). I used this approach, allowing the first interview to be a pilot, highlighting any amendments to the question schedule required. None were needed.

### 2.5.3. Qualitative interviews with healthcare professionals and homecare workers

The second phase involved conducting semi-structured interviews with a range of healthcare professionals and homecare workers who supported people living at home with dementia or their family carers. People living with dementia

experience numerous feeding-related challenges (which often increase as the disease progresses) that contribute to their risk of malnutrition (Jansen *et al.*, 2014). The scoping review identified studies which had focused on factors such as food fortification and changes to eating environments to promote oral intake of people with dementia. Many of the interventions tested relied on healthcare professionals providing support to family members and those with dementia to implement the changes. Evidence-based guidelines state that people living with dementia at home should be screened for malnutrition risk every 3-6 months, and more frequently if there are obvious changes to eating ability (Volkert *et al.*, 2015). Malnutrition screening can be carried out by any healthcare professional, or healthcare worker who comes in contact with someone living with dementia at home (BAPEN, 2019). Despite policy recommendations, people living at home with dementia are not routinely being screened for malnutrition risk, and the reasons for this require further investigation. It was, therefore, important to include other groups that provided support to those living at home with dementia and their family carers.

A case-study vignette was included as part of the semi-structured interview design, which was written to incorporate findings from the family carer interviews. I recognised that participants recruited to this second qualitative study, would represent a heterogeneous sample of care professions. By using a written vignette as a stimulus during the semi-structured interviews, I was able to understand what participants would 'do' next, and compare value-driven perspectives between professions (Sampson and Johannessen, 2020).

Vignettes are useful in eliciting awareness and attitudes in healthcare research; they offer a level of depersonalisation allowing the interviewee to think beyond

their own professional circumstances (Schoenberg and Ravdal, 2000). Vignettes have been used previously to compare healthcare professionals' attitudes to various aspects of patient care, providing an interesting dimension during semi-structured interviews (Wilson and While, 1998). Questions about vignettes are also useful in eliciting how certain contexts mould behaviour, and identifying any situational factors that the interviewee may consider important to the scenario (Bryman, 2015, p. 476).

The limitations of using a case-study vignette as part of the semi-structured interview are primarily ensuring internal validity. It was important to ensure that the vignette captured the research topics under question and this was strengthened by piloting the vignette with a group of healthcare professionals. The vignette was based on existing literature and professional experience, and written from the third person's perspective using a hypothetical scenario (Appendix A) (Hughes and Huby, 2004; Randhawa, Jiwa and Oremus, 2015).

A variety of primary healthcare professionals and homecare workers, of any band or grade were purposively selected to participate in the study. The professions invited to take part included:

- General Practitioners (GPs)
- Community dietitians
- Community social workers
- Homecare workers
- Community nurses
- Community occupational therapists

#### 2.5.4. Analysis of qualitative interviews

Interview recordings were transcribed using an external transcription agency (<https://www.sterlingtranscription.co.uk/>), and loaded into NVivo 11 (QSR International, 2017a) for organising the analysis. Hand-written participant diaries were also transcribed and all diaries were uploaded into NVivo to be incorporated into the data analysis.

All data collected was subjected to IPA. Each transcribed interview was read and re-read, to ensure that any new ideas and insights were generated (Hunt and Smith, 2004). Semantic content and language use was explored by initial noting, and as the transcript became familiar, emergent themes (of individual transcripts) were developed. Connections across themes were also identified, before moving onto the next participants' data with a 'fresh' approach and as far as was possible 'bracketing' the themes that emerged from the previous case (Smith, Flowers and Larkin, 2009). Once all participant data had been analysed, patterns across participants' responses were investigated.

The results were reported in line with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidance (Tong, Sainsbury and Craig, 2007). Further detail of the data analysis is described in Chapters 4 and 5.

#### 2.6. Intervention development

The findings of the scoping review and qualitative studies indicated that a training programme targeting homecare workers was required. Healthcare professionals and homecare workers believe that they have a 'duty of care' towards the nutritional status of someone living at home with dementia, yet they do not perceive that they have adequate knowledge in this area. The homecare workers who were part of the qualitative study described in Chapter 5, were of the opinion

that more training in this area would provide them with the knowledge required to identify nutritional issues and take appropriate action with clients. My next step was, therefore, to develop a prototype-training package that would increase the knowledge of nutritional care in dementia. This was intended for use by homecare workers initially, with scope for including other healthcare professionals and family carers in future iterations. Homecare workers were prioritised as the focus for the intervention, as they are a profession who have a pressing requirement for nutrition-related training. This is reinforced by audits of homecare agencies, which have highlighted knowledge gaps in the nutritional care of people living with dementia at home (Carter, 2016; Skills for Care, 2014). Homecare workers are likely to have regular interaction with people living at home with dementia who may be nutritionally vulnerable and, therefore, by improving their understanding of the nutritional issues associated with dementia, they are equipped to recognise those issues and act accordingly.

To guide my development of the training intervention, I used Intervention Mapping (IM). This is a logical and participative process, which incorporates experiential results from the views of stakeholders, together with appropriate theories (Bartholomew *et al.*, 2006; Sidani and Braden, 2011). Information processing and cognitive load theory are relevant to the training process and knowledge retention, particularly when exploring different modes of information delivery. The homecare workers included in the qualitative study guided the choice of intervention, which aimed to provide them with knowledge to facilitate behaviour change when delivering nutritional care. The homecare industry is under financial strain, and homecare workers have limited time to spend with an increasing numbers of clients. The intervention, therefore, had to be cost-effective and not

require homecare workers to spend too much time away from caring for their clients.

Homecare workers in Devon follow a mobile working pattern, visiting clients in their own homes and travelling by car. Traditional methods of training, usually involve face-to-face delivery or computer-based packages, but both require the employee to 'take time away' from visiting clients and are, therefore, expensive and disruptive to deliver. Training that can be delivered in other ways could reduce costs, and potentially be more attractive. Virtual or remote training methods have now taken on even greater importance with the introduction of social distancing and shielding as a result of the COVID-19 pandemic. Podcasts could be a solution, as they can be listened to whilst travelling between client visits, aligning with the mobile working model of a homecare worker. Importantly, the time-burden associated with training and the risk of having to re-schedule client visits is reduced. Podcasts correspond with constructivist learning theory because they facilitate the generation of new knowledge by the listener, and enhance opportunities for active learning (Kala, Isaramalai and Pohthong, 2010). Podcasts are defined as:

*'A digital audio file of speech, music, broadcast material, etc., made available on the internet for downloading to a computer or portable media player; a series of such files, new instalments of which can be received by subscribers automatically' (Oxford English Dictionary).*

Few studies have explored the use of podcasts as a training tool for healthcare professionals and homecare workers. They are effective as a means for continuing professional development for social workers, and an alternative mode



of recognising cardiac sounds for cardiologists (Donato, Kaliyadan and Wasser, 2014; Fronek *et al.*, 2015). A defining factor of the benefits of podcasts is that users decide when and where to listen.

A key design feature of the podcasts I designed was to include a variety of expert guests, specialists in their respective fields relevant to dementia and nutritional care. I used information gained during stakeholder consultations and experts were identified through the research team's professional networks. The experts, their area of expertise and the section of the podcasts they feature on is shown in Table 2.

Table 2 - Expert guests and area of expertise who feature on podcasts

<b>Name of expert guest</b>	<b>Area of Expertise</b>	<b>Podcast number and section featured on</b>
<i>Dr Mark Drake</i>	Consultant in Dementia Care	Episode 1, symptoms of dementia
<i>Julie Kemmner</i>	Team lead of a clinical community dietetics team	Episode 2, how to identify malnutrition risk
<i>Professor Mary Hickson</i>	Nutrition and Ageing	Episode 2, important nutrients to consider in older adults
<i>Teresa Beer</i>	Ward sister of a Care of the Elderly ward	Episode 2, considering dehydration
<i>Samantha Turner</i>	Lecturer in Occupational Therapy	Episode 3, environmental adaptations
<i>Clare Barham</i>	Speech and Language therapist	Episode 1, 2 and 3, importance of mouthcare, swallow assessments, and texture modified diets
<i>Diana Hawdon</i>	Registered dietitian and ex-chef	Episode 3, food enrichment and cookery demonstration

There are three podcasts, each approximately 30 minutes duration, and all take a conversational approach. They cover the symptoms of dementia that can affect someone's ability to eat and drink, how to identify if someone may be at risk of malnutrition, and how to make changes to someone's surroundings and meals to prevent nutritional decline. They also provide an overview of some of the key nutrients that are at risk in people with dementia, and some practical tips on mouth care, swallowing and textured diets. The content was based on current evidence-based guidelines for nutritional care and dementia (Prince, 2014; Volkert *et al.*, 2015). After the preliminary testing described in this thesis, I intend to continue developing the training resource and hope that the pandemic situation will encourage funders to support the initiative.

## 2.7. Feasibility study methodology

It is important that the key issues concerned with complex intervention design, are examined from several perspectives before implementing into practice (Richards and Hallberg, 2015). Interactions between intervention components and their effects on outcomes are not always linear or obvious, and influenced by several factors, which are more likely to be exposed during feasibility testing (Levati *et al.*, 2016). By conducting a feasibility study, procedures can be tested for acceptability, rates of recruitment can be estimated, retention of participants can be examined, and appropriate sample sizes can be calculated, and any unforeseen issues can be surfaced prior to pilot or RCT phase (Medical Research Council, 2008).

This is important to do prior to larger-scale studies, to reduce the research waste that may occur if resources are provided to trials that may fail (Morgan *et al.*, 2018). This concept was explored by Morgan *et al.* (2018) by examining

feasibility studies funded by the National Institute for Health Research's (NIHR) Research for Patient Benefit (RfPB) programme to determine how many had published findings, how many had applied for further funding for a full trial and the timeframe in which both of these occurred. Results indicated that 20 feasibility studies (from a sample of 120) were judged as not feasible by principal investigators, potentially saving £20m of further research funding which would likely to have not completed successfully. Despite this saving, planning a feasibility trial into the overall process, may incur a time delay and, therefore, some potential waste in the existing research pathway. For the purposes of this thesis, conducting a feasibility study was appropriate, due to the lack of existing research regarding podcasts and homecare workers.

A mixed-methods research design was appropriate for the feasibility study, as the combined approach generated a comprehensive set of data that addressed the following research aims:

1. To determine whether a nutrition and dementia podcast is acceptable to homecare workers as a training tool;
2. To test if it is feasible to use a podcast in a social care setting.

A mixed-methods approach allowed the exploration of homecare workers' experiences of using podcasts, but also the measurement of outcomes (such as knowledge of nutritional care), and development processes (such as number of podcast downloads) (Curry and Nunez-Smith, 2015).

Normalisation Process Theory (NPT) is an explanatory model that was used to understand the dynamics of implementing, embedding, and integrating the podcasts within a homecare agency (May *et al.*, 2015). The detail of how NPT guided this phase of work is presented in Section 6.2.1.

This study followed the University of Plymouth's principles for research involving human participants and the collection of personal information. Participants' details were stored electronically on the University of Plymouth's Microsoft One Drive and the document password protected in accordance with the Data Protection Act 2018 and confidentiality maintained. This will remain secure on the One Drive system for a maximum of 10 years. Only the research team involved in the project have password access to information.

The research team maintained openness and honesty throughout and participants were provided with information about the study (Appendix B). Participants were informed that they were under no obligation to participate and could withdraw at any time. Full contact details of the lead researcher were provided, and participants were able to contact that person at any time during the study. Participants were asked to provide written informed consent when they arrived to take part in a focus group (Appendix C). It was made clear that the focus group discussion will be audio recorded but participants were asked to avoid using names or other identifying information. Completed consent forms are kept in a locked filing cabinet in Room FF01, Peninsula Allied Health Centre, University of Plymouth. Participants were presented with information regarding their involvement in the study prior to completing the quiz before listening to the podcasts. By accepting and clicking to start the quiz, consent was provided. Participant details entered via the pre and post-test quizzes are stored within the password protected One Drive folder, and participant results kept anonymous during analysis and write up.

Participants' anonymity was maintained, and codes (e.g. HCW01) were allocated when the recording was transcribed and by the researchers conducting the

analysis. Any client details shared during the focus group were also kept anonymous at all times, and pseudonyms used if relevant during any write-up.

In the event that some participants experienced emotional distress during the focus group, the facilitator planned to acknowledge this in the first instance, and the participant asked if they would like time to recompose themselves and then, only if they wish, to re-join the focus group (Braun and Clarke, 2013). The participant could leave the focus group completely at any time if they wished to. The framework for considerations for novice researchers conducting qualitative research was followed (Dempsey *et al.*, 2016). This included ensuring a suitable location, the researcher having undertaken qualitative training, the provision of refreshments, and the researcher keeping a reflexive diary, to consider values, beliefs, perceptions that may influence the research process. A member of the research team attended the focus group with the facilitator to take notes, in the event of any issues occurring with the audio recording.

## 2.8. Rigour

The transferability and reliability of clinical research is subject to a degree of bias, the level of which will vary depending on how rigorously the researcher has adhered to the methodology (Maggs-Rapport, 2001). Furthermore, by demonstrating rigour in qualitative studies in healthcare, findings have the integrity to make an impact on future practice and policy (Hadi and Jose Closs, 2016).

The scoping review protocol was shared on an online research website, in an attempt to reduce bias, and ensure transparency (Richards and Hallberg, 2015). It is best practice to register systematic review protocols, to avoid publication bias, and ensure that outcomes from the final review are reported according to the

original plan, and any deviations explained (PLoS Medicine Editors, 2011). Stakeholder consultation was included as part of the scoping review, of which it is an important component as it adds further methodological rigour (Levac, Colquhoun and O'Brien, 2010). An advisory group which included a GP, a community dietitian and a family carer was formed at the start of the scoping review, and I met with them on two separate occasions to assist in the development of the review, and formation of overarching categories. This allowed the incorporation of multiple perspectives beyond the traditional research team in the planning and execution of the scoping review (Ray and Miller, 2017).

It can be difficult to ensure rigour with qualitative research, particularly when using approaches that involve hermeneutic methods (such as IPA). Strict adherence to evaluative criteria for qualitative studies, may stifle or conceal the unique attributes of using an interpretative method (de Witt and Ploeg, 2006). The rigour is often present in the interpretation (as opposed to the adherence of method) of participants' experiences, which must have strength and demonstrate reliable understanding (Thirsk and Clark, 2017). Interview transcripts were not sent to participants to check for validity. This is an area of current debate amongst qualitative researchers, raising ethical and practical issues (Hagens, Dobrow and Chafe, 2009; Mero-Jaffe, 2011). IPA assumes that the participant is describing their interpretation of an experience, which is unique in that moment (Smith, Flowers and Larkin, 2009). Their interpretation may change if asked to review the details of the interview at a later date. With regard to the sample size of participants for an IPA study, reaching data saturation is not deemed a valid assurance of rigour, but instead the amount of new information that the researcher gathers to understand and make sense of the topic (Thirsk and Clark, 2017). This is also the case when deciding upon sample sizes for feasibility

studies that include a qualitative research element, the range advised being typically between 5 and 20 participants (O’Cathain et al., 2015).

Feasibility studies allow the identification and discussion of methodological issues around the planning of future larger trials and observational studies (Lancaster, 2015). The Consolidated Standards of Reporting Trials (CONSORT) statement extension for pilot and feasibility trials, was used as a guideline when designing the feasibility study for this thesis. This ensured that transparency and quality were maintained throughout the study (Eldridge *et al.*, 2016).

In summary, I have taken a pragmatic approach to the research design of the studies underpinning this thesis. This has ensured that a balance is maintained between methodological rigour (such as appropriate sampling and measurement methods), and acceptance of relevance in the real-world context (such as usability and acceptability in a social care setting) (Geng, Peiris and Kruk, 2017).

## 2.9. Thesis structure

The four studies included within this thesis contribute collectively to the overall aim, but can also be interpreted individually. Accordingly, each one has been written as a manuscript and submitted (or will be submitted) to a peer-reviewed academic journal. The scoping review manuscript was published in *Health and Social Care in the Community* (Mole *et al.*, 2018). The family carers qualitative interview study was published in *Dementia* (Mole *et al.*, 2019a), and the healthcare professionals and homecare workers qualitative interview study was published in *BMC Geriatrics* (Mole *et al.*, 2019b). The feasibility study is being prepared for publication. The studies are presented in the format that was requested by the respective journals with the exception of the addition of Chapter numbers and references to appendices. Open access papers are included as

per University of Plymouth regulations stated in the Research Degrees Handbook (December 2019) Section 13.2.5. Each Chapter is introduced prior to presentation of the manuscript, and Chapters 3, 4, and 5 are followed by a Chapter conclusion to add further details and provide a narrative.

#### 2.9.1. Reflexivity

Reflexivity is an important component of any research as the influence of the researcher needs to be acknowledged and named. This is particularly true in qualitative research to enhance the quality. Self-reflexivity relates to exploring and highlighting your own values, particular biases and preferences relating to the research or topic area (Tracy, 2010). The researcher needs to consider the influence that their own background, assumptions, theoretical positioning and behaviour can have on the research process and outcomes. Reflexivity is part of the transparency of the project, and places value on the reflexive analysis of conclusions from the research (Smith, Flowers and Larkin, 2009). Reflexivity can, therefore, be regarded as a dynamic process, where at times the researcher is fully immersed and at others reflecting back on the process to consider what may be occurring (McKay, Ryan and Sumsion, 2003).

*I want to introduce myself at this stage of the research to provide an overview of my background, and acknowledge how this has influenced my PhD journey. I graduated with a degree in electronics engineering in 2005, following which I joined a large telecommunications organisation on a graduate training programme. I enjoyed using innovation and new technology to solve problems such as improving customer service for a particular product, and co-ordinating teams to work together on project delivery. After seven or so years working in a variety of roles, I felt that I was too removed from the customer, and found myself*



*yearning for a job that enabled me to help others. This led me to complete another undergraduate degree in Dietetics having had an interest in nutrition, and once registered, I worked as a dietitian in community and acute roles. I thrive when I am able to problem solve and find solutions to issues, particularly those that can improve the lives of others. My academic experience provided me with the confidence to challenge the status quo, value the importance of building relationships, and understand how I can initiate change. I also enjoy learning, so much so that when I came across an advert for a PhD opportunity that would enable me to combine my academic interests with my clinical experience I applied and was successful.*

*I have always been drawn to working with older adults, perhaps because my grandparents passed away when I was very young. I feel a sense of responsibility towards supporting older adults, as they have contributed to some of the privileges and freedoms that I am able to enjoy. I was fortunate to work with patients who had dementia in my dietetic roles, and I started to appreciate the challenges that they, and family members, had regarding eating and drinking. I always felt that there was a gap around knowledge of how the symptoms of dementia could affect someone's nutritional status, and remember seeing a number of patients with dementia being admitted to hospital who were malnourished. Speaking to the relatives of these patients, and hearing their concerns around their loved ones change in eating habits made me feel responsible as a dietitian to support them. At the time of applying for the PhD, there was more focus being placed on dementia, particularly regarding healthcare improvements to improve support following diagnosis.*

*Based on my prior experience as a dietitian, I already had an awareness of how someone with dementia could be at risk of malnutrition and set out with the intention of uncovering this further. I knew that I wanted to involve as many people as possible who engaged with people living at home with dementia, to find out more about their perspectives and understanding.*

*In the latter stage of my PhD, I moved into a lecturers on the dietetics programme at the University of Plymouth, where I started to understand some of the challenges associated with educating healthcare students particularly during a pandemic where remote technologies were relied upon. This, combined with my interest in innovation and technology, reinforced my decision to focus on mobile learning methods, such as podcasts, to support those supporting people with dementia.*

*I feel that with time and experience, my understanding of the world has changed. During my undergraduate dietetics degree, I felt more comfortable working within a positivist paradigm, using quantitative methods whilst in search of absolute answers to research questions. Having worked as a dietitian, and developing an understanding of dementia, I started to feel more comfortable in a more social constructivist paradigm and appreciate that how family members care for others is likely to be influenced by their own care experiences, and those of other's close to them. As the research progressed, I fostered an appreciation for individual experiences and felt comfortable representing them as such and not attempting to find definitive answers.*

*During data collection for the qualitative studies, I grappled with identifying as a researcher or dietitian. I decided prior to data collection that I would not conceal my profession, and although I was visiting participants as a researcher, I needed*

*to respect that I was asking them to remain honest and open about personal experiences so I needed to reciprocate. I recognise that during the semi-structured interviews, my pre-existing knowledge of nutrition and dementia may have influenced the conversations, particularly when prompting the participants if they were struggling to answer a question. My interpretation of the participants' experiences may have been influenced by my knowledge of the topic, and by my previous experiences of supporting people in their own homes with dementia in my role as a community dietitian.*

*Throughout this thesis, reflexive commentaries will appear at the end of key Chapters in italics with information from recorded reflections, discussions with supervisors and peers.*

### 3. A scoping review of nutritional care in dementia

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#### 3.1. Chapter overview

This Chapter describes a scoping review carried out to identify the existing evidence base concerned with nutrition and dementia for people living in their own homes. Using systematic methods, I examined the current literature to find out what is known about managing the nutritional status of people with dementia living at home. This study is published open-access in *Health and Social Care in the Community*, and is available at:

- <https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.12540>

Section 3.3 is primarily formed from the published paper, which has been amended to include references to relevant appendices, and full author names where appropriate<sup>2</sup>.

#### 3.2. Background to the current research

The symptoms of dementia are managed differently depending on whether someone is living at home, in a care home, or spending time in hospital. For those living at home, family members may provide assistance with daily tasks such as washing, getting dressed and eating meals, with or without external help from healthcare professionals (Abraha *et al.*, 2017). In care homes, interventions have been primarily focused on improving the approach to person-centred care (Abraha *et al.*, 2017). Responding to someone with dementia's needs in a care home can be inhibited by structural and procedural constraints, such as reduced staffing levels and carers reporting a culture of scrutiny (Rapaport *et al.*, 2018). An admission to hospital can cause distress for someone with dementia, and

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<sup>2</sup> Open access paper included as per University of Plymouth regulations stated in the Research Degrees Handbook (December 2019) Section 13.2.5

pharmacological methods (e.g. antipsychotic medications) are more likely to be prescribed (White *et al.*, 2017). The consistency and continuity of dementia care in hospitals has been found to be sub-optimal, due to a lack of dementia awareness training for medical staff and a delayed discharge process (Timmons *et al.*, 2016). The study reporting this was conducted across 35 hospitals in the Republic of Ireland; therefore, may not be representative of other locations. However, a realist review conducted in the UK found similar issues regarding staff training, and suggests that focus needs to be on senior management to create and embed a culture of care (Handley, Bunn and Goodman, 2017).

Systematic reviews on how best to improve the nutritional care of people living with dementia have recently been published (Abdelhamid *et al.*, 2016; Bunn *et al.*, 2016a). These reviews examined the efficacy of direct (e.g. prescribing ONS and indirect (e.g. playing soothing music during mealtimes) interventions to improve, maintain or facilitate food and drink intake, and improve nutritional status in people with dementia. The reviews primarily focused on the effectiveness of interventions in care homes and nursing homes, because most of the trials found were conducted in these settings, with very few conducted in participants' own homes.

The scoping review conducted as part of this thesis, therefore, focusses solely on the own home setting. It captures what is known about the nutritional care of people with dementia living at home, including results from interventions that may have been trialled or implemented, and studies documenting the views of people with dementia, family carers and other healthcare professionals. A broad view of the literature landscape concerned with this topic is presented.

Systematic reviews attempt to answer a clearly defined question, and often use explicit methodologies to assess the quality of included articles, which are usually RCTs (Brien *et al.*, 2010). Scoping reviews take a broader approach to find literature concerned with a topic rather than a specific question, and do not exclude studies based on quality, on the premise that they still provide useful insight into the topic (Pham *et al.*, 2014).

The Arksey and O'Malley (2005) framework was used for this review. The six-step framework, described in more detail in Section 3.3.3, has been used in previous scoping reviews in the field of dementia care (Lourida *et al.*, 2017; Martin, O'Connor and Jackson, 2018). It encourages stakeholder consultation to inform and validate findings, which is an important consideration when researching a topic such as dementia in the community, which is complex and involves many components (Arksey and O'Malley, 2005). Any gaps in the literature are identified, allowing recommendations to be made for future research (Daudt, van Mossel and Scott, 2013).

#### 3.2.1. Aims of the scoping review

The overall aim of the scoping review was to find out what is known about managing the nutritional status of people with dementia living at home. Additional areas which were addressed included:

1. What interventions have been trialled in this setting to improve or maintain nutritional status?
2. What are the difficulties with maintaining and/or preventing decline of nutritional status experienced by people with dementia who live at home?
3. What is known about the nutritional consequences of dementia by patients and/or formal and/or informal carers?

4. Where would carers of and/or people with dementia living at home (formal and informal) go to seek help regarding difficulties with eating and drinking?

### 3.3. The nutritional care of people living with dementia at home: A scoping review<sup>3</sup>

#### 3.3.1. Abstract

There are an increasing number of people with dementia living in their own home for longer, often supported by a family member. The symptoms of dementia can affect an individual's nutritional status, which can lead to a reduced quality of life for the person with dementia and their family members. A scoping review was conducted from July 2016 until September 2016, using a recognised framework, to explore what is currently known, and identify any gaps in the research, regarding the nutritional care of people living with dementia at home, including any interventions that may have been trialled or implemented, and the views of those living with dementia, carers, and clinicians. Six electronic databases were searched from inception to July 2016. A review team was involved in screening and data extraction for selected articles. Published qualitative and quantitative studies were included that explored the nutritional care of people living with dementia at home. Methods included data extraction and conventional content analysis. Stakeholders were involved in the development of final categories. Following screening, 61 studies reported in 63 articles were included. Most studies were cross-sectional (n=24), cohort (n=15) or qualitative (n=9). Only three were randomised controlled trials. Three overarching categories

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<sup>3</sup> Mole, L, Kent, B, Abbott, R, Wood, C, Hickson, M. The nutritional care of people living with dementia at home: A scoping review. *Health Soc Care Community*. 2018; 26: e485– e496.

represented the results: Timely identification of nutritional risk and subsequent regular monitoring of nutritional status, multi-component tailored interventions, and the influence of the caregiving dyad on nutritional status. Many studies identify people living at home with dementia as a vulnerable group prone to malnutrition, however a lack of interventions exist to address the increased risk. There is a lack of research exploring the role of homecare providers and healthcare professionals in the provision of nutritional care. Further research is required to explore how the emotional aspect of the caregiving dyad influences nutritional care.

### 3.3.2. Introduction

There are an estimated 850,000 people in the UK, and 5.4 million Americans living with dementia (Alzheimer's Association, 2016; Martin *et al.*, 2014). Symptoms of the different types of dementia (e.g. Alzheimer's disease and vascular dementia) that can affect nutritional status include changes in memory, motor skills, visuospatial ability, taste, appetite, and swallow function (Ikeda *et al.*, 2002; Kai *et al.*, 2015). The presentation of the aforementioned symptoms varies amongst individuals as the disease progresses (van der Linde *et al.*, 2014). At least 67% of people living with dementia in the US and the UK live at home, with an estimated 670,000 family and friends providing care in the UK (Martin *et al.*, 2014) and 15 million in the US (Alzheimer's Association, 2015). This role includes meeting the individual's health, emotional and social needs, which become more complex and demanding as the dementia progresses, and can have profound impacts on the individual and their family (Fauth and Gibbons, 2014).



Maintaining an individual's nutritional status including preventing unintentional weight loss (fat and muscle), and meeting fluid and micronutrient requirements, is particularly important in dementia. A decline in nutritional status positively correlates with a decline in cognition and vice-versa (Lee *et al.*, 2009; Spaccavento *et al.*, 2009). Nutritional decline can begin in the early stages of the disease, which if not addressed can increase the rate of deterioration, as well as increasing clinical vulnerability e.g. risk of falls, infections and pressure sores (Stewart *et al.*, 2005). Nutritional care in this context, relates to the care provided to people living at home with dementia, in ensuring an adequate intake of energy, protein and other nutrients (Jyvakorpi *et al.*, 2012). The management of symptoms relating to dementia will vary dependant on the care setting. Previous systematic reviews that have focused on randomised controlled trials (RCTs) in this area, have been carried out across all care settings (residential care facility, hospital ward environments and own homes), but to date have included minimal analysis of studies specific to 'own home' (Abdelhamid *et al.*, 2016; Bunn *et al.*, 2016a). Carer surveys have indicated that there is a need for increased primary care support relating to the nutritional needs and consequences associated with dementia in those living at home (Alzheimer's Society, 2012). Community-based homecare may form part of the support that the person with dementia receives, and, therefore, plays a significant role in helping maintain an adequate nutritional status. Best practice guidelines have been published to support managers of UK homecare agencies (Skills for Care, 2014); however, there is limited literature that evaluates the nutritional care that these agencies provide.

This scoping review sought to answer: what is known about managing the nutritional status of people with dementia living at home? Additionally, the review also explored:

- What interventions have been trialled in this setting to improve or maintain nutritional status?
- What are the difficulties with maintaining and/or preventing decline of nutritional status experienced by people with dementia who live at home?
- What is known about the nutritional consequences of dementia by people living with dementia, family carers, homecare providers, and healthcare professionals?
- Where would carers of people with dementia living at home (family carers and homecare providers) go to seek help regarding difficulties with eating and drinking?

For the purposes of this scoping review, healthcare professionals refer to any paid worker that interfaces with people with dementia at home, including but not limited to occupational therapists, general practitioners, dietitians, and social workers.

### 3.3.3. Methods

Scoping reviews are useful for gaining a comprehensive overview of the research field of interest. Furthermore, scoping reviews help in mapping the nature and extent of research activities and provide a rigorous and transparent methodology (Levac, Colquhoun and O'Brien, 2010).

The present study used the Arksey and O'Malley (2005) scoping review framework, which includes identifying the research question, searching for relevant studies, selecting studies, charting the data, and collating, summarising and reporting the results, and consultation with stakeholders to validate findings and facilitate opportunities for knowledge transfer and exchange. This framework

is suitable for the inclusion of a range of study types to answer a range of questions related to a broad topic.

A full scoping review protocol was written and agreed by the research team (Appendix D). Studies included those that featured any intervention, using any study design, with the primary aim of maintaining or improving the nutritional status of individuals (no age restriction, male and females) with dementia or mild cognitive decline, who live at home alone, with family carers, and/or with homecare providers. No restrictions were imposed on the measurement type of outcomes, providing they were focused on nutritional status. Studies focusing on mild cognitive decline were included due to the potential transferability of intervention outcomes with dementia. Studies were also included where a person with dementia, family carer, homecare provider or healthcare professional's knowledge of nutrition and dementia and awareness of available support was explored, as well as any studies that investigated the nutritional consequences of dementia.

Any studies that were carried out in other healthcare settings (including those focused on homeless populations) were not in the scope of this review. Where studies examined multiple participant groups (e.g. residential care, acute care), only results specific to participants living at home were included and if results were merged across sectors, the study was excluded. Furthermore, any studies concerned with the prevention of dementia were excluded, as well as any studies not written in the English language due to the resource implications of translation (only two were excluded on this basis). The reviewing team agreed to exclude conference abstracts, editorials and opinion pieces as part of the iterative process advocated by Arksey and O'Malley (2005). Authors of included abstracts of

interest were contacted if we could not locate a published paper. This was only required for one text which did not subsequently meet eligibility criteria. The scoping review commenced in July 2016.

A search strategy was developed in consultation with an information specialist. The strategy included the following key terms: “dementia” (Alzheimer’s, mild cognitive impairment) AND “home” (own house, non-institutionalised, sheltered accommodation, community, domestic) AND “nutrition” (food, meal, breakfast, lunch, dinner, snack, eat, drink, hydration, feeding, diet, vitamin, supplement, ingestion, cooking, appetite), and was adapted for searching each database (Appendix E). CINAHL, MEDLINE (OvidSP), PsycINFO, EMBASE, The Cochrane Library, and TRIP were all searched from date of inception (1937, 1946, 1967, 1974, 1996, 1996 respectively) to July 2016. Forward and backward citation searching was conducted on studies exploring interventions.

Returned article title and abstracts were screened according to the aforementioned inclusion criteria, by two independent researchers (Louise Mole and Chloe Wood), and any disagreements discussed with a third reviewer (Rebecca Abbott). The same three researchers similarly conducted full text screening.

Data extracted for quantitative studies included sample size, study method, outcome measures and recommendations. Data extracted from qualitative studies also included study method as well as any theoretical framework information.

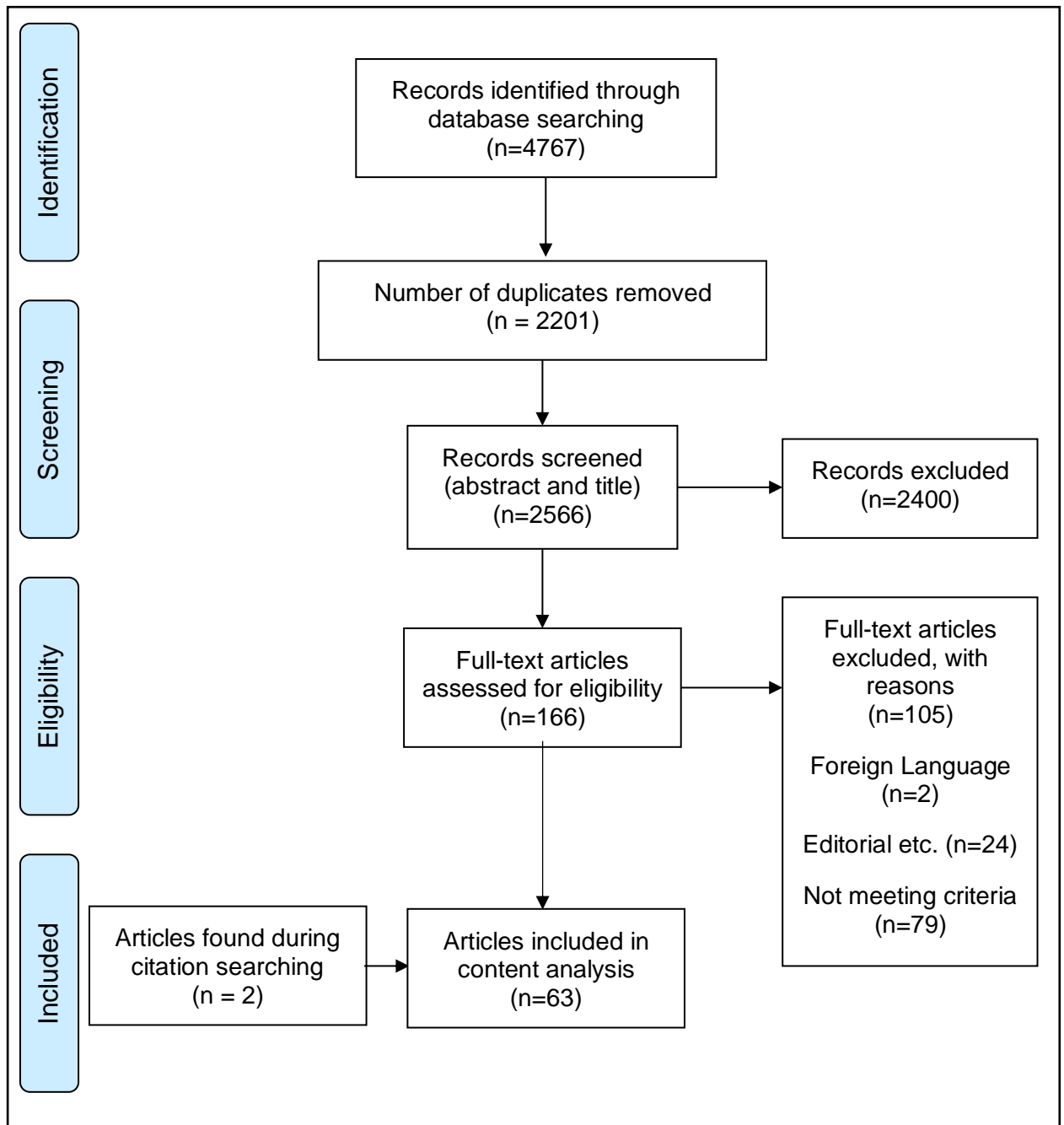
Data synthesis was conducted using a conventional content analysis approach (Hsieh and Shannon, 2005), in which the descriptive content about the population of interest, setting, study methods, primary and secondary outcome measures,

and any recommendations made by the authors were coded. Codes were then grouped into a series of sub-categories, and grouped again to form a smaller number of overarching categories, which represented the content of included studies. The sub-categories were presented to the project advisory group, which consisted of three stakeholders; a general practitioner, a community dietitian and a family carer. The advisory group was formed at the start of the scoping review through local contacts, and met with the lead researcher on two separate occasions to assist in the development of the review, and formation of overarching categories. Each category was discussed in terms of relevance, and how the stakeholders related their own experiences to it. The main overarching categories were then produced, which describe the existing literature regarding nutritional care of people living at home with dementia.

#### 3.3.4. Results

A total of 2566 unique articles were retrieved and screened, resulting in 61 studies reported in 63 articles (Figure 7).

Figure 7 - PRISMA diagram showing search results, N, number of citations



Most articles adopted a cohort or cross-sectional methodology (n=15, n=24), followed by qualitative (n=9), randomised controlled trials (n=3), reviews (n=2) and 'other' including protocols and pilot trials (n=10).

The studies were most frequently conducted in The Netherlands (n=14), France (n=10), Canada (n=8) and the US (n=6). Included studies focused either on the

person with dementia (n=43), the family carer (n=6), or both as participants (n=11). Healthcare professionals were the focus of only one study, and no studies involved homecare providers. Age of participants ranged from 58 to 84.9 years. Weight loss was the most common primary outcome measure or premise of the study, with a small number concerning micronutrient status. Intervention studies focused on providing nutritional education programmes, tailored nutritional guidance, and the effect of omega-3 fatty acid supplements on weight and appetite. The majority of included studies restricted the type of dementia diagnosis to Alzheimer's disease, and did not specify the 'stage' of dementia, although the Mini Mental State Examination (MMSE) was used as a measure in many studies. The MMSE (Folstein, Folstein and McHugh, 1975) categorises dementia stages as 'mild', 'moderate', and 'severe' with overlap between categories. The present scoping review included articles from across the MMSE classification (where stated): mild (n=10), moderate (n=22), a combination of mild to moderate (n=6), moderate to severe (n=1), severe (n=1), and studies that included the whole spectrum (n=4). All included articles are summarised in Appendix F.

The topics and results of included studies generated 26 descriptive codes during data extraction using a content analysis approach previously described (Table 3). These were grouped into eight sub-categories, which were discussed with the stakeholder group. As a result of the discussion, three over-arching interdependent categories were produced. It is worth noting that some codes overlapped between sub-categories, however for the purposes of this review the most relevant sub-category was used. The three over-arching categories were:

The importance of timely identification of nutritional risk and subsequent regular

monitoring of nutritional markers, the need for multi-component tailored interventions, and the influence of the caregiving dyad on nutritional status.

Table 3 - Development of sub-categories and over-arching categories

<b>Initial Coding (n=26)*</b>	<b>Sub-categories (n=8)†</b>	<b>Over-arching categories (n=3)‡</b>
<ul style="list-style-type: none"> <li>Regular monitoring of nutritional status</li> <li>Nutritional status is a risk factor for institutional placement</li> </ul>	Timely identification of malnutrition risk and regular monitoring	<p><b><u>Identification and measurement of nutritional status/risk</u></b></p> <p>(Annweiler et al., 2012; Bourdel-Marchasson et al., 2001; Buell et al., 2010; Burns et al., 1989; Chi et al., 2015; De Bruin et al., 2010; De Rouvray et al., 2014; E. Droogsma et al., 2013; Faxen Irving et al., 2009; Ferrario et al., 1996; Guerin et al., 2009; Guyonnet et al., 1998; Hagnelius et al., 2012; Ikeda et al., 2002; Keene &amp; Hope, 1998; Kwan et al., 2005; Lyngroth et al., 2015; Milward et al., 1999; Presse et al., 2008; Puranen et al., 2015; S. Rivière et al., 1998; Stéphanie Rivière et al., 2002; Salva et al., 2011; Scarmeas et al., 2009; Shatenstein et al., 2001; Shatenstein et al., 2007; Shatenstein et al., 2008; Silva et al., 2013; Soto et al., 2012; Suominen et al., 2015; Tully et al., 2003; Vellas et al., 2005; Venci et al., 2015; Winograd et al., 1991)</p>
<ul style="list-style-type: none"> <li>Holistic nutritional assessments</li> <li>Measurement of nutritional status</li> </ul>	Method of measuring/identifying nutritional status	
<ul style="list-style-type: none"> <li>Micronutrient supplementation</li> <li>Omega-3 may play a role for reduced conversion of MCI to AD</li> <li>Micronutrient deficiencies</li> </ul>	Micronutrient status	
<ul style="list-style-type: none"> <li>Hyperphagia</li> <li>Imbalanced dietary intake</li> <li>Suboptimal diet is evident early in the onset of AD</li> </ul>	Dietary Intake	
<ul style="list-style-type: none"> <li>Beverage contribution towards total energy intake</li> <li>Energy requirements and body composition</li> <li>Two types of weight loss in dementia: progressive and severe</li> </ul>	Energy Balance	
<ul style="list-style-type: none"> <li>Increased risk of malnutrition</li> <li>Degree of physical impairment is a risk factor for malnutrition</li> <li>Cognitive impairment may predict malnutrition risk</li> </ul>	Predictors of malnutrition risk	<p><b><u>Tailored nutritional guidance</u></b></p> <p>(Bilotta et al., 2010; Buffa et al., 2010; De Bruin et al., 2010; Erika Droogsma et al., 2014; Gillette-Guyonnet et al., 2000; Guerin et al., 2005; Isaia et al., 2011; Jyvakorpi et al., 2012; Lee, Hong, et al., 2009; Miyamoto et al., 2011; Nes et al., 1988; O'Neill et al., 1990; Riviere et al., 2001; Salva et al., 2009; Smith et al., 1998; Tombini et al., 2016; Wolf-Klein et al., 1995)</p>
<ul style="list-style-type: none"> <li>Nutritional education programmes</li> <li>Tailored nutritional guidance</li> <li>Multi-component interventions</li> <li>Day care facilities that involve attendees in food preparation can increase dietary intake</li> </ul>	Multi-component, tailored nutritional guidance	
<ul style="list-style-type: none"> <li>Supporting carers</li> <li>Caregiver nutritional status is linked with nutritional status of person they are caring for</li> <li>Caregiver burden is a risk factor for weight loss</li> <li>Caregivers may develop coping strategies</li> <li>Caregiver gender</li> <li>Increased dependency on the caregiver</li> </ul>	The Caregiving Dyad	<p><b><u>The Caregiving Dyad</u></b></p> <p>(Ball et al., 2015; Fjellstrom et al., 2010; Hua-Chen et al., 2013; Johansson et al., 2011; Keller et al., 2007; Keller et al., 2008; Puranen et al., 2014; Rullier et al., 2013; Shatenstein et al., 2016; Wlodarek &amp; Glabska, 2013)</p>

\*26 initial codes were noted whilst reviewing included studies. †These were then grouped into 8 sub-categories, and following discussions with stakeholders, ‡3 over-arching categories. MCI: Mild Cognitive Impairment, AD: Alzheimer's Disease



### ***Category 1: Identification of nutritional risk and regular monitoring of nutritional status***

Studies aligned with this category (n=35) included those focussed on methods of identifying and measuring nutritional status or risk (including micronutrient status), measurement of dietary intake and energy balance, and the timely identification and ongoing monitoring of nutritional risk.

There is no consensus as to the most appropriate screening or assessment tool for people with dementia. Most studies used the Mini Nutritional Assessment (MNA) or Short Form Mini Nutritional Assessment (SF-MNA) (n=16), which seemed appropriate for participants with dementia, as they contain specific questions regarding neurophysiological problems, as well as capturing high-level information regarding quantity of food and fluids consumed, and mode of feeding (Vellas *et al.*, 2006). The Nutrition Screening Initiative (NSI) checklist and the nutritional form for the elderly were used in two studies. No included study used the Malnutrition Universal Screening Tool (MUST) (BAPEN, 2016). It is notable that no malnutrition screening tool specific to people with dementia, such as the Edinburgh Feeding Evaluation in Dementia Scale (Watson, Green and Legg, 2001) was used.

A tendency towards undernutrition and dehydration was identified in participants in the early phases of Alzheimer's disease, which increased as the disease progressed. In this study Buffa *et al.* (2010), bioelectrical impedance vector analysis was used to measure body cell mass, and the authors propose it as a tool for screening and monitoring nutrition and hydration status in Alzheimer's disease. In contrast, two other studies using anthropometric and biochemical measures, found no significant differences in the nutritional status of participants

with dementia. One study investigated a group with dementia compared to a control group without dementia representing the general older population over one year, and the other study focussed on a group of people with dementia who were assessed at baseline and after six months (Burns, Marsh and Bender, 1989; Ferrario *et al.*, 1996).

Alternative predictors of reduced nutritional status included the clock-drawing test (Lyngroth *et al.*, 2015) and serum vitamin C levels (Rivière *et al.*, 1998). One study associated inflammatory markers with body weight change, finding it inversely correlated with plasma tumour-necrosis factor (TNF) (Kwan *et al.*, 2005). People living at home with dementia were found to have reduced serum markers of vitamin D (Annweiler *et al.*, 2012; Buell *et al.*, 2010), plasma vitamin E and retinol (Bourdel-Marchasson *et al.*, 2001), and serum haemoglobin levels (Milward *et al.*, 1999) compared to control groups. Increased incidence of behavioural and psychological symptoms of dementia were proposed as precursors to rapid weight loss (Guerin *et al.*, 2009).

Dietary intake of a variety of macro and micro-nutrients was the focus of some studies (n=8) included in this review. The overall dietary intake of participants with Alzheimer's disease in two separate studies was poor compared to cognitively intact age-matched controls, and the authors suggest that this led to a decline in body weight (Guyonnet *et al.*, 1998; Shatenstein, Kergoat and Reid, 2007). Both studies also noted a lack of routine nutritional assessments being conducted at outpatient clinics, a factor re-iterated by many studies included in this scoping review. Hyperphagia ('over-eating') was the primary subject of investigation in three studies of people with dementia (Chi *et al.*, 2015; Keene and Hope, 1998; Smith *et al.*, 1998). Hyperphagia was associated with increased

functional decline, however authors suggested that hyperphagia may be beneficial by promoting energy balance in people whose energy expenditures are increased (for example, due to agitation). One study focused on beverage consumption, which was found to contribute towards micronutrient intake, but provided minimal contribution towards average energy intake (~12.5%) in older adults with memory decline (Venci *et al.*, 2015).

The average daily dietary intake of Vitamin K was explored in one study, and found to be less in a community-dwelling group of participants with early-stage Alzheimer's disease compared to a control group, and attributed to a reduced dietary intake of green vegetables by the Alzheimer's group (Presse *et al.*, 2008). The same study also measured overall daily energy intake between groups, and found that the Alzheimer's group consumed ~293 kcals less than the control group. One study found that the consumption of a Mediterranean diet, which is rich in green vegetables, was associated with a reduced risk (48%) of progression from mild cognitive impairment to Alzheimer's disease (Scarmeas *et al.*, 2009); however the biological mechanisms producing this protective effect remain unclear.

Studies that measured the nutritional status of participants recommended that undernutrition risk should be identified as early as possible - using an appropriate tool, but none specified the best tool to use. The studies also suggested that nutritional status should be monitored regularly thereafter (Guerin *et al.*, 2005; Isaia *et al.*, 2011; Tombini *et al.*, 2016). No firm data are available for frequency but one paper recommends every 6 months (Guerin *et al.*, 2009). Most studies did not specify who should be responsible (i.e. family carer or healthcare professional) for identifying or monitoring the nutritional status of people living

with dementia at home. Healthcare professionals are, however, best placed to identify or monitor the nutritional status of both family carer and person with dementia (Tombini *et al.*, 2016).

### ***Category 2: Multi-component tailored interventions***

Providing nutritional education to caregivers of people living at home with dementia was trialled in three RCTs (Riviere *et al.*, 2001; Salva *et al.*, 2011; Suominen *et al.*, 2015), all of 1 year duration, and a quasi-experimental study of 6 month duration (Shatenstein, Kergoat and Reid, 2016). The interventions were all 'multi-component', and consisted of two or more of the following: carer group education sessions, physician training, carer advice leaflets, dietitian home visits with individual nutritional plans, micronutrient supplementation and oral nutritional supplementation. Two of the RCT studies reported a statistically significant increase in nutritional status (measured by MNA) in the intervention groups compared to the control groups (Riviere *et al.*, 2001; Salva *et al.*, 2011). Protein and calcium intakes increased (at statistically significant levels) in the intervention group of the third RCT study (compared to the control group); however, there was no difference in weight change (Suominen *et al.*, 2015). The quasi-experimental study, which measured the effectiveness of the application of clinical dietetic principles as well as increased weight monitoring, did not find an increase in dietary intake of energy, protein or fat in the intervention group (Shatenstein, Kergoat and Reid, 2016). Multi-component interventions appear to deliver some beneficial nutritional outcomes, and show potential for supporting the nutritional care of people living at home with dementia. Further intervention trials in this setting are needed to confirm this.

The impact of nutritional status on Quality of Life (QoL) of people living with dementia, was explored in one study, which recruited people with dementia and family carers as participants (Suominen *et al.*, 2015). QoL increased in the intervention group (statistically significant) who received tailored nutritional counselling. In particular, the dimensions that increased included: mental function, breathing, usual activities and depression (measured using the health-related QoL tool (Sintonen, 2001)). As protein intake also increased in the intervention group, the authors suggest that this may have influenced the increase in QoL, as well as a reduction in the number of falls.

Limitations existed in all intervention studies, which were likely to affect the outcomes. There were inconsistencies with caregiver characteristics between intervention and control groups in three of the four studies, including differences in age, and number residing with the person with dementia. One study included only spousal carers, and one did not specify the type of carer (only that it included spouse or children of person with dementia). The demographic characteristics of the carer are important to understand, as these may influence a number of factors including caregiver burden, knowledge of dementia and symptoms, and awareness of support services (Brodaty and Donkin, 2009). Furthermore, family values, formation and intergenerational relations may vary between age groups (Hoff, 2015). In the studies that documented the dropout rate of participants, this varied between 14% and 34.6%. This may have been due to research participant burden because of the study length and obligations of participants.

### ***Category 3: The Caregiving Dyad and the influence on nutritional status***

This category was represented in ten studies, and refers to the effects of physical and psychosocial interactions between a family caregiver and person with

dementia and the role this interdependent dyad has on the nutritional status of both parties. No study included in this review focused on the dyadic relationship between healthcare professional or homecare provider and person with dementia. Furthermore, the triadic relationship between family caregiver, healthcare professional or homecare provider and person with dementia was not explored. Some qualitative studies focused exclusively on the family caregiver and their perceptions of the everyday life aspects of cooking and coping with problematic eating behaviours (Ball *et al.*, 2015; Fjellstrom *et al.*, 2010; Hua-Chen, Hui-Chen and Jing-Jy, 2013; Keller, Edward and Cook, 2006). These studies show that the family carers involved felt unsupported and uninformed with respect to the nutrition-related care of the individuals with dementia, and wanted more input from professionals.

The importance of the caregiver and person with dementia having a trustful relationship was highlighted in one study (Johansson, Christensson and Sidenvall, 2011), which aimed to capture the self-description of managing mealtime tasks by people with mild to moderate dementia. The participants of this study demonstrated that maintaining independence was important to them, and they might not express difficulties at mealtimes for fear of losing this. This was the only qualitative study involving people with dementia as the main participants. A gender difference in the ability of spouses being able to cope with adequate nutritional intake for both themselves and their spouses with Alzheimer's disease was observed by one study (Puranen *et al.*, 2014), where male caregivers were reported to struggle more so than female caregivers. Increased caregiver burden was identified as a predictor of weight loss in people with Alzheimer's disease (Bilotta *et al.*, 2010; Gillette-Guyonnet *et al.*, 2000). The nutritional screening result (using MNA) of participants with Alzheimer's was

positively associated with the screening result of the caregiver in two separate studies (Rullier *et al.*, 2013; Tombini *et al.*, 2016).

One qualitative study involved healthcare professionals and dementia charity workers as participants, exploring the range of nutritional concerns they had experienced in their work with clients with dementia (Keller *et al.*, 2008). The main concerns included inadequate and imbalanced food intake of clients, inadequate access to food, and maintaining independence with meal preparation and eating.

### 3.3.5. Discussion

The purpose of this scoping review was to examine the available research on what is known about the nutritional care of people living with dementia at home, with the further aim of identifying any interventions that have been trialled in this setting. Additional aims included identifying any difficulties associated with maintaining and/or preventing decline in nutritional status experienced by people with dementia who live at home, and the knowledge of nutritional issues associated with dementia by people with dementia, carers and clinicians, including where they would go to seek help. People living at home with dementia at all stages of the disease have been shown to be at increased risk of undernutrition by many studies included in this review. The benefits of identifying nutritional risk as early as possible, and ongoing monitoring of nutritional status have also been demonstrated by many studies. The family caregiver role was examined in the context of the provision of nutritional care to people living with dementia, and the nutritional status of the caregiver and the person with dementia. Poor nutritional status of the caregiver was associated with poor nutritional status of the person with dementia, which may be due to increased

caregiver burden, coping strategies and adjustment to the physical and emotional changes associated with dementia.

#### *Interventions trialled in this setting*

The three RCTs included in this review focused on the provision of nutritional education to family caregivers and tailored nutritional guidance to people living at home with dementia. The interventions were all 'multi-component', in that they targeted a range of variables of nutritional care provision (e.g. family carer education, enhanced access to dietetic support, and regular weight checks). The interventions delivered small-scale but positive outcomes. These findings need to be developed to establish and test acceptable and effective ways to support nutritional care. Given the range of symptoms, the variable rate of progression, and the complex nature of adequate nutritional intake, it seems likely that successful interventions for this group will be complex and have built in flexibility to adapt to individuals' needs. Others have concluded that multi-component interventions appear to have advantages over single-component interventions including: reducing symptoms of depression, improving quality of life, reducing carer burden, and reducing the behavioural and psychological symptoms of dementia (Laver *et al.*, 2016). Therefore, interventions will need to be developed so that they target multiple determinants, across multiple levels of influence.

#### *Identifying any difficulties associated with maintaining and/or preventing decline in nutritional status*

The content analysis presented shows that the key issues relating to nutritional status in people living at home with dementia are identifying nutritional risk accurately, monitoring change regularly, considering not only energy balance but also micronutrient status, and the quality of the diet. The most suitable tool for



screening for the undernutrition of people with dementia has not yet been explored by any study; however, the SF-MNA has been shown to more accurately assess malnutrition risk compared to MUST in frail, older hospitalised patients (Slee, Birch and Stokoe, 2015). Therefore, it may be that a tool specifically tailored to people with dementia is required. Certainly, more work is needed to understand which screening tool will identify those at risk to enable more accurate targeting of interventions. Undernutrition screening tools provide a structured approach across care settings, but should not replace routine observation by carers and healthcare professionals. However, this relies upon these people having knowledge of the nutritional consequences associated with dementia, and this scoping review found little data to support this. In fact, we found no articles investigating what people with dementia or their carers understood about the possible dietary changes that might come with dementia. This is crucial to allow effective monitoring to ensure interventions are working or early identification of deterioration.

Evidence suggests that people with dementia may experience a wide variety of difficulties associated with eating and drinking, ranging from taste changes to reduced appetite, that make them susceptible to unbalanced dietary intake (both macro- and micro-nutrients), resulting in a greater risk of undernutrition (Droogsma, van Asselt and De Deyn, 2015; Ikeda *et al.*, 2002; Kai *et al.*, 2015). However, family caregivers may lack the information and resources required to assist with these difficulties (Shatenstein *et al.*, 2008), leading to a deterioration in nutritional status. As highlighted previously, caregivers may also lack the knowledge to successfully identify and monitor such changes. An improved understanding of the family carer's experience is essential for the development

of future nutrition interventions adapted to the needs of older adults with dementia and their caregivers (Silva, Kergoat and Shatenstein, 2013).

### *Nutrition knowledge and information sources*

In previous sections, we have shown that the knowledge of the family carers appears crucial. Qualitative studies suggest that caregivers recognise the importance of adequate nutrition but feel unsupported and uninformed regarding making changes. Despite this, no studies identified where carers of people with dementia would go to seek help regarding difficulties with eating and drinking. The lack of evidence in this area may be due to the recent expansion of support services available to family carers and people living with dementia at home, which have yet to be methodically explored. For example, in the UK setting alone, there are many online forums, social networking channels, charity support workers (local and national), volunteer agencies, health and social care professionals as well as friends and other family members who could provide advice to a caregiver, but no information exists on the content or quality of these sources. Caregivers may choose to seek advice regarding nutritional care from a non-professional source, due to potential delays in speaking with a healthcare professional, and perhaps due to existing trustful relationships with non-professionals. However, the information provided may be of questionable quality. No study has assessed the quality of nutritional guidance provided to people with dementia and their carers, whether online or from 'informal' networks. Only three qualitative studies included the person with dementia as a participant. This is perhaps due to a focus on the family carer role, since they are the people required to make more of the decisions regarding nutritional care as the dementia progresses.

Nevertheless, there exists a gap in the literature relating to the knowledge, experiences and views held by the people living with dementia themselves.

The role of homecare providers was not explored in any study. In the UK, the quality of care provided to people with dementia living in their own homes has only recently become a focus, following a survey conducted by the Alzheimer's Society (Carter, 2016). This highlighted the major issues regarding homecare as homecare providers lacking knowledge of the condition and how to adapt care provision, and only 2% of people living with dementia feeling that homecare workers have enough dementia training (Carter, 2016). In the US, a significant gap has been highlighted in the demand for healthcare workers who are trained to care for older adults and those choosing this as a career (Alzheimer's Association, 2015). A recent review has highlighted the potential benefits of including family carers and homecare providers as part of malnutrition screening, and having a role in the delivery of nutritional interventions for older adults (without dementia) living in the community (Marshall *et al.*, 2017). These findings may also translate to people with dementia, to improve nutritional status of care recipients and improve the quality of life for the caregiver

Healthcare professionals also have an important role in the provision of nutritional care to people living with dementia at home. There is, however, a lack of evidence exploring how different healthcare professionals perceive the importance of nutritional care in this group, and their role in the identification of undernutrition risk and subsequent nutritional care. Diagnostic guidelines are constantly evolving, and undernutrition screening is not routinely carried out in standard practice. There are many additional health factors to consider when supporting someone with dementia; therefore, nutritional care may not be an

immediate priority. Some healthcare professionals may also take a 'nihilistic' view since nutrition will not influence the prognosis (Iliffe *et al.*, 2009).

There is limited evidence regarding the impact of overall nutritional status on QoL for people living at home with dementia. A shortcoming of current QoL measurement tools is that they are not sensitive to changes over time, which is critical to evaluating participant response to treatment and determining the effects of dementia progression on QoL (Ready and Ott, 2003). Therefore, the relationship between nutritional status and QoL of people living at home with dementia warrants further investigation.

There are a lack of studies that have explored the emotional significance of the dyad relationship in the context of nutritional care provision, with most interventions focusing on manipulating the physical elements (e.g. improving oral intake, reducing weight loss, and caregiver education). This suggests that any intervention may need to be 'dyadic', in that it involves both parties. Previous reviews suggest that this approach has produced positive outcomes in future care-planning interventions in terms of relationship quality and social relations, as well as providing essential information to healthcare professionals when developing such plans (Braun *et al.*, 2009; Moon and Adams, 2012). The social aspect of mealtimes should also be considered in the context of the caregiving dyad. A 'family-style' dining environment in care homes (including eating with caregivers and familiar music being played during mealtimes) has been found to increase oral intake, body weight and quality of life (Bunn *et al.*, 2016a). Keeping routines (such as mealtimes) familiar for a person with dementia may evoke feelings of social 'security' and, therefore, maintain adequate oral intake (Brittain *et al.*, 2010). Future interventions aimed at improving nutritional care for people

living at home with dementia, should take into account the influence of such human factors alongside physical factors such as meal composition (Keller, Edward and Cook, 2006).

### *Limitations*

There are a few limitations worth noting. Since studies that involved mixed populations (dementia and non-dementia) and mixed settings were excluded, some relevant information may have been missed. Inconsistent terminology used in different countries for assisted home living, may have resulted in some relevant studies being excluded. Two non-English language papers were excluded; however, these are unlikely to substantially alter the overall conclusions. The intention of this scoping review was to provide a comprehensive overview of the research pertaining to a broad topic. The assessment of quality of included studies was not conducted, so recommendations have not been made for specific interventions that may promote improved nutritional status in people living at home with dementia.

### 3.3.6. Conclusion

Supporting the nutritional needs of people living with dementia in their own homes should be an important component of holistic primary care provision. The nutritional consequences of dementia can have profound impacts upon the individual, family carer's and primary healthcare services. Although many studies have highlighted the increased risk of undernutrition in this group, very few interventions have been trialled in this setting to address the issue. There is also a gap in the literature regarding the role that homecare providers and healthcare professionals have in providing nutritional care to people living with dementia at home. Families have expressed a need for more information and support

regarding nutritional care, and healthcare professionals need to consider how this can be provided in a cost-neutral manner. The provision of adequate nutrition is reliant upon not just knowledge and ability, but also the emotional influence of the caregiving dyad. Future intervention studies may need to consider using dyadic approaches to nutritional care provision in the home, which is a novel concept compared to the current patient-centred approaches to dementia care.

### 3.4. Chapter conclusions

The scoping review identified that there are few studies exploring the experiences of family members and healthcare professionals providing nutritional care to someone living at home with dementia. Homecare workers are another group whose experiences have been overlooked. With this in mind, the next logical step was to explore these experiences using a qualitative approach (Chapter 4 and Chapter 5). There is minimal research exploring the effectiveness of nutrition-based training interventions for homecare workers who work with people living at home with dementia. This was an important consideration when developing an intervention aimed at improving the nutritional care of people with dementia living at home (Chapter 6).

There were two areas that were identified during content analysis, which were not feasible to explore in detail as part of the published scoping review. These included malnutrition screening tools, and the role of homecare workers. These topics warrant further discussion as part of this thesis work.

The two most commonly used malnutrition screening tools that are used for people with dementia living at home, appear to be the Malnutrition University Screening Tool (MUST) and SF-MNA. The Mini Nutritional Assessment Short Form (SF-MNA) gives accurate screening results for older hospitalised adults

compared to MUST, but this has not been explored in the community setting, or specifically with people who have dementia (Slee, Birch and Stokoe, 2015). It may be better suited than MUST for use with people living with dementia at home, as it recognises that neurophysiological issues (such as dementia) will contribute towards the risk of malnutrition (Nestle Nutrition Institute, 2019). MUST was designed to be transferable across all healthcare settings in the UK, however it has been recommended that a different screening tool is used per setting, to take into account factors such as functional capacity and living arrangements (Leij-Halfwerk *et al.*, 2019). This makes sense, as environmental factors that can influence someone's risk of malnutrition vary between settings. For example, someone living with dementia at home may forget to eat a meal, and have no support remembering to do so. A care home or hospital ward will provide meals and snacks at regular intervals, removing the need for someone with dementia to remember to eat. The Patients Association Nutrition Checklist has been developed to be used by individuals or family members to screen for malnutrition risk, and has been validated with MUST in the community setting (The Patients Association, 2018). The checklist has started to show positive results in identifying malnutrition in the community setting, particularly as it has been designed for people to use at GP surgeries, day centres and by volunteers who work with people who may be at risk.

The results of the scoping review suggest that anyone with a diagnosis of dementia could be deemed at risk of malnutrition. Therefore, some action should be taken upon diagnosis to identify areas where someone may require more support with food shopping, preparation, or eating and drinking. If the person lives with a family member who is providing support with care, the family member's risk of malnutrition should also be considered, as they are likely to be

at greater risk too. Early identification of factors which could lead to malnutrition, and taking action to address them, will reduce the risk of malnutrition later when dementia symptoms worsen.

However, the role of homecare workers was not explored in any of the included studies within the scoping review. One reason for this could be that the homecare market is fragile, and the pressure to deliver a safe and stable service may be taking priority over research (Hall *et al.*, 2017). In the UK, the quality of care provided to people with dementia living in their own homes has recently been examined. A survey was conducted by the Alzheimer's Society highlighting the major issues regarding homecare (Carter, 2016). The three main issues highlighted by this study are:

- 38% of homecare workers do not receive any dementia training, and of those that do, 71% do not have training that is accredited;
- Only 2% of people affected by dementia say homecare workers 'have enough dementia training;'
- Half (49%) of people affected by dementia 'disagree' that 'homecare workers understand the specific needs of people with dementia.'

The lack of investment in adult social care services contributes to these issues, along with the high levels of staff turnover in this sector. Notably, nearly half of homecare workers are employed on zero-hour contracts (The King's Fund, 2018) reflecting the lack of funding available to deliver these services and the lack of recognition there is for the skilled work this group carries out. There are more homecare workers in England than nurses and doctors combined in the NHS (Carter, 2016). This makes them a substantial but underutilised resource that could do more to help prevent malnutrition in the people they care for living with



dementia. In 2014, nearly half of all people receiving homecare services in the UK, were visited more than ten hours a week (NICE, 2015), yet they may have only seen their GP six times a year (NHS Digital, 2009). Home care workers can help support nutrition simply by assisting with food preparation, encouraging eating and drinking, as well as screening for malnutrition and implementing other interventions to improve nutritional care (Marshall *et al.*, 2017). They will struggle to do this without significant investment for improved training and support (The King's Fund, 2018).

The following Chapters present qualitative studies exploring the perceptions and experiences of family members who care for another family member living with dementia in their own home (Chapter 4), and of healthcare professionals and homecare workers who may interact with patients and clients with dementia still living at home (Chapter 5), in respect of nutritional care.

## **4. Exploring the experiences of family carers when providing nutritional care to people living with dementia at home: A qualitative study**

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### **4.1. Chapter overview**

This Chapter presents the first qualitative study in this thesis, which explores the experiences of family carers when providing nutritional care to people living with dementia at home. As identified in Chapter 3, there is a lack of studies that have explored the role of family carers in the context of providing nutritional care to family members with dementia. There were no articles found that explored what family carers understood about the possible dietary changes that might come with dementia, and how they would approach these changes. The emotional significance of the relationship between someone with dementia and a family carer in the context of nutritional care provision was not explored in any study found in the scoping review. To address this gap in the literature, a study was conducted which provides an interpretative account of how family carers who live with someone with dementia perceive the provision of nutritional care. This study was published open-access in *Dementia* and is available at: <https://journals.sagepub.com/doi/full/10.1177/1471301219872032>.

The content of Section 4.3 is primarily formed from this published paper, which has been amended to include references to relevant appendices and further methodological details, and removal of author initials where appropriate<sup>4</sup>.

### **4.2. Background to the qualitative study**

The scoping review highlighted recommendations for the timely identification of nutritional issues and regular monitoring of nutritional status, as well as increased

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<sup>4</sup> Open access paper included as per University of Plymouth regulations stated in the Research Degrees Handbook (December 2019) Section 13.2.5

support and education for all types of carers involved with people living with dementia at home. Few studies have captured the lived experiences of family carers with regard to managing the nutritional needs of those being cared for. The scoping review also highlighted that consideration should be given to the caregiving relationship. The physical and emotional complexities of this could affect the nutritional status of the person with dementia and that of the carer. Interpretative Phenomenological Analysis (IPA) was a suitable method to achieve the aims of this study, because it encourages the exploration of the experience of a phenomena (in this case nutritional care).

#### 4.2.1. Aims of the qualitative study

The overall aim was to explore the experiences and perceptions of the nutritional care of people living at home with dementia from the perspectives of family members who support them. The study also:

1. Identifies the main issues based on the interpretative phenomenological analysis of data to reflect the concepts of family carer experiences and perceptions of the nutritional care of people living with dementia at home;
2. Informs the development of an intervention aimed at improving the nutritional care of people living with dementia at home;
3. Highlights areas for future research based on participants' experiences.

#### 4.3. Family carers' experiences of nutritional care for people living with dementia at home: An interpretative phenomenological analysis<sup>5</sup>

##### 4.3.1. Abstract

###### Objectives

Few studies have captured the experiences of family carers who manage the nutritional needs of family members living with dementia at home. The identification and management of symptoms that may affect nutritional status is often reliant upon the family carer. This interpretative phenomenological study aimed to explore the experiences and perceptions of the nutritional care of people living with dementia at home from the perspectives of the family members who support them.

###### Method

Semi-structured interviews were conducted between October 2017 and February 2018. Participants were also asked to keep a diary of experiences for two weeks before the interview. An Interpretative Phenomenological Analysis (IPA) approach was used throughout.

###### Findings

Eight participants, with a mean age of 69.6 years residing in South West England were recruited and represented a range of familial roles. Following analysis, three superordinate themes were identified: 'becoming carer and cook', 'changing role and relationships', and 'emotional eating'.

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<sup>5</sup> Mole, L., Hickson, M., Kent, B. and Abbott, R. (2019a) 'Family carers' experiences of nutritional care for people living with dementia at home: An interpretative phenomenological analysis', *Dementia*, pp. 231-246.

## Conclusion

Family carers make food and drink decisions daily, and feel a duty to take on the responsibility for food shopping and cooking. They are conscious about 'doing the right thing' when it comes to providing nutritional care, and some feel uncertain about the food choices they are making, particularly regarding a reliance on convenience foods. Changes in appetite, food preferences and mealtime habits related to dementia can lead to disruption affecting the dyad. It is important that family carers and people living at home with dementia are provided with adequate support regarding identifying nutritional risks, making appropriate food and drink choices, and preventing the risk of malnutrition in the dyad.

### 4.3.2. Background

There are an estimated 50 million people living with dementia globally (World Health Organisation, 2017). For those living with dementia at home, family carers take on the responsibility of managing health, emotional and social needs. These can become more complex and demanding as the dementia progresses, and can have profound impacts on the individual and their family (Fauth and Gibbons, 2014).

For someone living with dementia, nutritional status can be affected in many ways including changes in memory, motor skills, taste, appetite and swallow function (Ikeda *et al.*, 2002 Fukuhara, & Hodges, 2002; Kai *et al.*, 2015). The symptoms will vary amongst individuals as dementia progresses, and may also be dependent on dementia type (e.g. Alzheimer's disease or vascular dementia) (van der Linde *et al.*, 2014). Family carers are often the first ones to identify nutritional issues. This is one element of care amongst many others that a carer,

potentially with little experience or knowledge of dementia, may have to consider, increasing the risk of elevated levels of burden and stress, which may impact upon the quality of care provided, as well as emotional wellbeing (Brodaty and Donkin, 2009).

A recent scoping review identified three important factors which relate to the nutritional care of people living at home with dementia (Mole *et al.*, 2018). These included the timely identification of nutritional issues, regular monitoring of nutritional status, and increased support and education for all types of carers and healthcare professionals involved with people living with dementia at home. This review highlighted that the physical and emotional complexities of the caregiving relationship, or 'dyad', can affect the nutritional status of the person with dementia and that of the carer.

There is a paucity of studies capturing the family carer's experiences of managing the nutritional needs of the person with dementia, expressed in their own terms (as opposed to a set of predefined categories) (Smith, Flowers and Larkin, 2009). The issues associated with eating and drinking in dementia, as reported by family carers have been explored using semi-structured interviews (Ball *et al.*, 2015; Hsiao, Chao and Wang, 2013; L. Johansson *et al.*, 2014; Silva, Kergoat and Shatenstein, 2013). These studies described how coping strategies have been developed by family carers to adapt to feeding issues, which they found to be a significant challenge, and that little support was received from healthcare professionals. The aim of this research, therefore, was to understand the issues and concerns of family carers of people living with dementia at home relating to nutritional care in the UK setting. IPA was chosen as the research methodology. IPA seeks to examine, as far as is possible, the perceptions of the participant

(Alase, 2017). However, the process also involves the interpretative activity of the researcher, otherwise known as 'double hermeneutic' (Smith, Flowers and Larkin, 2009). Therefore, in-depth interpretative accounts for a small number of participants are presented when using IPA, instead of a generalised account for a larger sample.

#### 4.3.3. Methods

##### Study design

Semi-structured interviews were conducted with participants between October 2017 and February 2018. Participants were family carers who provided nutritional care (i.e. food shopping, cooking meals, providing mealtime assistance, monitoring weight) to a family member who is living with dementia at home. Participants were also asked to complete a record of their experiences two weeks prior to the interview using unstructured (i.e. not chronologically dependant) diary entries, to support their recollection during interviews. This qualitative mixed methods approach, allowed a greater understanding of the caring experiences encountered by family carer's regarding nutritional care, and supported them during the interviews, when they could recount specific events.

The consolidated criteria for reporting qualitative research (COREQ) checklist, was used during the design of this interview study, which supports ensuring quality reporting of important aspects of the methods, findings, analysis and interpretations (Tong, Sainsbury and Craig, 2007).

##### Participants

Following ethical approval from the University of Plymouth Faculty of Health and Human Sciences Research Ethics Committee (16/17-778) (Appendix G), the

study was registered on the Join Dementia Research website ([www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)). Participant information sheets (Appendix H) were attached to the online advert. Local carer groups and memory cafes were also approached and asked to advertise the study amongst their members. Purposive sampling aligns with IPA, as it ensures that participants are carefully selected on the basis that they can share their own perspectives on the phenomena of interest. This approach offered flexibility during the research process, and ensured that findings reflect what is occurring in the field. To be eligible for inclusion, participants were: family carers providing nutritional care to a family member living with dementia at home; able to take part in a semi-structured interview; able to record diary entries; and residing in South-West England. It was not a requirement that the family carer resided with the person living with dementia, so that a variety of familial relationships were explored. Written consent was provided prior to interview (Appendix I), and verbal consent was also audio recorded. Pseudonyms were used to protect participant identity.

Eight family carers volunteered to take part in the study and were either a spouse or child of the person with dementia (*Table 4*). The average time since diagnosis was 4.1 years, and the average age of family carer was 69.6 years.



Table 4 - Participant demographics (family carer study)

<b>Pseudonym of family carer (age, years)</b>	<b>Sex (M/F)</b>	<b>Relationship to person being cared for</b>	<b>Type of dementia</b>	<b>Number of years since diagnosis (if known)</b>
Anne (66)	F	Daughter caring for Mother	Vascular Dementia	12
Sarah (48)	F	Daughter caring for Father	Alzheimer's Disease	3
Paul (77)	M	Husband caring for wife	Alzheimer's Disease	unknown
Jeff (55)	M	Son caring for Mother	Vascular Dementia	2
Joyce (69)	F	Wife caring for husband	Alzheimer's Disease	2
Tony (79)	M	Husband caring for wife	Alzheimer's Disease	4
Stan (90)	M	Husband caring for wife	Alzheimer's Disease	2
Keith (73)	M	Husband caring for wife	Alzheimer's Disease	4

#### Data collection

Participants were interviewed at their own homes or on University premises according to their preferences. Interviews lasted between 16 and 53 minutes, and were audio recorded and transcribed verbatim. An interview schedule was developed and piloted, and used for prompting where necessary (Appendix J). Topics included exploring the type of nutritional care participants provided, how they cope providing nutritional care, and what they felt would support them. Blank diary templates (Appendix K) were sent to participants prior to the interview for recording mealtime experiences, and were transcribed prior to analysis. Participants were asked to record thoughts around eating and drinking, and descriptions of mealtimes that they felt were particularly positive or challenging. Some participants referred to diary entries during the semi-structured interviews, using them as a prompt to provide further explanation and meaning. Some participants did not use the provided template, but diarised entries in their own preferred format. Some participants used the templates as a food diary, to

capture foods and quantities consumed over a 2 week period. These were still included for analysis.

### Analysis

Data were analysed in accordance with an IPA methodology using NVivo 11 (QSR International, 2017a) to aid coding and organise emergent themes. Each transcribed account and diary was read and re-read whilst listening to the semi-structured interview recording, ensuring that any new ideas and insights were generated (Hunt and Smith, 2004), and detailed notes on semantic content and language use were made. These collectively formed a new set of 'source notes' (Pietkiewicz and Smith, 2014). An iterative cycle was then taken to condense the notes into a few words which captured the central meaning of the participants' lived experience, from which themes were formed (Alase, 2017). Connections across themes were then identified before the next participant account was approached separately and the themes that emerged from the previous case were 'bracketed' (Smith, Flowers and Larkin, 2009). A 'break' between analysing participant accounts and use of a reflexive diary supported the bracketing process. Bracketing enabled me to place attitudes and assumptions to one side, and focus on the participants account (Fischer, 2009). Once all accounts and diaries had been analysed, patterns across these were investigated, which were represented by sub-themes. Super-ordinate themes were developed from the sub-themes that captured the shared experiences of the participants. These super-ordinate themes are constructs that apply to all participants, but may manifest in different ways within individual participant accounts (Smith, Flowers and Larkin, 2009). This systematic approach ensured traceability of the development of themes from participants' original accounts and diaries. IPA provided an open, adaptable approach that enabled deeper understanding of

participants' experiences, particularly of those who may be in greatest need of support (Pringle *et al.*, 2011).

### Author's perspectives

I led the interviews, transcription and analysis and kept a reflective diary throughout the process. The research team have clinical and qualitative research experience in the field of dementia and nutrition, and I am a registered dietitian. Although my profession was not communicated to participants prior to the interview, it was not purposively concealed, and emerged during some conversations. This enhanced discussions about the participants' experiences of following nutritional guidelines and the challenges associated with this.

### 4.3.4. Findings

Three super-ordinate themes were developed by identifying patterns between sub-themes. These represent the interpretation of how participants experienced providing nutritional care to a family member with dementia (Table 5).

Table 5 - Superordinate themes with sub-themes (family carer study)

<b>Becoming carer and cook</b>	<b>Changing role and relationship</b>	<b>Emotional eating</b>
<ul style="list-style-type: none"> <li>• Adapting food provision</li> <li>• Dietary changes for all</li> <li>• Routine rules</li> <li>• The carer's experience</li> </ul>	<ul style="list-style-type: none"> <li>• Evolving relationship</li> <li>• Relationship strains</li> <li>• Carer is now head chef</li> <li>• Taking full control</li> </ul>	<ul style="list-style-type: none"> <li>• Muddling through mealtimes</li> <li>• Learning to adapt diet strategies</li> <li>• Food guilt</li> </ul>

These super-ordinate themes represent the complexities involved in supporting a family member with dementia, and how carers strove for balance between daily

'dilemmas' and the positive aspects of dementia. They described how, as they transitioned into a caring role, their relationships with the person with dementia changed, particularly around mealtimes. These changes caused strains between dyads, with the carer accommodating personality changes of their spouse or parent. Roles were often 'reversed' in both a practical (e.g. taking on responsibility for cooking meals), and emotional sense (e.g. putting spouse or parent's needs first). This ultimately resulted in the carer feeling responsible, and taking control of the person with dementia's needs, such as making decisions about food. The transitional journey of becoming a carer for someone living with dementia, and the impact that this had on nutritional care are represented by the themes. The super-ordinate themes epitomise the increase in the emotional burden carers took on, often without choice, which involved feelings of constant guilt and worry about 'doing the right thing', particularly where nutritional care was concerned. Nutritional care can become subsumed within the encompassing carer role, with priority given to other issues such as dealing with forgetfulness and personality changes. Each super-ordinate theme is presented in detail, with supporting excerpts from the interviews and diary entries.

#### Becoming carer and cook

Becoming a 'carer' was a role that caregivers found themselves taking on without choice. This transition often happened quickly. This meant that family members did not have time to rationalise their new role, and how this was juxtaposed with the role of spouse or child. As well as the caring role, participants also took on (or maintained) the role of cooking for the family. Thought needed to be given to selecting food, preparing it, and presenting it to the family member with dementia.

Carers described how they felt they had little option or choice regarding caring

for a family member. This dissolution of choice affected participants (often emotionally) and was prevalent in their accounts.

‘Yeah, but you have to, don't you? It's - I can't not do it ... I thought I could cope, and I think you do cope because you have to, when he's here.’ (Joyce, Wife caring for Husband, interview)

‘Well, she doesn't remember I suppose how to do things, or she's become reliant on me to do it ... it's okay. I've gotten used to it. It's what I've got to do.’ (Jeff, Son caring for Mother, interview)

Allowing the person with dementia to have choice over what they ate was particularly important for Anne, who was keen to implement her mother's own views expressed at a time before dementia. It was important to her to make that memory a reality, as her mother was unable to do so. Anne endeavoured to ‘liberate’ her mother's diet, and not impose restrictions.

‘My mum said at the time when people are old, they should be allowed to eat what they like ... So, I have that memory in my mind. So, I give her what she likes ... if she's not hungry, she might have a bit of cake, and I don't care because it's what she wants.’ (Anne, Daughter caring for Mother, interview)

Routine was perceived as an essential component of effective care, and was described by carers as a positive achievement or something to strive towards. It was a success criterion of their new role, which brought structure, reducing the likelihood of unplanned and unexpected events. Food shopping was viewed as a new routine adopted by male carers; however, the women with dementia were purposefully excluded from this task as their presence was perceived as a hindrance. This suggests that these carers preferred to complete these tasks rapidly and see them as something that ‘needed to be done’. The person with dementia was excluded from this routine task, even if they had spent many years doing the food shopping for the household, and perhaps found the task enjoyable.

'Got into a routine of doing things. ... I go and do the shopping on a Friday, but I don't take her with me because she was wandering off and stuff, so it's quicker, easier for me to just go and do it on my own and come back and pack it away.' (Jeff, Son caring for Mother, interview)

'It's difficult in a supermarket. I prefer to go shopping by myself now, because that sorts that.' (Paul, Husband caring for Wife, interview)

Dementia can result in feeling a loss of independence for both the person living with it and the family carer. Ironically, even though the carer may decide to take away an element of independence from the person with dementia (e.g. revoking their driving license), they experienced a loss of their own independence as a result (e.g. having to give up hobbies).

'Oh, I'm feeling doors closing all the time ... that's the sort of thing we were doing only four or five years ago. That's all tailed off now.' (Keith, Husband caring for Wife, interview)

'I used to rise early and do stuff before Emily got up. Now am constricted in time to do my things due to sorting Emily. Have to attend to my and Emily's routine medical challenges, so suffer from as less time for physical activity and keeping up with friends and relations. Frustrating.' (Paul, Husband caring for Wife, diary)

Carers learnt to make adaptations to help them cope in difficult situations when supporting a family member with dementia. As their role evolved, they created strategies and developed routines in an effort to reduce the time spent in caring activities. They often needed to work around the person with dementia's routine, which took precedence. An example of an adaptation is mealtime planning, where shortcuts were considered necessary to ensure that there was minimal interruption to important routines.

'I'll try and cook properly a couple of days and other days it will be quick and easy stuff, just because it's quick and easy ... Because mum likes watching all the news quite a lot ... I've got to fit it around that ... I've got to get out and do that while that's going on. Try and fit in with her really.' (Jeff, Son caring for Mother, interview)

The role of family carer was complex, and involved balancing many practical elements as well as making moral decisions. Food shopping was an example where family carers took a 'task-based' approach in order to 'get things done quickly'. Routine seemed to help family carers, and they made adaptations to cater for the person they were caring for.

### Changing role and relationships

The caring role can result in unforeseen changes within relationships, and this presented difficulties for carers to deal with. The carer and familial relationship roles did not seem to exist harmoniously and there was unease associated with the term 'carer'. Although caring for a family member resulted in taking more control, more responsibility and becoming the primary decision maker, participants felt demoted and undervalued.

The person with dementia became the primary concern, and the carer's needs were de-prioritised. This presented a challenge for carers in terms of how they accepted and managed this disruption, particularly around food provision, to what was once an equal marital partnership.

'I just find it up until 18 months ago, I couldn't take this word carer. It was just too alien. She was my wife. I still find it difficult comprehending this term carer. But it's a fact. One is caring for or helping or looking after or whatever.' (Tony, Husband caring for Wife, interview)

'Anybody who we have a contact with where necessary knows that she's got dementia. So as soon as we see anybody it's always, how's Maureen? Then if it's about me it's, how are you managing with Maureen?' (Stan, Husband caring for Wife, interview)

This demotion was a source of frustration for carers, as they felt as though their family member's dementia diagnosis took precedent. They argued, in fact, that when considering changes to nutritional intake, they recognised more changes in

their own diet than the person they are caring for. These changes were not always seen as positive, and affected the quality of the mealtime experience for the carer.

‘But, yes, my mum struggles because things that they’ve always had for meals, he won’t touch anymore. So, if she bought lamb chops or something, he won’t touch that any more. He doesn’t like it ... So now she finds herself eating quite blandly, quite boring, not as much.’ (Sarah, Daughter caring for Father, interview)

‘Before mum came to live with us we never ate any ‘convenience’ food or anything from a packet.’ (Anne, Daughter caring for Mother, diary)

Family members who are caring for a parent felt duty bound to take on this role, and they recognised an element of role reversal taking place. The adult child recognised that the parent once met their physical and emotional needs and felt obliged to do the same.

‘Well, I’m flesh and blood so I’ve got to do it. She’s brought me up when I was a child and baby and all that. A little bit of role reversal I suppose. I just carry on looking after her, looking after her interests.’ (Jeff, Son caring for Mother, interview)

This care role extended further, ensuring that meals were prepared exactly how the person with dementia wanted them. Taking the effort to meet these standards did increase the amount of food the person with dementia ate, alleviating concerns for the family carer.

‘Mum likes mayonnaise with many things and is fussy about sandwiches being just how she likes them – it makes the difference between her eating or not eating something if you get it right’. (Anne, Daughter caring for Mother, diary)

The role reversal can impact upon the person with dementia as well as the carer. Men may once have had the traditional role of ‘head of the family’, and women may have taken the lead role during special occasions (e.g. Christmas lunch). Their confidence to continue in this role can be diminished by dementia. Where



family meals were once an occasion to look forward to, these no longer take place. The disappearance of this positive family 'ritual' can affect the emotional significance of mealtimes for the whole family, as well as affecting nutritional intake.

'But now he just doesn't have an interest in food like he perhaps used to. He used to like it when we had a roast dinner and he'd carve the meat, and he can't do any of that anymore. I don't know whether it's his own knowledge that he can't do things to help or whether it's just the fact he doesn't have an appetite anymore.' (Sarah, Daughter caring for Father, interview)

'[She] used to do all the cooking. She's done Christmas lunches and things like that. She hasn't got a chance of doing them now. She can't sequence anything and everything. She wanders off and leaves things.' (Paul, Husband caring for Wife, interview)

For husbands who are caring for their wives with dementia, there was a marked transition in the role of food provider for the household. This was embraced with varying degrees of experience, but they felt a sense of responsibility to ensure an adequate and balanced nutritional intake.

'On retiring, I took over some of the things but basically, she was head cook and I was bottle washer and vegetable peeler and so on ... I decided I'd have to take over the cooking at some stage, so the idea in my mind was that I would gradually take over some of the meals each week from her, but somehow it clicked in her mind and it became me all the time, which is fine, you know. I'm happy enough doing that. So, I do the shopping, the cooking, all of that sort of stuff.' (Keith, Husband caring for Wife, interview)

Conversely, where women cared for husbands with dementia, although they maintained their traditional role of main food provider, this was diminished as a result of their husband's change in food preferences. Where once they held the matriarchal role in terms of providing food for the family, their efforts were perceived to be unappreciated and this made them feel undervalued and redundant. Sarah noticed this with her mother who lives with her husband who

has dementia.

‘... but my mum feels a bit, well it's all microwave meals. She doesn't feel like she's involved in the cooking there, really ... It's been almost her role to do that and seeing that potentially [Dad's] not, I suppose appreciating is the wrong word, but he's pushing things away when she's gone to the effort to... She feels very down about it herself ...’  
(Sarah, Daughter caring for Father, interview)

When a family member became a carer for someone with dementia, they felt that their needs were often de-prioritised, particularly with regards to their own diet. They felt obliged to make adaptations to meals for the benefit of the person with dementia, but not necessarily themselves. Where the person with dementia may have particular requirements regarding food, these were met without question in the hope that they were more likely to consume more. Traditions involving food were affected by matriarchal and patriarchal role changes, which saddened family carers.

### Emotional eating

Having a family member diagnosed with dementia brought daily food and drink dilemmas, which were sometimes difficult for family carers to manage. These predicaments were characterised by the emotional impact they had upon the carer, particularly when they felt that an important component of their relationship had been lost.

Monitoring fluid intake was an example that one carer, Tony, used to explain how he now needed to oversee how much his wife drinks. Whilst recalling the example, he described how his wife no longer remembered how he takes his cup of tea which upset him. This illustrates how dementia can have a profound impact upon daily tasks that are often taken for granted.

'She enjoys a glass of wine in the evening. But I've got to watch her a little bit now. She's always been very much a one glass in the evening and now I see she will refresh that glass. I'm just a bit conscious of that. I'll just keep an eye on that. Because I don't think she realises she's had a drink and that's the dilemma. Same with tea. She'll constantly ask about - and would you believe it, after 54 years of marriage, she asked me, do you take sugar, Tony, in your tea? It hurts actually.' (Tony, Husband caring for Wife, interview)

Carers were conscious about 'doing the right thing', whilst trying to eliminate a guilty conscience about making their family member unhappy in the process. This was particularly applicable to decisions regarding food, where a particular food that was deemed by the carer to be 'unhealthy' in terms of nutritional content, may also bring pleasure and joy to the person with dementia.

'So, I'm conscious of that. Should I be buying these things where she - like biscuits and things of that nature. But she obviously enjoys it. So, I've got a dilemma there in terms of should I get this or shouldn't I? Should I hide it away or shouldn't I?' (Tony, Husband caring for Wife, interview)

Balancing the feelings of guilt with providing a healthy diet for the person with dementia led to frustration for the family carers.

'So I don't know, from a nutritional point of view, it's trying to get the balance right and especially - even if you try and put a nutritionally balanced meal in front of him, he might not eat it. So we can try and give him things that we think he'd like.' (Sarah, Daughter caring for Father, interview)

Amongst the difficult aspects of caring for someone with dementia, carers recognised the positive components of their role. Some mealtimes brought joy and humour, providing light relief in an otherwise challenging environment. Carers who recognised positive aspects of their situation tended to feel that they were coping better. They strove to maintain a positive demeanour despite their situation, and were more accepting of the caring role.

'She likes potatoes but she doesn't like them in the pie. So, we always have this, is this one of those Yorkshire things? Where are the potatoes? In the pie? What, in the pie? Every time, because of the

dementia. Every time. It just makes us laugh.’ (Anne, Daughter caring for Mother, interview)

The nutritional care a family member provided to a loved one with dementia was underpinned by a range of emotions. They tried to manage these emotions whilst feeling that they had to supervise the food and drink intake of the person they are caring for. They tried to balance feelings of guilt regarding the nutritional value of the food they provided, whilst wanting to ensure the person with dementia still enjoyed food and drink. Amongst the negative emotions, there was lightness and fun in mealtimes shared with someone with dementia.

#### 4.3.5. Discussion

The aim of this study was to explore the family carers’ experiences, expressed in the participants’ own terms, providing an alternative view to a clinical perspective of nutritional care in dementia. To the best of our knowledge, these findings contribute the first detailed interpretative phenomenological account of the experience and perceptions of nutritional care for those living at home with dementia based on family carers’ own descriptions. The personal accounts highlight three superordinate themes central to this experience.

There is increased responsibility that comes with caring for a family member with dementia, particularly where nutritional health is concerned. Convenience foods were used by some as a coping strategy to meet the time demands of fitting into routines, as well as for those carers who were inexperienced with cooking. These foods were viewed by carers as sub-standard, and concerns expressed over whether they were providing adequate nutrients. There is limited research regarding the nutritional adequacy of convenience food for people living with dementia; however, some studies have included home-dwelling older adults as participants, also finding that this group tend to associate negative meanings with

convenience food (Peura-Kapanen, Jallinoja and Kaarakainen, 2017). Although a reliance on foods such as ready-meals may not provide adequate nutrients to meet nutritional requirements (Howard, Adams and White, 2012), they remain an important source of nutrition for many vulnerable older adults. Dietitians and nutritionists should be involved during ready-meal formulation, as well as acting in an advisory capacity to support appropriate choice of meals, which would be a potential method of addressing nutritional deficiencies in this population (Hoffman, 2017).

To deal with the day-to-day tasks that caring for a family member with dementia involves, many carers rely on a routine or task-based model of care provision. Food and drink becomes a function and any emotional attachment lost. Within the nursing profession, task-based care is perceived as unable to fulfil true person-centred care (Sharp, McAllister and Broadbent, 2018). Relationship-based care is a model of nursing care delivery that focuses on the care provider's relationship with the care recipient, with themselves, and with colleagues (Koloroutis, 2004, p. 4). Family carers could be supported to provide elements of relationship-based care, which could result in improved health outcomes for the carer and person being cared for. This may enable food to be enjoyed together as part of the relationship, rather than a cause for concern.

Carers expressed how mealtimes had become frustrating, due to behaviour changes of the family member with dementia. The severity of behavioural changes in people with dementia may predict an increase in feelings of 'role overload' amongst family carers (Gaugler *et al.*, 2000). The balance between wanting to provide nutritious meals, but also to ensure that the person with dementia continues to enjoy food has been identified in other studies involving

family carers (Keller, Edward and Cook, 2006). Mealtimes for these carers are at risk of becoming an occasion that is feared, or even avoided. This is of particular concern, as mealtimes have been shown to provide rich opportunities for social interaction that can be supportive for someone with dementia (Keller *et al.*, 2015). Family carers were upset that the person with dementia no longer wanted to take the lead role in family occasions involving food. This could be explained by the changes caused by dementia, such as struggling to remember meaningful roles (Genoe *et al.*, 2010). Male carers caring for female relatives, describe how they have taken full control of food provision in the household, including shopping for food. It has been reported that they do not feel obligated to take on this role, rather that it is an opportunity to reciprocate care (Atta-Konadu, Keller and Daly, 2011). This activity rarely involved the person living with dementia, due to carers feeling stressed and frustrated if they were present. Engaging in everyday tasks however, such as food shopping, can promote continuity as well as having positive impacts on personhood and quality of life (Phinney, Chaudhury and O'Connor, 2007). Allowing someone with dementia to continue engagement in domestic activities can also improve wellbeing and is an example of relationship-based care, where family carers play a pivotal role in facilitating this in the own home setting (Chung, Ellis-Hill and Coleman, 2017). Family carers require support with involving a family member with dementia in everyday tasks such as food shopping or cooking. This would also be an opportunity to provide guidance regarding the selection and preparation of suitable food choices that meet the dyads nutritional needs.

Some family carers noticed changes in their own diets as a result of the dietary changes of the person with dementia. These changes were not always viewed as positive; however, they accepted them as part of the caring role. The

increased burden associated with caring for a family member, has been found to predict weight loss in people with Alzheimer's disease (Bilotta *et al.*, 2010; Gillette-Guyonnet *et al.*, 2000). Similarly, a positive correlation has been identified between the malnutrition risk of people living with Alzheimer's disease and their family carer (Rullier *et al.*, 2013; Tombini *et al.*, 2016). Researchers and healthcare professionals should consider not only the nutritional care for the person living with dementia, but also that of the family carer.

Considering nutritional needs is one element in the myriad of caring duties for someone with dementia. Progressive loss of cognitive function leads to additional support being required with Activities of Daily Living (ADL's): bathing, dressing, grooming, toileting, walking, and eating (Prizer and Zimmerman, 2018). As highlighted in the present study, some family carers take a 'trial and error' approach to adapting diet strategies in an attempt to meet the nutritional needs of the person with dementia. This approach has also been found to be taken with wider aspects of care (Gaugler *et al.*, 2005). Eating disturbances (e.g. change in food preferences, swallowing dysfunction, and taking a long time to eat) could be argued to be one of the more complex care needs, as it can be impacted by functional, cognitive, and behavioural symptoms of dementia, although is often referred to as a single symptom, which could undermine the overall impact (van der Linde *et al.*, 2014).

Dyadic multicomponent interventions have been explored by some studies, and could improve carer burden, and relationship quality compared with carer-focused interventions (Laver *et al.*, 2016; Moon and Adams, 2012). Nutritional interventions focused on supporting family carers and people living at home with dementia have been explored and shown benefits short-term (Mole *et al.*, 2018).

Although no studies have focused on adherence to dietary strategies for people with dementia, older adults who have experienced support from others have described developing a liberated approach to eating and drinking which has enabled them to maintain healthy behaviours (Greaney *et al.*, 2004). Liberation of diet for people living with dementia is an area that warrants further exploration, particularly as dietary preferences can change with associated changes in the person with dementia.

### Strengths and Limitations

This is the first study to report the experiences of dementia on nutritional intake from carers of people living with dementia at home in the UK. Using a diary method combined with semi-structured interviews enabled a deeper understanding of the caring experiences encountered by family carer's regarding nutritional care. However, there are disadvantages to using a diary method, including the time burden placed upon already busy carers, and the reliance upon participants having the appropriate literacy or technological skills. Some participants kept very thorough diaries (and reported that they found the process cathartic), however others were unable to keep a diary due to time constraints. Caregivers were mainly recruited through the Join Dementia Research network ([www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)); therefore, already had an interest in taking part in dementia research, which could have imparted volunteer bias. The duration of some of the interviews may be considered short for a phenomenological study. This was due to the interviews reaching a natural end, with no new accounts being provided by participants. Finally, this study only explored the family carer experience of mealtimes. The results, therefore, do not give a full description of the experience for the dyad, which could be explored



further by including the person with dementia in the interviews.

#### 4.4. Conclusions from study

This study presents detailed interpretative phenomenological accounts of the experience and perceptions of nutritional care for those living at home with dementia based on family carers' own descriptions. The essence of this phenomenon is captured within three superordinate themes: '*becoming carer and cook*', '*changing role and relationships*' and '*emotional eating*'. As family carers transition into the role of carer, they make difficult decisions daily (including food and drink choices). They may decide to exclude the person with dementia in activities such as food shopping, which could otherwise be a beneficial and meaningful activity. Dementia-related changes in appetite, food preferences and mealtime habits can lead to disruption and frustration for carers, which can affect their own nutritional intake. Family members feel that it is their duty to take control of food provision, regardless of the type of relationship with the person with dementia. They are conscious about 'doing the right thing' when it comes to providing nutritional care, and some feel uncertain about the food choices they are making, particularly regarding a reliance on convenience foods. The findings reinforce the importance of ensuring family carers and people living at home with dementia are provided with adequate support regarding identifying nutritional risks, making appropriate food and drink choices, and preventing the risk of malnutrition in the dyad. Healthcare professionals may be best placed to provide this support, and future research should focus on their role in this context.

#### 4.5. Chapter conclusions

This study addresses a gap found in the literature regarding how family carers experience providing nutritional care to another family member with dementia.

During analysis, there were two areas identified which were not feasible to explore in detail as part of the published study. These were diet liberalisation and gender roles. These topics warrant further discussion as part of this thesis work.

A liberated diet is one that focuses on an individual's food preferences, instead of their dietary recommendations for their health conditions. This may include: not restricting foods high in sugar for someone with Type 2 diabetes, or including butter instead of a polyunsaturated oil-based spread for someone at risk of cardiovascular disease. Diet liberalisation could reduce the risk of malnutrition, because the person can eat and drink what they enjoy, rather than what is recommended, which may not be their preference. Diet liberalisation has been shown to have modest detrimental effects on glycaemia in older adults with diabetes mellitus, but deemed to be a positive approach (Farrer *et al.*, 2015). However, the evidence is not yet substantial enough to make changes to dietary recommendations. The American Academy of Nutrition and Dietetics have published a positioning paper which states that the quality of life and nutrition status of older adults, in various healthcare settings, can be enhanced by individualised nutritional care (Dorner and Friedrich, 2018). The Academy paper encourages a dietary intake that not only meets the health and nutritional needs of the individual, but also enhances their quality of life. Diet liberalisation could be helpful for preventing malnutrition in people living at home with dementia, particularly as the symptoms of dementia can affect food preferences (e.g. taste, texture, temperature). Until more research identifies whether diet liberalisation is appropriate for this group (i.e. any detrimental effects of liberalisation are offset

by other improved outcomes), dietary recommendations should take into account health conditions, medications, social circumstances and food preferences. Dietitians are ideally placed to support by interpreting these recommendations and advising on a tailored approach for the individual.

Husbands caring for their wives who have dementia, expressed a willingness to take on the role of food preparation, some even enjoying it. Their experiences align with an ethnographic study which found that husbands caring for wives with dementia, preferred to take on the cooking responsibilities in the relationship, instead of other domestic tasks such as household cleaning (Boyle, 2013). In fact, the aforementioned study found that men exercised choice and control over whether their wives were able to be involved in cooking, even if it was something enjoyed by the wife prior to developing dementia.

People over 65 years old tend to be more supportive of traditional gender roles, compared to younger generations who favour a balance between males and females when it comes to dividing household tasks, including cooking. Despite this, Park *et al.* (2013) found that in 2012, to differing degrees, women are much more likely than men to always or usually care for sick family members, shop for food items, do the household cleaning and prepare the meals. Attitudes towards gender roles have changed over generations, but the behaviours have not. The National Centre for Social Research survey results mirror Boyle's (2013) observations that whilst women continued to provide men with dementia with home-cooked meals, men found alternative means of supplying dinners, including buying ready-made or take-away food or organising meals outside the home (whether purchased or provided by another family member). These findings warrant further research to be conducted with male carers, to identify

what support they require with food preparation and/or meal delivery and the best way to deliver this support.

#### 4.6. Reflexive commentary

*This study was my first experience of qualitative research, having previously aligned with a positivist approach and having a preference towards quantitative methods. I soon realised, as I started to meet people living with dementia and their carers at various memory cafes and support groups, that everyone's experience of dementia is very different and unique. I felt that I would need to ensure that my approach provided the opportunity for participants to share their unique experiences and perceptions of what it is like to care for a family member. By taking an interpretivist approach to the study design, I felt confident that the views of the participants who provide nutritional care for a family member with dementia would be represented.*

*IPA was the best choice of method for this study, due to its focus on the interpretation of an experience. It respects that someone's interpretation of an experience may be very different to another, and I particularly felt at ease that I could be involved as part of the interpretative process. I would not have felt comfortable attempting to 'remove' myself from the findings, particularly as I have professional experience in this area.*

*I soon realised that for some participants, the research interview became an opportunity for them to voice concerns regarding their overall experiences that were not limited to eating and drinking. This was difficult for me to manage at times, as I wanted them to remain on the topic of nutrition and dementia. This focus may have impacted the analysis, because I was only looking for participants' interpretation of providing nutritional care, and not overall*

experiences. However, after one participant thanked me for the interview, as it had made them feel a bit better about things having the opportunity to voice it, I ensured that I let participants voice any other concerns and would wait until they had finished before steering them back to talk about nutritional care.

It was interesting how participants decided to make use of the diary templates. Some used them as a reflective tool, commenting on their emotions surrounding the experience of caring for a family member with dementia. Others used them like a food diary, recording the type and quantity of food eaten. One participant commented that using the diaries had helped them to understand their role as carer, and been a 'cathartic' process. This was an interesting finding in itself and presents an opportunity to explore how encouraging family carers to reflect on their experiences may help them to manage any negative emotions.

There appeared to be a difference in how carers had accepted the diagnosis of dementia. Those that seemed comfortable with the diagnosis, tended to appear more relaxed and at ease during the interviews, and were also able to comment on positive elements since diagnosis. Those that seemed less comfortable with the diagnosis tended to become more emotional during the interviews. I felt particularly uncomfortable during the interview of one participant, who appeared to be frustrated with many factors of his family member's dementia. The interview did not go as well as I would have hoped, as he was reluctant to expand on his answers when prompted. He also challenged my reasons for doing the research, which at the time made me feel quite defensive. After the interview, I spoke with my supervisor which helped me reframe the experience. He was struggling to come to terms with his wife's diagnosis of dementia, as well as how her symptoms were affecting life at home. I wonder whether by focusing on the dementia

*symptoms made him feel uncomfortable in that moment and, therefore, he reacted by becoming defensive himself. Looking back, we both become defensive for different reasons! The experience has helped me understand how to be better prepared for research interviews, from a practical and emotional perspective.*

*I have decided to refer to those providing support to family members living at home with dementia as family carers. Having now met many family carers, I appreciate that this term is not readily accepted, and in fact, resented by some. I am not comfortable with the terminology but it is what best fits in this thesis. Although the term carer is used throughout to distinguish them from the person with dementia, it should be noted that they did not necessarily identify themselves as carer. I asked the question to my followers on Twitter (some retweeted so it reached more people who care for family members with dementia), and it provoked an interesting debate. Most were adamant that they wanted to be referred to in terms of their relationship to the person with dementia, whether that be husband, wife, daughter etc. They felt that using the term carer was upsetting, particularly in the presence of the person with dementia. One respondent felt that dementia should not change the titles of family relationships, as this could risk changing the family dynamic. Another felt that the use of first names and the recognition of the relationship helps, as just being referred to as a carer does not feel good as it ignores the original relationship. This experience has helped me reflect on my own practice as a dietitian and educator. In future, I will give more consideration to how a patient or participant wishes to be referred to in terms of their relationship to the person with dementia.*

#### 4.7. Chapter summary

This study provides a glimpse of what it is like for a group of family carers who provide nutritional care for another family member living at home with dementia. The findings suggest that food-related activities, such as shopping and preparation are inherently adopted as part of the carer role. Family carers experience many emotions regarding nutritional care on a daily basis. They may feel confused about whether the food and drinks they are providing to the person with dementia are appropriate. They may also feel guilty that some foods and drinks they provide for the person with dementia may not be the best choices, but by doing so life is made easier. The confusion and guilt, combined with the frustration of dealing with the dementia symptoms that affect mealtimes, are likely to contribute to the burden felt by family carers. These feelings may also contribute towards changes in some family carers' own dietary intake since becoming a carer, usually for the worst. Participants in this study felt that they needed more information and support from health care professionals regarding appropriate food and drink choices for someone living with dementia. As identified in the scoping review (Chapter 3), there is a paucity of studies that explore the experiences of health care professionals who work with people living at home with dementia and the family carers. It is, therefore, not known whether such professionals currently feel they have the necessary knowledge and skills to provide this information. The next logical step in developing an intervention to improve the nutritional care of people living at home with dementia, was to explore the experiences and perceptions of health care professionals and homecare workers. The study presented in Chapter 5, uses IPA to address this gap in the literature.

## **5. Exploring the experiences of healthcare professionals and homecare workers when providing nutritional care to people living with dementia at home: A qualitative study**

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### **5.1. Chapter overview**

This Chapter presents the second qualitative study that provides an interpretative account of how healthcare professionals and homecare workers perceive the provision of nutritional care to the people living at home with dementia who they work with. This study was published open-access in *BMC Geriatrics* and is available at:

<https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-019-1270-4>

The content of Section 5.3 is primarily formed from this published paper, which has only been amended to include references to relevant appendices, and removal of author initials where appropriate<sup>6</sup>.

### **5.2. Background to the current research**

The scoping review presented in Chapter 3 identified a paucity of studies examining the views and experiences regarding nutritional care, of healthcare professionals who may interact with people living with dementia at home. It also highlighted that the physical and emotional complexities of the caregiving relationship, or 'dyad', could affect the nutritional status not only of the person with dementia but also that of the carer. Carer surveys have indicated that there is a need for increased primary care support relating to the nutritional needs and consequences associated with dementia in those living at home (Alzheimer's

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<sup>6</sup> Open access paper included as per University of Plymouth regulations stated in the Research Degrees Handbook (December 2019) Section 13.2.5



Society, 2012). To reduce the care burden experienced by family members, homecare support may be used, and can contribute to helping someone with dementia maintain an adequate nutritional status whilst living at home. Best practice guidelines have been published to support managers of homecare agencies (Skills for Care, 2014), however there is limited literature that evaluates the nutritional care that these agencies provide. Family members who care for someone living with dementia at home feel that they would benefit from additional support with nutritional care from healthcare professionals (Chapter 4). However, it is not known how healthcare professionals and homecare workers perceive nutritional care for people living at home with dementia, and their role in providing or supporting this care. IPA was used for this study, allowing experience and perception to be explored.

#### 5.2.1. Aims

The overall aim was to explore the experiences and perceptions of the nutritional care of people living at home with dementia from the perspectives of healthcare professionals and homecare workers who support them. The study also:

- Identifies the main issues based on the interpretative phenomenological analysis of data arising from the experiences and perceptions of the healthcare professional and homecare worker in respect of the nutritional care of people living with dementia at home.
- Informs the development of an intervention aimed at improving the nutritional care of people living with dementia at home.
- Highlights areas for future research based on participants' experiences.

5.3. 'It's what you do that makes a difference' An interpretative phenomenological analysis of healthcare professionals and homecare workers experiences of nutritional care for people living with dementia at home<sup>7</sup>

5.3.1. Abstract

Background

People living with dementia at home are a group who are at increased risk of malnutrition. Healthcare professionals and homecare workers, are ideally placed to support nutritional care in this vulnerable group. Yet, few, if any studies, have captured the experiences of these workers in respect of treating and managing nutritional issues. This interpretative phenomenological study aimed to explore the experiences and perceptions of the nutritional care of people living with dementia at home from the perspectives of healthcare professionals and homecare workers.

Methods

Semi-structured interviews were conducted between December 2017 and March 2018, and supplemented with the use of a vignette outlining a scenario of a husband caring for his wife with dementia. Healthcare professionals and homecare workers were purposively recruited from local care providers in the south west of England, who had experience of working

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<sup>7</sup> Mole, L., Kent, B., Hickson, M. and Abbott, R. (2019) 'It's what you do that makes a difference' An interpretative phenomenological analysis of health care professionals and homecare workers experiences of nutritional care for people living with dementia at home', *BMC Geriatrics*, 19(1), pp. 250.

with people with dementia. An interpretative phenomenological analysis approach was used throughout.

## Results

Seven participants took part including two homecare workers, a general practitioner, dietitian, occupational therapist, nurse and social worker. The time in their professions ranged from 3 to 15 years (mean=8.9 years). Following analysis, four superordinate themes were identified: 'responsibility to care', 'practice restrained by policy', 'in it together', and 'improving nutritional care'. This group of healthcare professionals and homecare workers recognised the importance of improving nutritional care for people living with dementia at home, and felt a responsibility for it. However they felt that they were restricted by time and/or knowledge. The importance of supporting the family carer and working collaboratively was highlighted.

## Conclusions

Healthcare professionals and homecare workers require further training to better equip them to provide nutritional care for people living with dementia at home. Models of care may also need to be adapted to enable a more flexible and tailored approach to incorporate nutritional care. Future work in this area should focus on how healthcare professionals and homecare workers can be better equipped to screen for malnutrition, and support changes to nutritional intake to mitigate malnutrition risk.

### 5.3.2. Background

There are an estimated 50 million people living with dementia globally (World Health Organisation, 2017). For those living with dementia at home, family carers take on the responsibility of managing health, emotional and social needs. These can become more complex and demanding as the dementia progresses, and can have profound impacts on the individual and their family (Fauth and Gibbons, 2014).

For someone living with dementia, nutritional status can be affected in many ways including changes in memory, motor skills, taste, and appetite and swallow function (Ikeda *et al.*, 2002; Kai *et al.*, 2015). The presentation of symptoms will vary amongst individuals as the disease progresses, and may also be dependent on dementia type (e.g. Alzheimer's disease or vascular dementia) (van der Linde *et al.*, 2014). The initial identification and management of nutritional issues are often reliant upon the family carer. This is one element of care amongst many others that an inexperienced carer may have to consider, increasing the risk of elevated levels of burden and stress, which may impact upon the quality of care provided, as well as emotional wellbeing (Brodaty and Donkin, 2009).

Carer surveys have indicated that there is a need for increased primary care support relating to the nutritional needs and consequences associated with dementia in those living at home (Alzheimer's Society, 2012). Family carers are conscious about 'doing the right thing' when it comes to providing nutritional care, however feel uncertain about the food choices they are making (Mole *et al.*, 2019a). To reduce the 'care-burden' experienced by family caregivers, domiciliary homecare support may be used, and can contribute to helping

someone with dementia maintain an adequate nutritional status whilst living at home. Best practice guidelines have been published in the UK to support managers of homecare agencies (Skills for Care, 2014), however there is limited literature that evaluates the nutritional care that these agencies provide. There is also a paucity of studies examining the views and experiences of homecare workers, and other healthcare professionals who may interact with people living with dementia at home (e.g. general practitioner's (GP's), community social workers, and community dietitians).

The reason for the delayed identification of malnutrition risk and the inconsistent monitoring of nutritional status could be because some healthcare professionals perceive a lack of benefit to the patient (i.e. taking a nihilistic view) (Iliffe *et al.*, 2009). However, the timely identification of nutritional issues, regular monitoring of nutritional status, and increased support and education for all types of carers and healthcare professionals involved with people living with dementia at home are important factors, highlighted in a recent review of the literature (Mole *et al.*, 2018).

The aim of this study was to understand the experiences and perspectives relating to nutritional care of healthcare professionals and homecare workers, who interact with people living with dementia at home. Interpretative phenomenological analysis (IPA) was chosen as the research methodology. IPA seeks to examine, as far as is possible, the perceptions of the participant. However, the process also involves the interpretative activity of the researcher, otherwise known as 'double hermeneutic'. Therefore, in-depth interpretative

accounts for a small number of participants are presented when using IPA, instead of a generalised account for a larger sample.

### 5.3.3. Methods

#### Study design

All participants took part in one semi-structured interview between December 2017 and March 2018. As part of the interview, a vignette was used that had been specifically developed for this research. All participants were shown and read the same vignette, which outlined a fictitious scenario of a husband caring for his wife with dementia at home (Appendix A). The vignette had been piloted with a group of healthcare professionals prior to interviews, to ensure internal validity. Vignettes have been shown to be useful in eliciting awareness and attitudes in healthcare research, as they offer a level of depersonalisation allowing the interviewee to think beyond their own professional circumstances (Schoenberg and Ravdal, 2000). The consolidated criteria for reporting qualitative research (COREQ), was used during the design of this study (Tong, Sainsbury and Craig, 2007).

#### Participants

Following ethical approval from the University of Plymouth Faculty of Health and Human Sciences Research Ethics Committee (16/17-778) (Appendix G), a variety of healthcare professionals and homecare workers were purposively recruited from the lead author's professional network. A copy of the participant information sheet (Appendix L) was sent to prospective participants.

To be eligible for inclusion participants were: healthcare professionals and homecare workers residing in South-West England, who had experience

engaging with people living with dementia at home. Written consent was provided prior to interview (Appendix M), and verbal consent was also audio recorded.

Seven healthcare professionals and homecare workers volunteered to take part in the study with an average duration in their profession of 8.9 years, and were predominantly female (1 male, 6 female) (Table 6). This sample size aligns with other IPA studies involving healthcare professionals, to provide a manageable number of detailed individual accounts (Smith, Flowers and Larkin, 2009; Jarman, Smith and Walsh, 1997). IPA acknowledges that each participants' experience will be unique, therefore, theoretical saturation (or data saturation) is not suitable (Pietkiewicz and Smith, 2014).

**Table 6 - Participant demographics (healthcare professionals and homecare workers study)**

<b>Profession</b>	<b>Code</b>	<b>Male/Female (M/F)</b>	<b>Time in profession (years)</b>
General Practitioner	GP	M	15
Community Social Worker	SW	F	3
Community Occupational Therapist	OT	F	3
Community Dietitian	CD	F	15
Community Nurse	CN	F	11
Care Worker 1	CW1	F	8
Care Worker 2	CW2	F	7

### Data collection

Participants were interviewed at their own home, at their place of work (outside of working hours), or on university premises according to participant preference.

Interviews lasted between 20 and 39 minutes, and were audio recorded and transcribed verbatim. An interview schedule was developed and piloted, and used for prompting where necessary (Appendix N). Topics included exploring the nature of their role, their experiences of nutritional care in this group, and what they felt would improve nutritional care for people living with dementia at home.

### Analysis

I analysed the data in accordance with an IPA methodology using NVivo 11 (QSR International, 2017a) to aid coding and organise emergent themes. Each account was read and re-read, ensuring that any new ideas and insights were generated (Hunt and Smith, 2004), and semantic content and language use were explored. Connections across themes were then identified before the next participant account was approached and the themes that emerged from the previous case were 'bracketed' (Smith, Flowers and Larkin, 2009). Once all accounts had been analysed, patterns across accounts were investigated and superordinate themes created that captured the shared experiences of the participants. Throughout analysis, emergent and superordinate themes were discussed with Mary Hickson, Bridie Kent and Rebecca Abbott. This systematic approach ensured traceability of the development of themes from participants' original accounts.

### Authors' perspectives

I led the interviews, transcription and analysis and kept a reflective diary throughout the process. The research team have clinical and research experience in the field of dementia and nutrition, and I am a registered dietitian. The impact of an existing professional relationship between the interviewer and interviewee was taken into account during data analysis through the researcher's



reflexive diary entries.

#### 5.3.4. Findings

Four superordinate themes were identified that brought together the data from the seven participants (*Table 7*). One theme (*responsibility to care*) was identified in all seven transcripts. However, three themes (*in it together [6/7 participants]*, *practice restrained by policy [5/7]*, and *improving nutritional care [5/7]*), although clearly identified in some transcripts, were not evident in all.

The vignette offered the opportunity for participants to explore their own feelings regarding a scenario which many had experienced in their professional practice.

Some of this insight contributed towards the themes, however the response to the vignette is summarised separately.

Table 7 - Superordinate themes with sub-themes (healthcare professionals and homecare worker study)

<b>Responsibility to care</b>	<b>Practice restrained by policy</b>	<b>In it together</b>	<b>Improving nutritional care</b>
<ul style="list-style-type: none"> <li>• Care is a constant</li> <li>• Dealing with dementia as a GP</li> <li>• Monitoring and auditing</li> <li>• Promoting an active role</li> <li>• Responsibilities and measures</li> <li>• Role of the district nurse</li> <li>• The attributes you need to care for someone with dementia</li> <li>• The extended role of health professionals</li> <li>• The role of carers</li> <li>• The role of the social worker</li> </ul>	<ul style="list-style-type: none"> <li>• Time is limited</li> <li>• The value and disvalue of other support services</li> <li>• Tensions and frustrations</li> <li>• Resource Policy and Care Provision Models</li> <li>• Power removed</li> <li>• Assessments and Care Plans</li> <li>• A happy social environment can't be measured</li> </ul>	<ul style="list-style-type: none"> <li>• Family carers need as much support</li> <li>• How care workers can support</li> <li>• Male carers cope better than females</li> <li>• Nutritional care is everyone's responsibility</li> <li>• Togetherness</li> <li>• We are all in it together</li> <li>• Working with family caregivers</li> <li>• Worry and concerns involved with nutritional care</li> </ul>	<ul style="list-style-type: none"> <li>• Taking a problem-solving approach</li> <li>• Opportunities for improvement</li> <li>• Meal delivery is not enough</li> <li>• Malnutrition management</li> <li>• Making it better</li> <li>• Generational changes in nutritional knowledge</li> <li>• Awareness vs. knowledge</li> </ul>

#### Theme one: Responsibility to care

This theme explores how the participants perceive the role that they play in supporting people with dementia living at home, and the responsibilities they feel they have to enable this. It examines the extended role that healthcare professionals and homecare workers may have, and the attributes that participants believe are important for working with this population.

Although the specific role of each health professional differs, there was a commonality expressed by participants linked to ensuring a safe environment and promoting wellbeing. Often, this was assessed against an established framework or screening tool, such as the 'Care Act'.

'Our function is that we'd go out, assess the person against the Care Act, which has quite clear eligibility... Statutory-wise it would be safeguarding. We'd have a duty of care making sure that they're safe, well, and at home if home is the best environment for them.' (SW)

All professionals felt a 'responsibility to care', and the GP in particular ardently expressed the magnitude of this responsibility.

'Oh my goodness! I'm basically responsible for their whole care.' (GP)

Some professionals perceived their role as not limited to their specialism, but recognised the importance of exercising an extended role, especially as they may be the only healthcare professional to have visited the person with dementia at home in a while. The community dietitian expressed how they would focus on nutrition, but also observe other health factors during a visit.

'It's nutrition but then also eyes. We're the eyes of - Somebody might not have seen a GP for a long time or have seen nobody for a long time. You're just looking around and making a judgment generally... For example, one of the questions I would routinely ask is what's your skin like? Are your pressure areas intact and if there's any concerns about that then it's a case of okay who is seeing that? Does anybody know about it?' (CD)

Homecare workers are amongst the professionals who may visit people at home on a regular basis, and describe their role as encouraging enablement and promoting an active role for the individual with dementia. This was particularly relevant when discussing food preparation, and one care worker described how important they felt it was to involve the person with dementia in this process. This was, however, caveated by the recurring issue of time constraints with delivering

care.

'I just think that with dementia, to get their minds working as well and actively doing something, I think cooking - maybe someone could go in and cook twice a week with them and make meals up that can go in the freezer... So getting them actively involved, you'll see a significant difference, you would, because their mind's - they're using their mind rather than letting it seize up.' (CW1)

Some participants discussed the important attributes that they feel are required when working with someone with dementia. 'Patience' was cited as one of these attributes, and the community nurse described how this was important if visiting a patient around mealtimes.

'We try not to do our visits around mealtimes, because they need to be protected really, especially with somebody with dementia that might take a long time to eat their meals. Some people even forget how to use a knife and fork, so you don't really want to be interrupting that... You need a lot of patience, got to have patience. If people haven't got patience, then you can't support people if you haven't got patience with dementia.' (CN)

#### Theme two: Practice restrained by policy

This theme explores the impact that hierarchical influences, such as policies and care provision models, had upon the participants' practice. It explores the issues expressed regarding time constraints concerned with providing adequate nutritional care, and how other support services can be helpful or a hindrance. The level of policy, models, assessments and care plans was an area of focus for many participants, and resulted in feelings of tension and frustration. Some expressed feeling a dissolution of power, where senior management made all decisions regarding care provision. The inability to effectively measure important outcomes, such as ensuring a happy, and social environment, was seen as a limitation of the healthcare system, which was perceived as being focused only on measurable outcomes.

Issues with time constraints were mentioned by a few participants, however the homecare workers were most sensitive to how time can impact upon their role in the context of nutritional care for the individual with dementia.

‘As a carer, I know that sometimes you only have a certain amount of time to go in. A lunch call could be half an hour. In that time with someone with dementia you might have given them so many options and they choose one and then they decide they don't want that... It's just unfortunate that support workers are only given a certain amount of time and the people that dish out the time will be sitting there saying well hold on a minute, she's got dementia, she's got carers three times a day. That's where ours stops. Well it shouldn't. That's not a duty of care. Duty of care is to promote independent living at home.’ (CW1)

Dementia was expressed by some participants as a ‘social care issue’, and one which requires multidisciplinary input. Memory cafes (which support people with dementia and their family members in a safe, social setting) were viewed as a valuable resource by the GP, and one which differs to that of formal health provision services, such as memory clinics.

‘Memory cafes are very popular because they're not them and us, type of thing. It's very - they're very level playing fields. Whereas, when you go to the memory clinic, the consultant, the specialist, he's them and we're the patient.’ (GP)

Many participants described their roles framed within referral policies and procedures. This was deemed necessary to manage a large number of referrals with limited resources, but there were challenges associated with this, particularly in the context of changing strategies to prevent hospital admissions.

‘We would put an individualised nutritional care plan in place and then we would monitor that. We aren't able to monitor as closely as we would like because of the level of the dietetic service... I'm a bit biased, but I think we need more dietitians.’ (CD)

The tension between the cost of nutritional care provision and client requirements

was perceived as an issue in social care. Many clients will be supported by meal delivery services. Although a cost-effective option, social workers are aware that this does not meet many of their client's needs, who would perhaps benefit from increased carer support during mealtimes.

'It's really quite hard, because of the budgets and stuff like that, they want to cut down on care. So, when we put care packages in, it has to be timed. They don't like us putting in carers to cook a meal. So, instead, they will say Community Meals or microwave meals.' (SW)

Measured outcomes and targets are not reflective of the benefits of social interaction, as perceived by one of the homecare workers. They serve a purpose, however the importance of creating an environment where people are able to interact to promote improved wellbeing, may produce positive yet unmeasurable outcomes. This insight does not align with a time-based model of care provision.

'I don't think we can ever underestimate social interaction. I think there is so much now based on outcomes, but we don't actually appreciate enough just socially how important that is...we have targets and of course we can always have things to work to, but I think the fact that we can provide an environment to come in and socialise and be happy, because obviously all those things affect your mental health, your wellbeing.' (CW2)

### Theme three: In it together

This theme explores how participants recognise the importance of the partnership that is required between themselves and family carers of people living with dementia at home. It describes how some family carers may cope better than others, and how participants feel they provide help and support with regards to nutritional care. Nutritional care is perceived by many participants as being a collective responsibility, in which everyone can play a part and it is recognised how healthcare professionals, homecare workers and family carers need to work together.

The recognition of how family carers cope with providing nutritional care for someone living with dementia at home was noted by a homecare worker in response to the vignette. The requirement for there to be as much support for the family carer as for the person with dementia was also noted.

'I think that must be the hardest bit is the guilt, that they have the mixed emotions of what they must go through. They must go through so much frustration. They must get to the point where they get so exasperated by it all. That would be perfectly what you'd expect. I think he'd need just as much support in a different way.' (CW2)

Male family carers were perceived by one participant to cope better than females. The occupational therapist who perceived this suggested this was due to females having carried out a 'caring' role for the family throughout their lives, and may feel more of a burden as a result of caring for a male spouse with dementia. Male family carers may take to unfamiliar tasks such as cooking and shopping with an organised and methodical approach.

'Just the change in the role is a really difficult thing for a carer to take on, but I personally always think that men manage it slightly better...maybe the husband has not had to do so much of that during their lifespan and then, although it's difficult, seems to take it a lot better and although it's maybe unfamiliar tasks with cooking and things like that, they're very organised.' (OT)

The way in which homecare workers support family carers was explored, in response to the vignette. Homecare workers can be a source of 'strength' for the family carer if they are struggling, and provide structure and support. They can be limited to how they support family carers, and are aware of providing advice but not dictating how nutritional care should be delivered.

'He's going to get his strength from her, and maybe if he watched what she did with him, he might get an idea of how they can get in a routine or prompting her to eat her meals...Or maybe [he] just needs to be sat down and said look, we can do this, or get a food plan

together...You're limited to what you can say. You can advise them but you can't tell them.' (CW1)

It was important to the community dietitian that nutritional care was a shared responsibility. Although dietitians can be key in driving positive change towards improving someone living with dementia's nutritional status, they are not solely responsible. Other healthcare professionals and family carers have a part to play in keeping someone well for as long as possible.

'Also it's not just a dietitian's responsibility, I should say, in that everybody who's come into contact there; so the carers and any other healthcare professionals involved, can actually start to put in some steps to support them other than it just being the dietitian.' (CD)

The concept of shared responsibility for nutritional care was explored further by another participant, who discussed the importance of family carers and people with dementia doing things 'together' that would contribute to improved nutritional care, such as shopping.

'But they could make a shopping list; they can go shopping together. If she's putting loads of stuff in the basket, in her mind she's saying oh I like that, I like the thought of having that. So maybe having something that she likes, that she's going to eat, but as long as it's got the nutrition for her, I don't think it's that bad.' (CW1)

#### Theme four: Improving nutritional care

Some participants explored how they felt nutritional care could be improved for people living with dementia at home. There was a recurring theme of the importance of increasing awareness of nutritional issues and more training in nutritional care for healthcare professionals, homecare workers and family carers. For homecare workers, a 'generational knowledge gap' regarding nutritional care is thought to have an impact for clients with dementia living at home. The perceived issues with meal delivery services were referenced by a



few participants, but also the benefits that they can offer to both family carers and people with dementia.

Raising awareness of nutritional issues associated with dementia for patients and carers at point of diagnosis were recognised by one participant to be beneficial for the future. Family carers or the person with dementia may then notice nutritional issues before they escalate.

‘Step one is at the point of diagnosis and at that point we hope we’ve diagnosed them early enough where nutritional issues won’t be a problem. But, if we raise awareness at that point, that could be helpful in the future.’ (GP)

The level of nutritional knowledge amongst participants varied. Aside from the community dietitian (‘the experts in the nutrition side of things’), participants felt that they lacked knowledge in the area of nutritional care for people living with dementia at home. Many felt that more training in this area would provide the knowledge required to identify nutritional issues and take appropriate action.

‘No. I’ve probably got no - zero knowledge of nutritional care in that sense... Are the microwave meals really that bad? I don’t - we don’t know. I don’t know whether that - they’re bad or not bad.’ (SW)

‘I think education for everybody because there’s quite often lots and lots of people involved with a person... it would be just be a bonus to have it because we are aware, we realise that food and drink is really important and that it’s an issue, but I wouldn’t say that we actually have the right knowledge to maybe do what we need to do about it.’ (OT)

The age demographic of homecare workers was considered an issue in the context of nutritional knowledge for one participant. Differences in school education over the years regarding cooking and nutrition was cited as the reason for this.

'We have young members of staff coming in now that have absolutely no idea about nutrition and about - I think it's the schools. I think the schools need overhauling on it, I really do.' (CW2)

The efficacy of meal-delivery services were raised by some participants. Most were dubious regarding their value, particularly with regards to the method of delivery. Participants felt that recipients of the meals were left confused and with little guidance regarding the meals, which inevitably resulted in them not being consumed.

'...all of their hot meals with big bold stickers on the front saying please eat immediately do not freeze. You have a look in their freezer and there's about 20 of these meals. The alarm bells start ringing.' (CD)

'They just turn up. You might have somebody by themselves or whatever and they turn up, they give them the meal, and then they leave, literally, at the door. That causes all sorts of problems.' (SW)

Carers being able to spend time cooking with people living with dementia at home was suggested by participants. This would provide an enjoyable activity for the person with dementia, and increase the likelihood of meal consumption; therefore, improving nutritional intake.

'I'm quite sure that carers in the community that'll be commissioned would love to cook somebody a meal. I'm sure they would, and I'm sure that's a problem, and we would love them to cook the meal. But that's the - it's coming from the budget holders.' (SW)

'I just think that with dementia, to get their minds working as well and actively doing something, I think cooking - maybe someone could go in and cook twice a week with them and make meals up that can go in the freezer.' (CW1)

### Reactions to the Vignette

The vignette offered participants the opportunity to reflect on a scenario, based on a real-life situation (Appendix A). The vignette describes a husband's experience whilst caring for his wife who has Alzheimer's disease. These include

having to take over the cooking duties, concerns regarding eating adequately, weight loss, and the impact of memory loss. They were able to then relate their own experiences to the scenario, as well as how they felt about the situation. Participants recognised the scenario, and many accepted that it was something they see frequently in their professional practice.

‘It's kind of a familiar situation. It is something that we come across quite often.’ (OT)

‘Yeah, that is sad, but yeah, totally understand where he's coming from and I've seen that.’ (CN)

‘That's the kind of patient we see on a daily/weekly basis. Obviously really tough situation isn't it.’ (CD)

Participants sympathised with the family carer's situation in the scenario, and were empathetic towards the change in his role, as well as how his wife's dementia diagnosis may be affecting him.

‘In terms of her husband Peter, it's been a massive life change for him and his feelings and thoughts for the changing role; a quite devastating time for him really.’ (CD)

‘I think the bereavement, the grief, it must be so hard. If somebody dies and you have to come to some kind of acceptance at some point that you aren't going to see that person again, but when that person is disappearing in front of you, I think that's so tough.’ (CW2)

As well as a focus on the health status of the person with dementia (‘there are red flags coming out around nutrition’ CD), the health of the family carer was also an area of concern for participants. This ranged from social and emotional support, to medical support.

‘Obviously he's not very aware of the whole situation, is he? He knows that his wife's got this dementia and he doesn't actually know how to deal with it because she's always been the actual role; she's looked after him. So now he just needs a little bit of backing up really doesn't he?’ (CW1)

'Then, of course, we might want to look at him as well. What medication and support might he want?' (GP)

Participants explored how homecare workers could add value by offering practical support. This ranged from providing reassurance, to helping the family carer plan meals for the week.

'So if they had someone come in and they taught them about what does she like to eat, how does she like to cook it, because it's guaranteed as soon as she gets in that kitchen she'll be saying oh I used to do it this way... Or maybe he just needs to be sat down and said look, we can do this, or get a food plan together.' (CW1)

A range of solutions were offered by participants to help the couple. These included hot meal delivery to take the onus off the family carer, and modelling appropriate behaviours like eating meals together.

'Depending on where they live...we can have hot meals delivered; quite a lot of villagers, like the local pub would deliver a hot meal and things like that. So I'd probably try to look in to what's available in their area. If he's concerned about whether he's cooking the right things and things like that, and also just to take a bit off of him, if he's not used to having to cook. Making sure that they've got the nutritious meals coming in would probably be something that I'd want to prioritise.' (OT)

'Sometimes if you sit down and eat with someone, they will eat as well. It's what they can see, not feel. She might be thinking oh I haven't eaten that so he's eaten, I'll eat. It's what you do...that makes a difference.' (CW1)

#### 5.3.5. Discussion

The aim of this study was to understand the experiences and perceptions of healthcare professionals and homecare workers who interact with people living with dementia at home relating to nutritional care. To the best of our knowledge, these findings contribute the first detailed interpretative phenomenological account of such experiences. The personal accounts highlight four superordinate themes central to this experience.

Healthcare professionals and homecare workers feel that they have a responsibility towards the health of someone living at home with dementia. This was termed a 'duty of care' by some participants, who viewed it as an integral component of their professional role. This is important because healthcare, particularly nutritional care, often involves uncertainty and risk for individuals who are reliant on the competence of the healthcare professional (Allinson and Chaar, 2016). Trust within healthcare relationships is thought to be reliant on healthcare professionals being non-judgemental listeners and 'acting as a mirror for family strengths' (Robinson, 2016). Surveys have found that older people in the UK feel that they are not involved in the wider homecare system, which they find difficult to understand, and does not make the effort required to tailor care to their health needs (Sykes and Groom, 2011). Future service development must recognise that health systems are complex, and require integration of trust to enable successful outcomes (Gilson, 2003).

It has been demonstrated that reductions in health and social care resource in England, UK are associated with increased mortality (Watkins *et al.*, 2017a). It is, therefore, important to ensure that all healthcare professionals and homecare workers who visit people in their own homes, are able to take responsibility to identify potential health risks that may lead to deterioration of health, such as malnutrition. More focus is required on promoting holistic and non-siloed training and working approaches to care, particularly for those with complex long-term conditions (Burger *et al.*, 2018).

Participants discussed the use of assessments and care plans, either conducting these themselves, or using them as a reference to ensure they understood the person living with dementia's requirements. Care plans form an important part of a patient's health journey, particularly in long-term conditions, and provide an opportunity for health services to measure outcomes. However, care plans that are focused on a chronic condition may not factor in the patient's or professionals' wider perspectives on goals or behaviour changes (Burt *et al.*, 2014). A trial of the effectiveness of a care plan delivered by memory clinics, and developed specifically for patients with Alzheimer's Disease showed no difference in functional decline compared to usual care (Nourhashemi *et al.*, 2010). Care plans should have a broader focus, particularly as many people living with dementia also have other comorbid medical conditions (Bunn *et al.*, 2016b). Nutritional care should be an integral component of personalised care plans for people living with dementia at home, however more research is required concerning reducing the time burden of the care planning process for primary care practitioners and patients (Edwards, Dorr and Landon, 2017). A potential remedy for this issue is to allow the patient and family carer to derive their own meaningful outcomes.

Participants felt that many issues regarding the effectiveness of nutritional care were as a result of limited time available for homecare workers per visit. People with dementia may experience difficulties planning mealtimes, and may miss or leave meals if left unsupported (Nygård and Johansson, 2001). Eating meals with others, playing background music, and allowing longer mealtimes may help, however more research is required to test such interventions, and whether homecare workers could facilitate them (Bunn *et al.*, 2016a). Meal delivery was a solution proposed by some participants, however this was sometimes viewed

as a sub-standard replacement to an extended homecare visit. Delivered meals have been found to improve nutritional status and dietary intake in older adults (without a diagnosis of dementia) who reside in their own home (Wright *et al.*, 2015; Zhu and An, 2013). Despite this, some studies have found that this group tend to associate negative meanings with convenience food (Peura-Kapanen, Jallinoja and Kaarakainen, 2017). There is a paucity of studies exploring the effects of delivered meals for people living with dementia at home.

Participants were unanimous in their view that healthcare professionals and homecare workers required more training and support regarding effective nutritional care. This view aligns with a recent survey that found that 86% of homecare workers in the UK believe that dementia training would help them provide better care (Carter, 2016). In the care home setting, studies have explored the importance of considering the meaning of the mealtime experience, and how residents can be empowered to make food and drink choices (Murphy, Holmes and Brooks, 2017; Watkins *et al.*, 2017b). More research is required into how similar approaches may be used within the 'own-home' setting, and with people living with dementia. Homecare workers may be best placed to facilitate these approaches, however the complexities of their role and the training they require is under-researched (D'Astous *et al.*, 2019).

### Strengths and Limitations

This is the first study to report on the experiences and perceptions of healthcare professionals and homecare workers regarding nutritional care for people living with dementia at home. Using a vignette during the semi-structured interview

allowed participants to think creatively and provide responses that could be compared between professions. However, participants were asked to respond to the vignette from their own perspectives, which may have resulted in participants giving answers that were expected of their profession, rather than what they would do themselves. Participants were recruited through the lead researcher's professional networks, which may have affected the interview dynamics and results. This was mitigated by ensuring transparency of the existing relationships between interviewer and interviewee, and by keeping a reflexive diary throughout the study. The diary allowed the lead researcher to actively explore how the information shared by participants impacted upon her own pre-existing beliefs and knowledge in order to understand the phenomenon of interest which was how healthcare professionals and homecare workers provide nutritional care.

#### 5.4. Conclusions from study

This study explored the experiences of healthcare professionals and homecare workers when providing nutritional care to people living with dementia at home. This group felt a sense of responsibility to ensure that people living with dementia received adequate care. The family caregiver was recognised by participants as needing support. However, challenges to providing effective nutritional care and support include limited time to spend with individuals, knowledge of appropriate food and drink choices, and decisions to replace carer support with meal delivery to reduce cost. The healthcare professionals and homecare workers in this study recognised that working together as a team can improve care outcomes. Ideas for improvements focus on raising awareness of nutritional needs and developing training aids regarding nutritional care and dementia. The findings reinforce the importance of ensuring healthcare professionals and homecare workers are provided with adequate training regarding identifying nutritional risks, helping



family carers make appropriate food and drink choices, and preventing the risk of malnutrition in the dyad. Future research should focus on the efficacy of interventions to improve nutritional care from the healthcare professional and homecare worker's perspective, as 'it's what you do that makes a difference'.

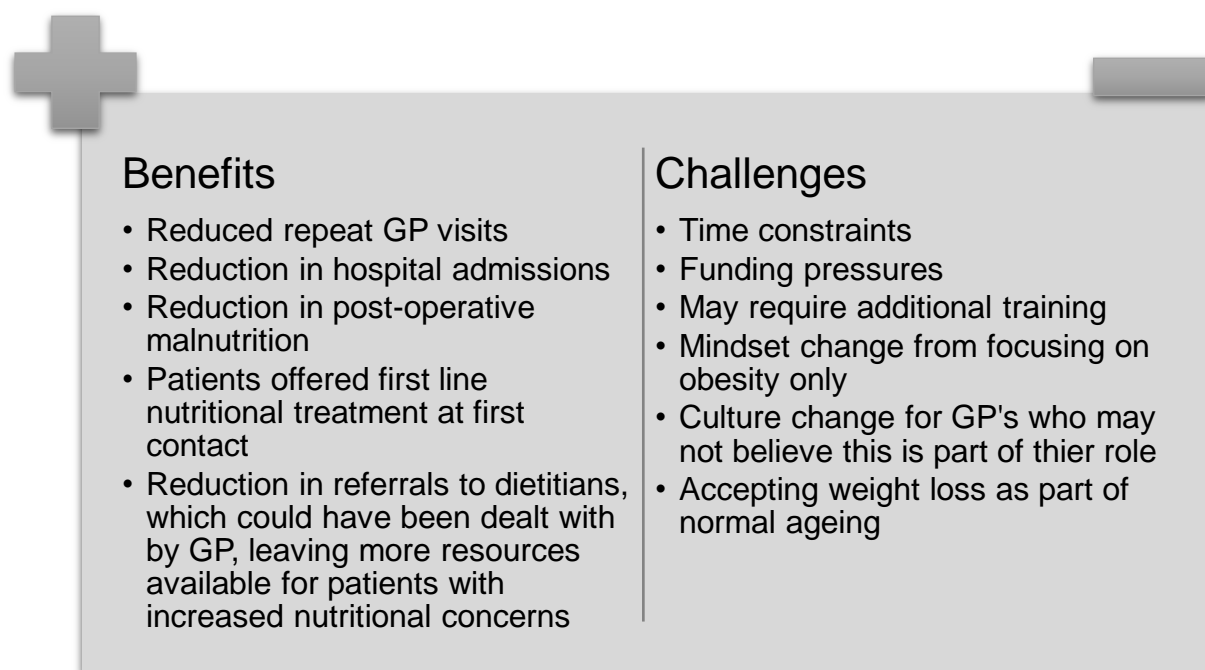
## 5.5. Chapter conclusions

This study addresses a gap found in the literature regarding how healthcare professionals and homecare workers experience the provision of nutritional care to people living with dementia at home.

During analysis, there were three areas identified which were not feasible to explore in detail as part of the published study. These were healthcare professionals' knowledge of nutritional issues, the impact of the social care system on nutritional care and dementia, and the efficacy of meal delivery services. These topics warrant further discussion as part of this thesis work.

There is a recurring debate regarding the practice boundaries between dietitians and other healthcare professionals when it comes to nutritional care. In particular, the role of the GP is important to understand, especially when it involves identifying patients who may be at risk of malnutrition and taking appropriate action. The benefits and challenges associated with screening patients for malnutrition as part of a GP visit are summarised in *Figure 8*.

Figure 8 - The benefits and challenges of GPs screening patients for malnutrition (adapted from Adamski et al. (2018) and Murphy, Mayor and Forde (2018))



The National Institute for Health and Care Excellence recommends that patients should be screened on registration with a GP, and this should be repeated where there is clinical concern (NICE, 2017). The Royal College of General Practitioners (RCGP) advocates that it is important for GPs to be able to identify vulnerable patients in their care who are at risk of malnutrition and dehydration. They should also be able to identify relevant services to provide additional support (Royal College of General Practitioners, 2015). As discussed in Section 1.6.1, a person with dementia is at an increased risk of malnutrition, and appropriate screening should be carried out at every primary care contact. The onus is not just on GPs to screen for malnutrition, as practice nurses or community pharmacists may also have opportunities during general health

checks or medication reviews (Darzi, 2014). Despite this, primary care settings are failing to screen patients as they should, and a barrier to this may be due to a lack of suitable tools (Elia and Russell, 2009). The 'Nutrition Wheel' (Wessex Academic Health Science Network, 2019), discussed in Section 1.4.1, is a novel tool which is intended to be used by volunteers and healthcare professionals. A tool like this could be used by GP surgery reception staff, who are being upskilled to undertake enhanced roles in active signposting as part of the General Practice Forward View (NHS England, 2016).

Some GPs may feel that there is no time to include a conversation about nutrition within a ten minute consultation. For patients who may benefit from weight management support, or are thought to be misusing alcohol, brief intervention statements are recommended (NICE, 2011; Public Health England, 2017). Brief intervention statements are very short conversations of around 30 seconds, identifying that the patient is at risk, explaining how best to change behaviour, and referring to obtain help (Public Health England, 2017). They have been shown to be both acceptable to patients and an effective way to reduce weight (Aveyard *et al.*, 2016), but there are no recommendations or guidance for the use of brief interventions for patients with or without dementia who may be at risk of malnutrition, and this warrants further research.

Delivered meals was a topic raised by some participants in this study, and there was ambiguity regarding their nutritional value, and whether they were even consumed by the person living with dementia. Since publication of this study, a systematic review has suggested that home-delivered meals for older adults do have a positive effect on dietary intake of energy, protein and calcium (Walton *et al.*, 2020). However, if older adults are relying on home-delivered meals to

provide the majority of their recommended daily allowance of energy, they are unlikely to meet these (O'Dwyer, Corish and Timonen, 2009). One solution suggested is legislation to standardise and improve the nutritional content and portion size of delivered meals. Both studies used dietary recall methods to measure dietary intake, which may not be a suitable method for someone with dementia. Changes to someone's mealtime environment may encourage them to eat more of a delivered meal. This could involve a family member or homecare worker sitting with them while they eat, or playing gentle music (Ragneskog *et al.*, 1996). Further research is needed to identify whether delivered meals are a suitable option for people living at home with dementia and how to optimise their use.

The homecare workers included in this qualitative study are part of a wider social care system in England that aims to help people live independently by providing support with the basics of daily life, such as eating, bathing and getting dressed in their own home or in a care home. This system is under immense financial strain, and has been one of the main topics of political debate in the past few years (Charlesworth *et al.*, 2017). The financial pressures have arisen from a lack of public funding, coupled with a growing demand as people live longer with an increased prevalence of diseases such as dementia (Thorlby *et al.*, 2018). The stability of the homecare industry is also under pressure, with the annual rate of homecare workers leaving jobs rising, due to factors such as low wages, zero-hour contracts, and a lack of training and development opportunities (Gershlick *et al.*, 2017). Combating financial pressures and implementing social care system reformation will need to be on the government's agenda to meet the increasing demands for social care. There are factors that can be improved in the current system, such as creating training opportunities for homecare workers,

in topics such as dementia and nutritional care. The homecare workers included in the qualitative study were amongst the majority of participants who felt that more training in this area would provide them with the knowledge required to identify nutritional issues and take appropriate action with people living at home with dementia.

#### 5.6. Reflexive commentary

*As this was the second IPA study conducted, I felt more at ease with the methodology and approach. I also felt more confident interviewing healthcare professionals and homecare workers compared to interviewing family carers. This may have been because I knew some of the participants. I also think that I feel more comfortable amongst other healthcare professionals, as it is what I know. As I have worked with some of these healthcare professionals, I already knew a little about how they worked with patients and what their role involved. Having this pre-existing knowledge may have influenced my interviewing technique; for example, I perhaps did not go into as much depth with the community dietitian participant as I had done that role myself previously. This may have also affected the analysis, as my knowledge and experience would have influenced my interpretation of the participant's accounts.*

*I am fortunate to not have experienced the impact of dementia to family members. I was motivated to carry out work in the area of dementia, not from a position of experience, but because I saw the impact that dementia had on people who were admitted to hospital, particularly related to nutritional status. I felt compelled to do something that would try to minimise this impact before it became severe.*

*Since conducting the studies, I have had the opportunity to experience being a primary carer for another family member. I had a baby at this stage and took some time away from thesis work. Becoming a primary carer to another person has enabled me to understand some of the emotional and physical demands that are associated with being a family carer, and the impacts these have on the health of the carer. I have been conscious about doing the 'right thing' when it comes to food, sleep and development, and the life transition has at times, made me feel anxious. Caring for a baby is not the same as caring for an adult with dementia, but I do relate more to how challenging the carer role is.*

*Although the interviews felt more comfortable for me, I did find that the participants would tend to answer questions on behalf of their professions, using 'we' instead of 'I'. This was common with all participants. This could have been explored further during the interviews using appropriate questions; I think that with more interview experience I would have been able to identify this at the time and explore it.*

*I have enjoyed exploring the IPA methodology and analysing the interview data. It demonstrates the complexities of the home setting with regard to delivering appropriate healthcare. In my experience as a dietitian, healthcare professionals tend to focus on following a protocol and physical outcomes when it comes to working with community patients. The impact of psychosocial factors is often overlooked, yet they have an impact upon a person's nutritional status. For example, family carers may experience grief at the loss in part of their family member as mental capacity deteriorates. It should be considered what stage in the process of grief the carer is, as this will certainly affect whether they feel ready to implement any recommendations to care provision. The family carers involved*

*in the study described in Chapter 4 were in different stages of a grief, and this did influence how they were providing care to the person with dementia and how receptive they were to change. Blandin and Pepin (2017) have recognised this, and proposed a model aimed at dementia caregivers who experience pre-death grief. It outlines three stages; acknowledging loss of aspects of the person with dementia, tolerating difficult feelings which occur in response to symptoms, and adaptation to being in a relationship with a person who is changing dramatically and becoming substantially different to how they once were.*

*I feel that after conducting these studies my own clinical practice has improved. Most importantly, I will always consider the psychosocial factors of a patient and their carer in my future work, and take the time to incorporate these factors into treatments and advice I provide.*

## 5.7. Chapter summary

This study provides a view of the experiences of some healthcare professionals and homecare workers regarding the nutritional care of people living with at home with dementia. The findings indicate that this group of healthcare professionals and homecare workers admit that they all have a responsibility to ensure that the people with dementia, who they provide care for, are adequately nourished. However, they acknowledge that there are barriers preventing them from doing this properly. These include not having enough time, and knowledge limitations. They were keen to understand more about what they could do to help prevent the risk of malnutrition.

The homecare workers in particular felt that they played a key role in supplying, cooking, and feeding some clients who have dementia, but there was uncertainty around these tasks. The scoping review (Chapter 3), identified that there are no

intervention studies that have focused on upskilling homecare workers to provide adequate nutritional care. Family carers indicate that they want increased support regarding nutritional care and dementia from healthcare professionals and homecare workers (Chapter 4). However, healthcare professionals and homecare workers feel that they needed more knowledge in this area (Chapter 5). These findings assisted in deciding upon the mechanism (training aid) and audience (homecare workers) of an intervention aimed at improving nutritional care in people living with dementia at home. The development of a series of podcasts containing information about how to provide adequate nutritional care to someone living at home with dementia is described in Chapter 6.



## **6. Developing and testing an intervention to improve the nutritional care of people living at home with dementia**

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This Chapter provides the detail of intervention development, and the design, methods and results of a study to test whether a nutrition and dementia podcast for training homecare workers is feasible. The data collected as part of this study, will inform future intervention development, and add to the existing body of evidence regarding interventions that can improve the nutritional care for those living at home with dementia. It will also identify whether this method of training is suitable for homecare workers, and offers potential for communicating further topics relevant to their role.

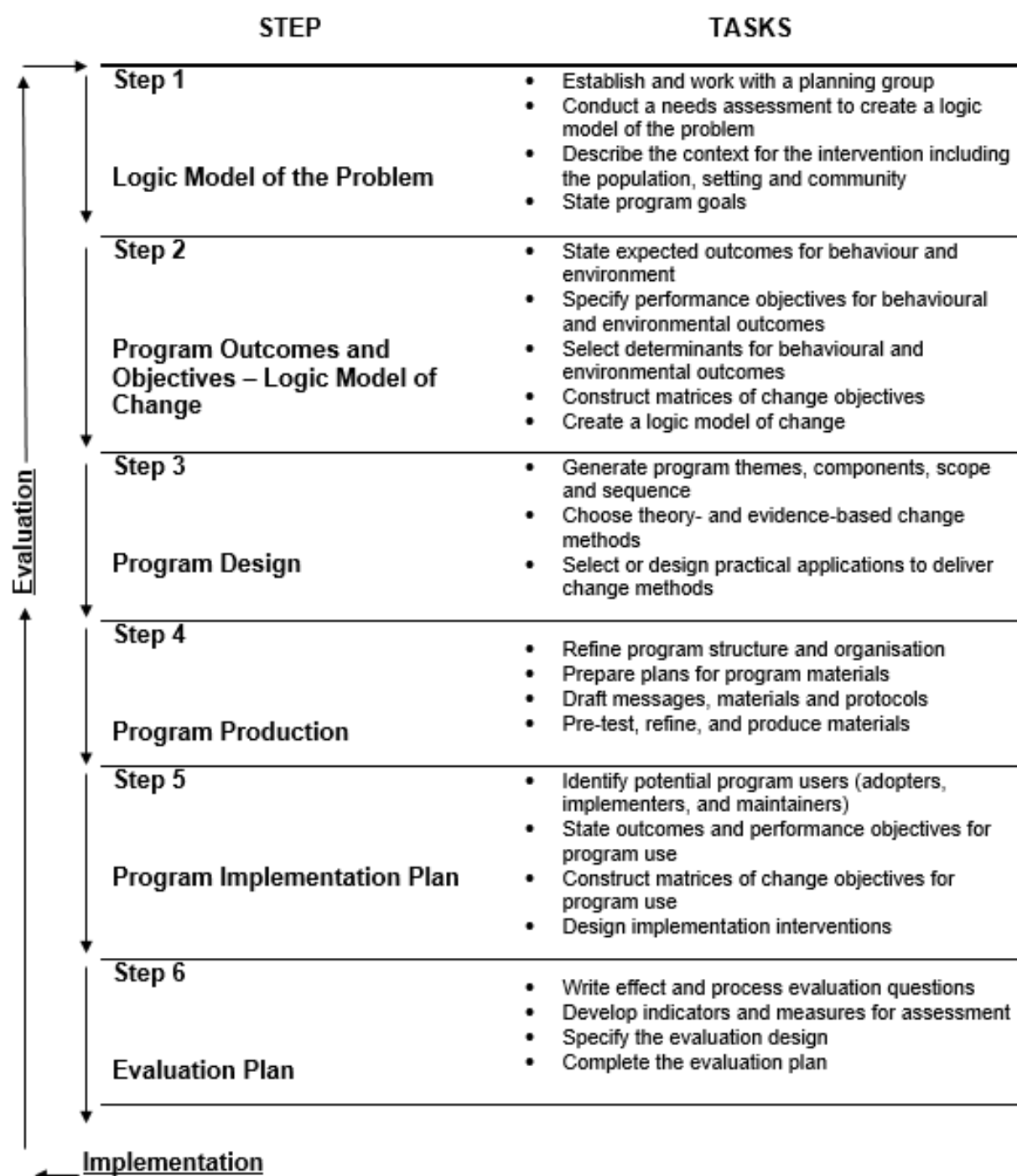
### **6.1. Intervention Development**

The MRC complex intervention framework described in Section 2.2 guided the development of an intervention to improve the nutritional care of people living at home with dementia. The intervention, a podcast, was designed for use with homecare workers with the aim of improving knowledge of nutrition and dementia so that they could provide improved nutritional care to clients. The outcomes of the scoping review (Chapter 3) and qualitative studies (Chapters 4 and 5) provided important data to assist in the selection of the recipients (homecare workers), the method of delivery (podcast), and content. Literature was reviewed to examine current practice and context, particularly regarding training methods and theories of learning (Bleijenberg *et al.*, 2018). Using an established approach (intervention mapping) to guide the development ensured that individual components and mechanisms of the intervention could be understood.

Intervention mapping is a six-step framework that enables the developer to move back and forth between steps, gaining perspective and information that builds on

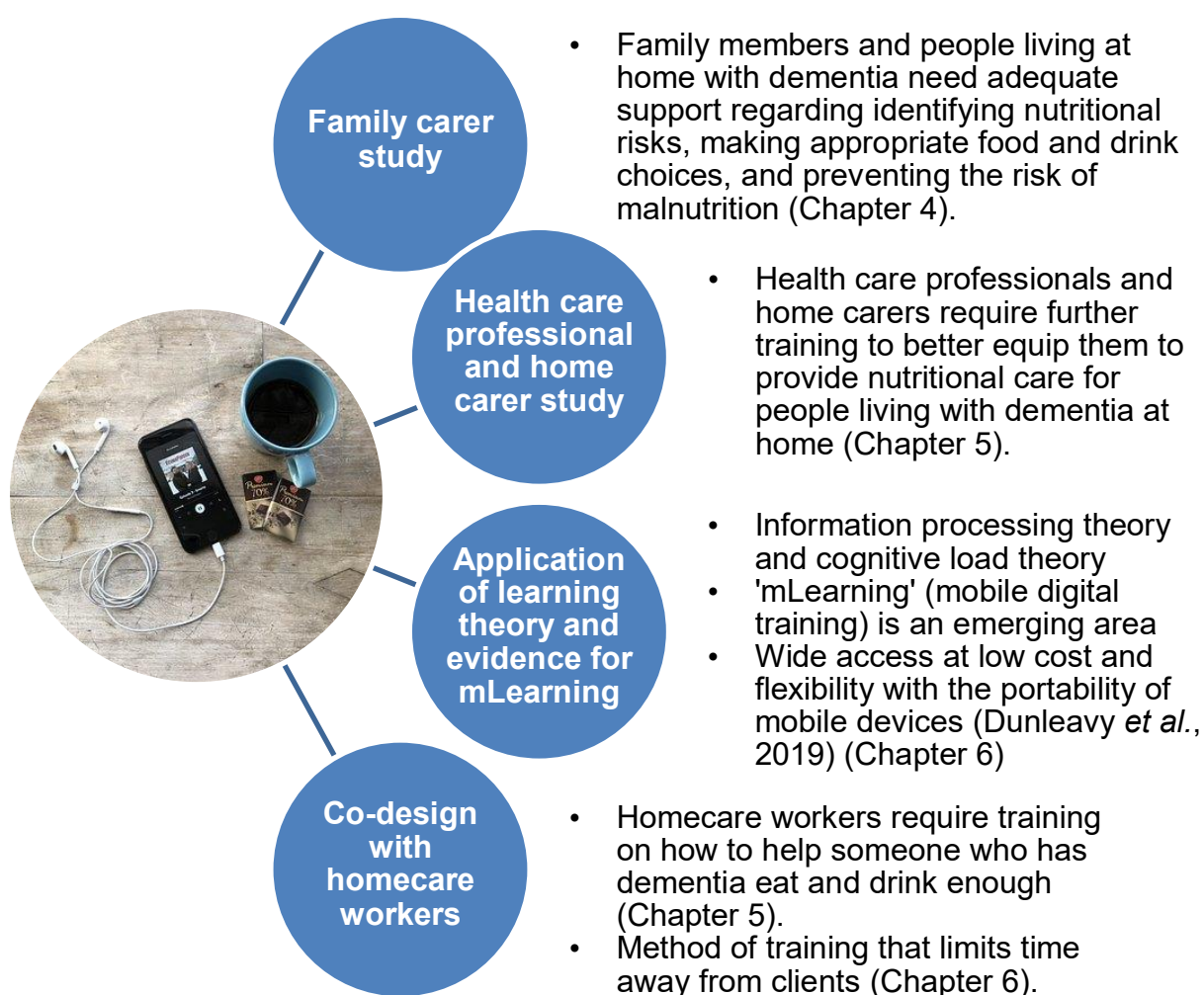
empirical and theoretical foundations (Bartholomew Eldredge, 2016), shown in *Figure 9*. The development of the intervention in this thesis is focussed on the first four steps of this approach, which align with the development and feasibility or piloting components of the MRC complex intervention framework. Future work would develop an implementation plan for embedding the intervention into practice, and establish an appropriate evaluation plan.

Figure 9 – Six-step intervention mapping approach (adapted from Bartholomew Eldredge (2016))



When developing an intervention, it is important to include existing literature and established theory, as well as the views of stakeholders who will be using the intervention. Figure 10 shows how the outcomes from my previous studies, and a workshop and further literature reviews (described in this Chapter), together provided the rationale for a training tool on nutrition and dementia aimed at homecare workers.

Figure 10 – Outcomes from previous studies, workshops and literature searches

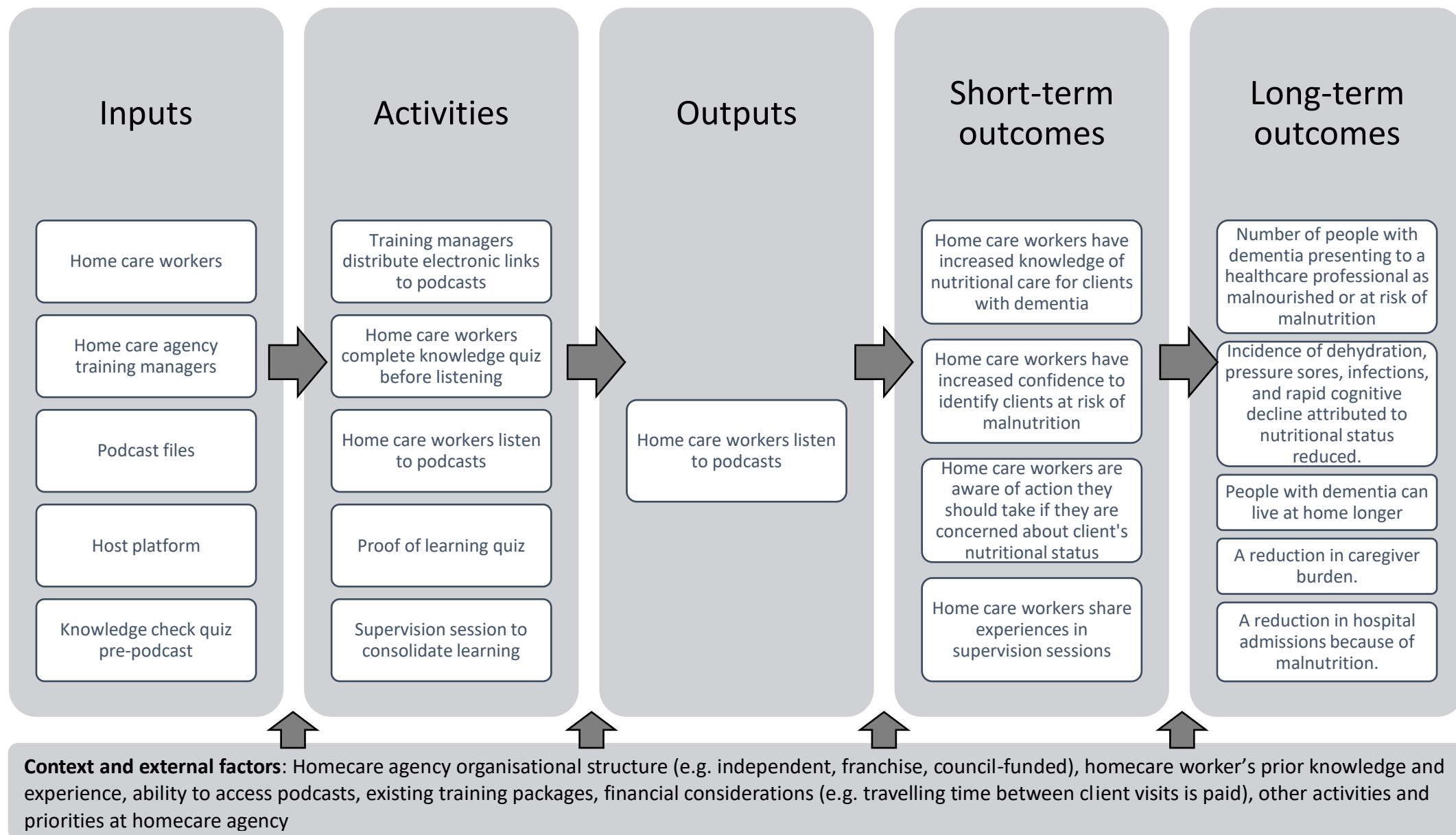


A method that could deliver the information, but not require homecare workers to take time away from client visits was needed. Podcasts were chosen for this purpose, as they are an emerging method of accessing information and content. Podcasts are digital audio files, which are accessed through a number of media

devices such as laptops, tablets and smartphones, and can be listened to whilst undertaking other activities without looking at a screen (MacKenzie, 2019). Homecare workers have a mobile working pattern that involves time spent driving between clients' homes'; therefore, exploring whether podcasts are feasible as a method of training on nutrition and dementia is worth investigating. At the time of this research, to the best of my knowledge, there has been no published research that has trialled podcasts with homecare workers.

The outcomes from my previous studies, homecare worker workshops and literature searches enabled the formulation of a logic model to define the processes that underpin an intervention aimed at homecare workers (Figure 11). This figure shows the potential short and long-term outcomes of using podcasts to deliver training to homecare workers about nutritional care and dementia.

Figure 11 - Logic model for podcast intervention



#### 6.1.1. Podcasts

It is estimated that 7.1 million people in the UK listen to podcasts each week (Ofcom, 2019). In 2018, a survey conducted with a sample of 2214 podcast listeners in the UK found that more listeners were male (63%), aged between 25 and 34 years old (21%), and preferred to listen to podcasts on a smartphone (67%) (Backtracks, 2018). These data provide an indication of the typical user profile of podcasts', however, it cannot be generalised due to the small sample size relative to the total number of podcast listeners in the UK, and response bias (participants self-reported seven day's podcast use). These data do indicate that most people tend to listen to podcasts using a mobile phone. For the purposes of this thesis, podcasts will be considered within the broader category of 'mLearning' (mobile digital learning).

Educational podcasts in particular are growing in popularity (Cho, Cosimini and Espinoza, 2017), and research has explored the benefits of podcasts for student education (Alarcón, Blanca and Bendayan, 2017; Zanussi *et al.*, 2012). Participants described podcasts as easy to use and engaging, enabling broad exposure to content and targeted learning. They reported often listening to podcasts while doing other activities and, being motivated by an ever-present desire to use their time productively. However, this practice can lead to challenges retaining and applying content learnt from podcasts to clinical work (Riddell *et al.*, 2020). A systematic review and meta-analysis identified that online training in the form of webinars, interactive online modules and podcasts have also become increasingly popular among healthcare professionals as a tool to help advance knowledge (Richmond *et al.*, 2017). However, there is a paucity of evidence demonstrating the efficacy of podcasts as a training medium, or best practices in producing podcasts. More rigorous studies evaluating efficacy,

changes in listener behaviour, and the subsequent influence upon patient-related outcomes need to be performed in order to substantiate the value of podcasts amongst health care professionals (Cho, Cosimini and Espinoza, 2017).

Podcasts could be a novel approach to training that also aligns with a constructivist learning theory, promoting decision-making skills which are important in a homecare worker's role (Kala, Isaramalai and Pohthong, 2010). Despite this, there is a lack of consistency in studies examining the knowledge transfer process, and the underpinning learning theories (Thomas *et al.*, 2014).

The physical structure of the brain and its processes provides a neuroscientific rationale for constructivist cognition, implying that pedagogical methods such as active learning (where students engage with taught material through activities such as role play) should be encouraged (Dennick, 2016). Podcasts could enable homecare workers to put into practice the taught material soon after listening, therefore, subscribing to an active learning approach. Podcasts could be a useful addition to an active learning toolkit, but would need to be used in combination with other learning methods to promote successful knowledge transfer (Popova and Edirisingha, 2010).

#### 6.1.2. Learning theories

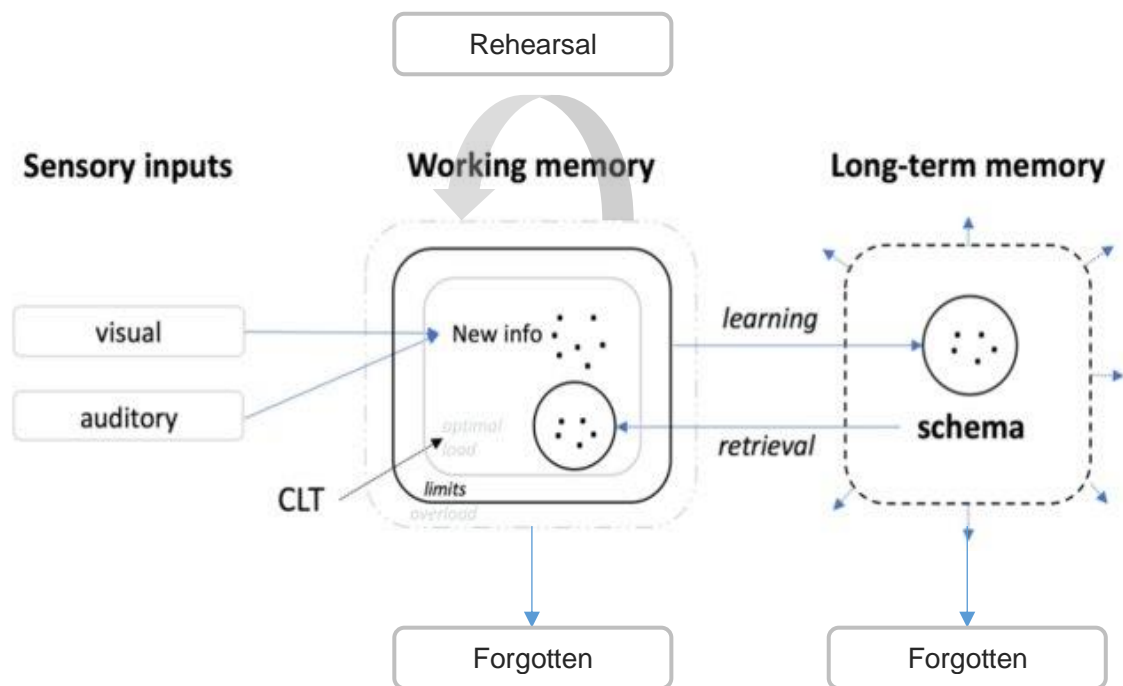
Three learning theories have influenced my thought process when developing the intervention for homecare workers. These include: information processing theory, cognitive load theory, and information control theory.



### Information processing theory

According to information processing theory, during learning, information is held in the working memory until it has been processed sufficiently to pass into the long-term memory (*Figure 12*) (Orru and Longo, 2019). Rehearsal of information ensures that information can be combined with experiences and contexts to form schemas that reside within the long-term memory. The working memory's capacity is believed to be limited, and if too much information is presented at once, or through too many sensory channels, cognitive load theory states that much of the information may be lost (Leppink, 2017). An auditory-only input (such as a podcast) appears to be an effective way to communicate a small amount of verbal information for a short period of time, based on the information processing and cognitive load theories (Mousavi, Low and Sweller, 1995; Van Merriënboer and Sweller, 2010). Furthermore, having the opportunity to rehearse new information soon after listening (e.g. when a homecare worker is visiting a client after listening to a podcast in the car beforehand), enables context and experience to promote the formation of schemas for long-term memory storage.

Figure 12 - Information Processing and the role of Cognitive Load Theory (adapted from (Mind Tools, 2020; Orru and Longo, 2019))



CLT: Cognitive Load Theory

### Cognitive Load Theory

Training methods that combine video and audio narration (dual-modality) have been found to be more effective for undergraduate student learning than methods that use video or audio in isolation (single modality), because they provide authentic, meaningful and real-life situation contexts (Sulaiman *et al.*, 2017).

However, it has been suggested that humans have a processing limit of combined visual and audio material, resulting in cognitive overload in which the learner's intended cognitive processing exceeds the learner's available cognitive capacity (Mayer and Moreno, 2003). The theory states that people have limited cognitive abilities to process new information, resulting in cognitive overload. It has been suggested that older individuals are more likely to be affected by small changes in cognitive load than younger individuals (Savage, Spano and Bowers, 2019).

This should be considered when developing training for homecare workers, as the average employee age is 43 years old, and a fifth over 55 years old (Griffiths *et al.*, 2019). Single modality learning methods such as audio-only podcasts, require less initial processing effort; therefore, may increase the potential for effective learning.

### Information control theory

Information control theory states that allowing an individual to have control over the pace and mode of information delivery, increases the motivation to learn, and improves understanding (Eveland and Dunwoody, 2016).

Attention is a complex process that interacts with perception, memory, and conscious experience. It has voluntary and involuntary components and can be influenced by factors such as interest, motivation, and self-regulation (Lodge and Harrison, 2019). It has been suggested that the attention of an adult learner starts to reduce after 20 minutes, due to the limits of the working memory and distractions (Chika and Ombajo, 2017; Cooper and Richards, 2017).

#### 6.1.3. Design, structure and content of podcasts

The design of the podcasts was underpinned by the cognitive load theory in multimedia learning, which has been used in previous mLearning trials (Bajpai *et al.*, 2019; Mayer and Moreno, 2003). Podcasts allow the user to control when, where and how they listen to information, with the option of listening as many times as they desire. This increases elaboration and information control, whilst reducing cognitive load, leading to the increased likelihood of behaviour change (Ko, Turner-McGrievy and Campbell, 2014). In terms of my proposed intervention, this would be demonstrated by homecare workers accessing and listening to the podcasts, and after doing so, feeling more equipped to identify

clients with dementia who are at risk of malnutrition, and feeling more confident in taking appropriate remedial action. Cognitive load theory, information control theory and information processing theory guided the formatting of each episode and lent support to the use of podcasting over other delivery methods.

There is little published documentation on the average travel time for homecare workers in the UK, but feedback from a meeting with a training manager at a local homecare agency indicated that homecare workers spend up to 15 minutes in the car driving between client's homes. This will vary depending on the geographical location of the agency, and whether it is rural or urban. The training manager also gave opinions on the optimal length of the podcasts being no more than 30 minutes long. This influenced the decision to produce three separate podcasts, each of 30 minutes duration. Due to the flexibility of the podcast format, they could be paused and replayed, therefore, homecare workers would be likely to listen in 10 or 15 minute segments, if they were listening in the car, or walking, in between client visits. The podcasts developed took a conversational interview format which is a popular approach and has been reported as desirable when developing podcasts for medical education (Cho, Cosimini and Espinoza, 2017). The training manager requested information from a range of health experts in areas relating to the nutritional care of people living at home with dementia.

The content of the podcasts was co-designed with the training manager during a second meeting (Appendix O). Current evidence-based guidance regarding nutrition and dementia was also incorporated into the podcast content (Volkert *et al.*, 2015). *Table 8* shows the main topics and rationale for inclusion. The training manager felt that different guests on the podcast would provide variety and keep homecare workers interested. The guest speakers interviewed as part of the

podcasts were part of my professional network. Outline scripts (Appendix P) were provided to the podcast guests, however, there was no requirement to follow these exclusively.

**Table 8 - Topics included in podcasts and rationale**

<b>Podcast Episode</b>	<b>Topic</b>	<b>Rationale</b>
<b>Episode 1</b>	Malnutrition	<ul style="list-style-type: none"> <li>• People with a diagnosis of dementia are at higher risk of malnutrition.</li> <li>• It is important for homecare workers to understand the definition and consequences of malnutrition in order to prevent it in clients.</li> </ul>
	How do symptoms of dementia affect eating and drinking?	<ul style="list-style-type: none"> <li>• People experience different symptoms throughout the course of dementia, and many of these will impact upon nutritional status.</li> <li>• Important for homecare workers to be able to identify symptoms in clients that may impact ability to eat and drink.</li> </ul>
	Mouth care	<ul style="list-style-type: none"> <li>• If clients are eating or drinking sugary foods, and/or taking oral nutritional supplements they will require regular tooth brushing.</li> <li>• This will reduce risk of cavities and poor oral hygiene which could lead to dentist visits and distress.</li> </ul>
<b>Episode 2</b>	Important nutrients	<ul style="list-style-type: none"> <li>• The recommended intakes of some nutrients for older adults, and people with dementia will change to reflect additional nutritional requirements.</li> <li>• Many clients the homecare workers care for are likely to be deficient in some nutrients due to poor oral intake. For some who are house-bound, they may also be deficient in Vitamin D.</li> </ul>
	How to identify an issue	<ul style="list-style-type: none"> <li>• How to assess whether a client is at risk of malnutrition. Weight loss, but also other signs such as loose clothes, jewellery or dentures.</li> <li>• Some behaviours that may indicate an issue, such as hiding food, increased activity (e.g. pacing). These may lead to reduced oral intake and increased nutritional requirements.</li> <li>• Guidance for homecare workers regarding what to do next if they believe a client is at risk of malnutrition.</li> </ul>
	Dehydration	<ul style="list-style-type: none"> <li>• Reduced fluid intake is common in people with dementia, particularly those living at home.</li> <li>• This may be due to clients being reluctant to visit the toilet, associated with a fear of falls.</li> <li>• Dehydration will impair cognition further, and may lead to infections requiring hospitalisation.</li> </ul>
	Swallowing issues	<ul style="list-style-type: none"> <li>• People with dementia may experience swallowing issues in the moderate to later stages of the disease.</li> <li>• It is important for homecare workers to understand how to identify the signs of a swallowing issue with clients and what to do next.</li> <li>• Using straws may be dangerous for someone with a swallow impairment.</li> </ul>
<b>Episode 3</b>	Environmental adaptations	<ul style="list-style-type: none"> <li>• The mealtime environment can affect how well someone with dementia eats and drinks. Eating with others, adaptive crockery and cutlery, and involvement in food preparation may help.</li> <li>• Homecare workers can implement changes to the mealtime environment of their clients with dementia.</li> </ul>
	Food enrichment	<ul style="list-style-type: none"> <li>• For someone at risk of malnutrition, maximising energy and protein intakes can reduce rapid weight loss. If appetite loss is also an issue, enriching foods and drinks can help.</li> <li>• Homecare workers can support with adding energy-dense foods (e.g. full fat milk and cheese) to prepared meals, and purchasing full-fat options when food shopping for clients.</li> </ul>
	Texture modified foods and drinks	<ul style="list-style-type: none"> <li>• Someone living with dementia may have swallowing issues and require a texture modified diet and/or thickened fluids.</li> <li>• It is important for homecare workers to understand some of the challenges associated with these diets, e.g. once heated puree meals can be very hot but cool very quickly making them unpalatable.</li> </ul>
	Oral nutritional supplements	<ul style="list-style-type: none"> <li>• Some people living at home with dementia will have been prescribed ONS. The effectiveness of ONS will depend on client flavour preferences and presentation of ONS (which can be adapted – e.g. added to puddings).</li> <li>• It is important for homecare workers to understand the differences between ONS, and how to promote intake.</li> </ul>

The prototype podcasts, titled 'Teatime Talks', accompany the electronic version of this thesis (Appendix Q). The title of the podcasts represent the study title (Training for **EAT**ing and drinking In De**ME**ntia: 'TEATIME'), the medium (audio: 'Talks'), and the duration is suitable to listen whilst having a tea break.

## 6.2. Feasibility study

Feasibility studies can identify potential issues across a range of areas in an intervention prior to piloting. These may include how participants react to the intervention (acceptability), or how an intervention can be delivered with resource or time constraints (practicality) (Bowen *et al.*, 2009). This study focused on whether podcasts are acceptable to homecare workers, and the feasibility of carrying out further intervention trials in this setting. *Table 9* outlines the questions this study sought to answer, including the proposed method of assessment and successful outcome statement.

**Table 9 – Objective questions and type, assessment methods and outcome statements (feasibility study)**

#	Question	Acceptability Feasibility or Development ?	Assessment method used	Successful outcome statement
<b>Quantitative objectives</b>				
1	Can enough participants be recruited to the trial?	Feasibility	Number of homecare workers who attend focus groups	At least 12 homecare workers in total attend focus groups.
2	How many homecare workers require additional technical support accessing the podcasts?	Feasibility	Number of homecare workers who contact project lead for support during trial	No homecare workers required technical support
3	How many homecare workers drop out during the trial?	Feasibility	Number of homecare workers who received link to podcasts vs. those who volunteer to attend a focus group	No homecare workers dropout of study
4	How long does it take to develop the podcasts?	Development	Number of hours required to record audio and produce podcasts	An estimated reasonable time of 8 hours per podcast
<b>Qualitative objectives</b>				
5	Do homecare workers accept the podcasts as a suitable training tool?	Acceptability	Self-reported during focus groups	Homecare workers accept the podcasts as a training tool
6	What did stakeholders (homecare workers and managers) think about the training?	Acceptability	Self-reported during focus groups	Positive feedback reported from homecare workers and managers
7	Is the content acceptable to all stakeholders?	Acceptability	Self-reported during focus groups	Homecare workers feel content is acceptable
8	Is the duration of the podcasts acceptable to homecare workers?	Acceptability	Self-reported during focus groups	Homecare workers feel duration of podcasts is acceptable
9	Is the sequencing of podcasts acceptable to homecare workers?	Acceptability	Self-reported during focus groups	Homecare workers feel sequencing of podcasts is acceptable
10	Can the podcasts be distributed to homecare workers as intended?	Feasibility	Self-reported during focus groups	Link to podcasts successfully received by homecare workers.
11	Do homecare workers access and listen to the podcasts?	Feasibility	Self-reported during focus groups Number of 'hits' on hosting platform	Home care workers access and listen to podcasts
12	Is the duration of the podcasts feasible to be listened to during a working day?	Feasibility	Self-reported during focus groups	Homecare workers report that duration of podcasts fits into working day
13	Is the duration of time provided to listen to podcasts before measurement of outcomes appropriate?	Feasibility	Self-reported during focus groups	Homecare workers report adequate time to listen prior to focus groups
14	How long does it take for homecare workers to listen to all of the podcasts?	Feasibility	Self-reported during focus groups	Homecare workers able to report a period of time they would need to complete this task
15	Does knowledge improve after listening to the podcasts?	Feasibility	Self-reported during focus groups Increase in knowledge demonstrated via before/after quiz	Self-report that they are doing things differently Quiz scores higher after listening to podcasts
16	What outcome measures should be used to evaluate the training tool?	Feasibility	Self-reported during focus groups	Future outcome measures discussed during focus group
17	Are participants willing to be randomised?	Feasibility	Self-reported during focus groups	Homecare workers are willing to be randomised in future trials



### 6.2.1. Normalisation process theory

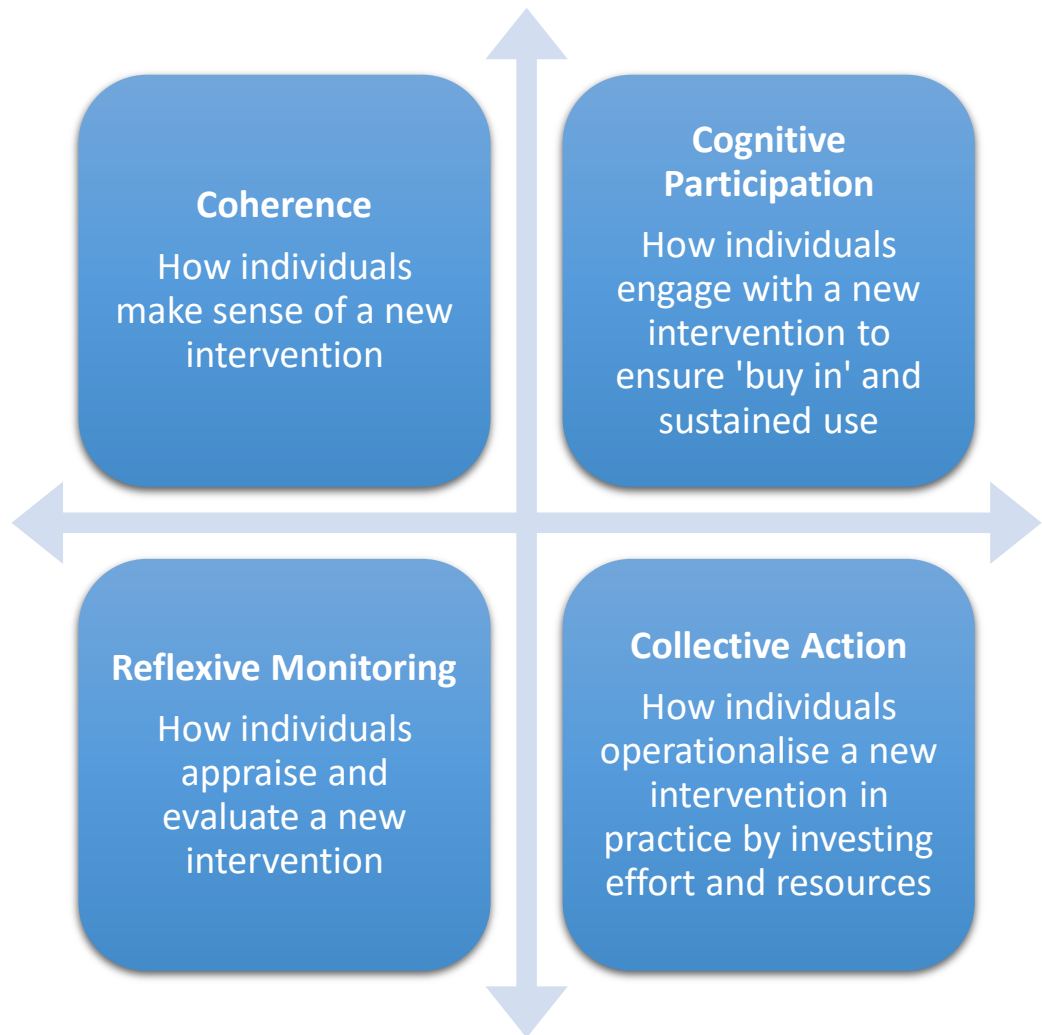
Normalisation Process Theory (NPT) allows issues to be explored and surfaced regarding the implementation, embedding and sustainability of new working practices, particularly for innovative healthcare interventions (McNaughton, Steven and Shucksmith, 2020). NPT focuses on what people do when presented with a new way of working, and the way they construct what they do as individuals and collectively as part of a socially organised group to work towards a specific outcome (May and Finch, 2009). It is important to understand the factors that promote or inhibit the implementation of a new health care intervention during feasibility trials to reduce the risk of unnecessary financial investment as discussed in Section 2.7. When new practices have been normalised by a healthcare professional and the group that they work within, they will become routine, and improve patient-related outcomes.

NPT can be used to design feasibility studies to aid intervention development and implementation (May *et al.*, 2018). It has synergy with the MRC complex intervention framework, as it acknowledges the multiple interactions that take place between professionals, patients, managers and others (Murray *et al.*, 2010).

NPT was an appropriate theory to guide the research design, analysis and reporting for the podcast feasibility trial, because it offered the opportunity to explore the social processes within a team of homecare workers, as they begin to embed an innovative health technology.

There are four main NPT theory core constructs (Figure 13).

Figure 13 - Normalisation Process Theory core constructs (adapted from May et al. (2015))



#### 6.2.2. Methods

In order to collect the information needed to assess acceptability and feasibility the study took a mixed-method approach. *Table 9* indicates the qualitative and quantitative elements. The two main tools used in this study were a focus group with homecare workers, and an online quiz to assess knowledge before and after listening to the podcast. Homecare workers from a single agency were approached and invited to take part in the study. This included two phases, downloading and listening to the podcasts, and completing the online quiz before

and afterwards, along with attendance at a focus group to discuss the podcasts specifically and their use as a training tool. See Appendix R for the study procedure, which specifies the homecare workers involvement throughout the study.

#### 6.2.2.1. Inclusion and exclusion criteria

Eligibility to participate is summarised in the following inclusion and exclusion criteria:

##### *Inclusion criteria*

- Employed as a homecare worker in Plymouth, Torbay or Exeter UK
- Works with people living at home (and/or family carers) with dementia or mild cognitive impairment.
- Willing to attend a 60-minute focus group held at the agency office.

##### *Exclusion criteria*

- Does not have access to a smartphone, laptop or music player capable of playing .mp3 audio files.

#### 6.2.2.2. Sample size

Sample sizes for qualitative research in feasibility studies are usually small, and can be typically between 5 and 20 participants (O’Cathain *et al.*, 2015). Faulkner (2003) found that only ten participants identified 80% of problems, and 20 participants 95%, when testing an intervention using web-technology for usability, illustrating that only a small sample size was necessary for this part of the study. Feasibility studies involving a qualitative element have aimed to recruit 12-15 participants (Julious, 2005; Watkins *et al.*, 2019). Therefore, the present study aimed to recruit a minimum of 12 and maximum of 16 participants. Recommendations for focus group size advise no more than eight participants

per group to enable a rich discussion but also to manage it appropriately (Braun and Clarke, 2013). My aim was to facilitate two separate focus groups depending on the number of participants recruited to the trial.

#### 6.2.2.3. Recruitment

A group of homecare workers were selected by the training manager and invited to participate by the training manager at the care agency via email (Appendix S).

The participant information sheet (Appendix B) was included in the email. Paper copies were available from the training manager if requested. Links to the podcasts, a podcast user guide (Appendix T), and pre-test quiz to check knowledge of nutrition and dementia were also included in the email.

The podcasts were hosted on a suitable platform (<https://libsyn.com/>) which was easily accessed by participants, from a range of devices. Only participants with a unique URL were able to access the podcasts, and they were removed once the trial was complete. In the event that non-participants accessed the link, a copyright disclaimer was added. The podcasts did not contain any confidential or sensitive information.

Potential participants were told that if they were interested in taking part in the study, they would be invited to attend a focus group at least four weeks following enrolment. This ensured that participants had adequate time to complete the pre-quiz and listen to the three podcasts. Focus group arrangements were coordinated with the training manager of the homecare agency, and in the event of more than eight participants wishing to take part in the trial, further focus group dates could be scheduled. Preference was, therefore, allocated on a 'first-come-first-served' basis, until an adequate number of participants were recruited

(minimum of six per focus group, maximum of eight). The researcher maintained a log of participants who attended the focus groups (Appendix U).

Financial incentives for participants in adult social care studies have been shown to improve recruitment (Cyhlarova, Clark and Knapp, 2020). In order to acknowledge the contribution of the homecare workers who participated in the focus group, a £10 Amazon gift voucher was given.

#### 6.2.2.4. Ethical considerations

Ethical approval for the study was given by the Faculty of Health & Human Sciences ethics committee (Appendix V). The ethical process described in Section 2.7 was followed. All participants had to provide signed informed consent.

#### 6.2.2.5. Online quiz

Participants were asked to complete a short online quiz (created using Jisc; <https://www.jisc.ac.uk/online-surveys>) to test knowledge (Appendix W). The quiz questions were multiple choice, some with one correct answer and others with more than one correct answer. A link to the quiz for the pre-test was sent to participants with the links to access the podcasts. The post-test was completed by participants during the focus group on an electronic tablet.

Results from the pre and post-test quizzes were downloaded from Jisc and analysed using SPSS statistical software (IBM Corp, 2016). The median and range was calculated for the two sets of quiz results, and the difference checked using a Wilcoxon signed rank test. A Spearman's correlation was used to identify whether time-spent working as a homecare worker was associated with pre and post-test quiz scores.

#### 6.2.2.6. Focus Group

The focus group schedule (Appendix X), was designed using prompts from the NPT constructs presented in Figure 13. This allowed a focus on how the introduction of the podcasts was received by homecare workers, and how they individually and collectively made sense of them (May *et al.*, 2015).

I transcribed the focus group recording and used NVivo 12 (QSR International, 2017b) to organise the analysis.

#### 6.2.2.7. Stakeholder Feedback

A link to the podcasts were emailed to ten stakeholders (Appendix Y), who were invited to listen and provide feedback against six questions that aligned with the feasibility study objectives (*Table 9*). The stakeholder group consisted of the following healthcare professionals and research colleagues, some whom feature in the podcasts:

- Ward doctor
- Food and Nutrition advisor
- GP
- Care of the Elderly Ward Sister
- Speech and Language therapist
- Occupational Therapist
- Care of the Elderly Consultant
- Community Dietitian
- Group Project Manager/PenARC Operations Deputy Director
- Professor of Dietetics

The responses were analysed using NVivo 12 (QSR International, 2017b) using thematic analysis and the NPT constructs, and coded (e.g. EM01, EM02 etc.) to provide anonymity. Stakeholder feedback was analysed and summarised separately to the focus group transcript.

#### 6.2.2.8. Focus group and stakeholder analysis

The focus group transcript and stakeholder feedback were analysed using a hybrid process of inductive and deductive thematic analysis (Braun and Clarke, 2006). This process involved inductive coding (from participant and stakeholder contributions from the focus group and emails) followed by deductive coding (derived from the NPT constructs) (Fereday and Muir-Cochrane, 2016). Generic, descriptive codes from the focus group and stakeholder feedback accounts were added to a coding manual, and then related to the most relevant normalisation process theory core construct and components (May *et al.*, 2015). Through this process, it was possible to identify how themes were generated from the focus group findings and stakeholder feedback to uncover meanings in relation to whether podcasts are acceptable to homecare workers, and the feasibility of carrying out further intervention trials in this setting.

#### 6.2.3. Results and findings

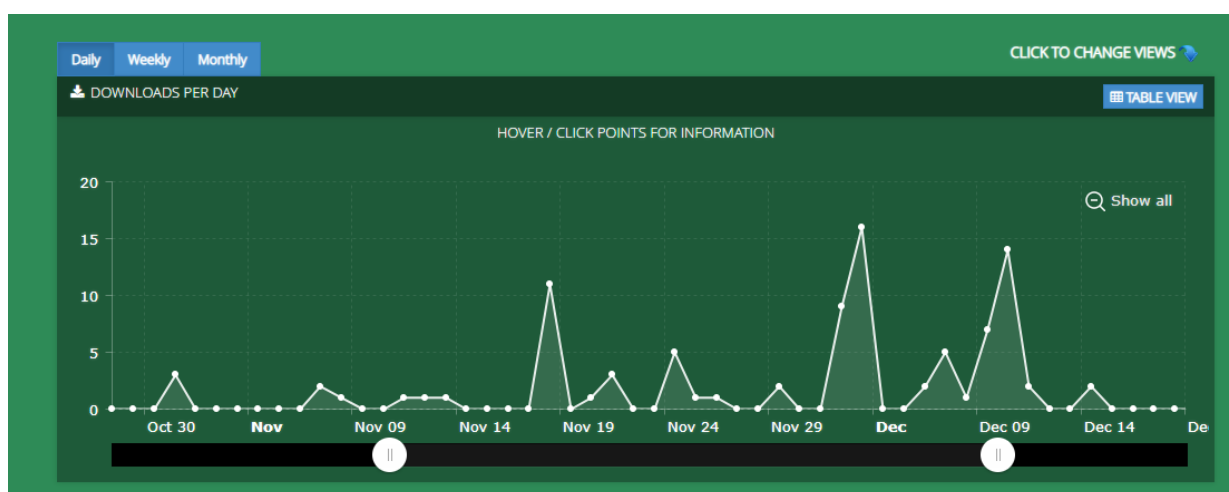
The pre and post-test quiz was completed by six homecare workers (1 Male and 5 Females) from one homecare agency. Time spent as a homecare worker, on average, was 13.4 months (range = 6 to 18 months).

The post-test quiz was completed during the focus group held on 10<sup>th</sup> December 2019. The pre-quiz was attempted prior to the focus group, between 31<sup>st</sup> October and 6<sup>th</sup> December 2019. One homecare worker attempted the pre-test quiz twice,

on different dates, therefore, only the first attempt was included within the analysis.

Figure 14 shows the number of times the podcasts were downloaded over the trial duration. Although there was limited usage data available from the host platform (Libsyn), the data indicates that participants could have accessed the podcasts multiple times.

Figure 14 - Downloads per day of podcasts from Libsyn hosting platform



The interviews with guests took approximately 8 hours to record, with an estimated 16 hours spent editing podcasts. Cost of production included fuel costs when travelling to interviews (estimated £20), and subscription to Libsyn (£30).

#### 6.2.3.1. Knowledge acquisition

Home care workers' answers to each question for pre and post-test attempts, were rated '1' if answered correctly, or '0' if answered incorrectly. Total scores per participant for pre and post-test attempt were calculated. The median score for the quiz taken before listening to the podcasts was 5.5 (range = 5 to 7), and after listening was 7.5 (range = 6 to 9). There was a statistically significant difference ( $p=0.023$ ) between the test scores, indicating that participants knowledge did improve.



To test the hypothesis that the longer the individual had worked as a homecare worker the higher their score would be, Spearman's correlations between years of experience and test score were assessed: pre-test  $r=-0.48$ ,  $p=0.34$ ; post-test  $r=-0.59$ ,  $p=0.22$ . There was no significant correlation and no evidence that length on time working in the role had any relationship to score.

#### 6.2.3.2. Focus Group

The focus group was attended by all six homecare workers who enrolled for the study and two members of the research team (Louise Mole and Mary Hickson).

Eight themes were identified that represented the views of the participants (*Figure 15*). These were mapped against the four constructs; Coherence ('initial thoughts' and 'taking part in a trial'), cognitive participation ('usability' and 'why we liked it'), reflexive monitoring ('what we do', 'format and presentation', and 'what could be better'), and collective action ('what we learnt'). The focus group findings are presented within the four NPT construct headings.

Figure 15 - NPT constructs aligned with themes

<b>Coherence</b>	How home care workers make sense of the podcasts  Themes: 'Initial thoughts' and 'Taking part in a trial'
<b>Cognitive participation</b>	How home care workers engage with podcasts to ensure 'buy-in' and sustained use  Themes: 'Usability' and 'Why we liked it'
<b>Collective action</b>	How home care workers operationalise podcasts in practice  Theme: 'What we learnt'
<b>Reflexive monitoring</b>	How home care workers appraise and evaluate podcasts  Themes: 'Format and presentation', 'What could be better', and 'What we do'

#### 6.2.3.2.1. Coherence

This construct explores how homecare workers made sense of being presented with the podcasts as a new way of learning information that is needed for their job role. It includes how homecare workers differentiated the podcasts from traditional methods of training, and how they understood the value, benefits and importance of doing things differently. The themes from the focus group which are aligned with this construct, provide the initial thoughts about a new way of learning, and their thoughts about taking part in a trial.

Some homecare workers were familiar with the concept of podcasts, and had listened to them previously when driving and at home whilst doing other tasks such as cooking dinner.

'I listen to podcasts while I'm driving anyway, they generally tend to be based around diet and nutrition and lots of different specialities, working with Alzheimer's, dementia, Parkinson's and lots of dietary, so diabetes, heart disease etc. So it was a continuation for me.' (HCW03)

I have listened to them, so I thought actually it's quite easy because you can put it on. I put it on while I was cooking dinner for the kids and stuff like that, and then...yea...it's not something that you have to sit and do, you can fit it in.' (HCW01)

Others were new to the concept of podcasts, and were surprised by their transferability between devices.

'So it went through the earphones, it went through the car, it suddenly went everywhere on the laptop and I thought 'ahhhh that's what they do then'.' (HCW06)

There was agreement amongst the homecare workers, that using podcasts to learn about nutritional care for people living at home with dementia was much easier than other training methods. Training is typically provided in their break-time, and they are required to attend in person at the care agency office.

'It's when they can fit it in, which is why the podcasts are so good because you can just fit it in.' (HCW02)

'It's just easier.' (HCW04)

'More versatile than anything we have done yet' (HCW06)

One factor that homecare workers were in agreement with, was that they had received very little, or no nutritional training as part of their role.

'I haven't had no training on nutrition.' (HCW02)

'Personally none.' (HCW06)

'No' (HCW05)

With regard to being involved with the podcast trial, some homecare workers were honest about their initial reluctance to get involved.

‘Oh god more work (laughter)...I’m sorry that was it’ (HCW06)

‘I just thought cheers! (laughter), what have you signed me up for (laughter).’ (HCW01)

However, they found the trial process straightforward to follow. The incentive to take part was particularly well received, and they thought it would support recruitment for future trials involving homecare workers as participants.

‘Yea the email we got was like 1,2,3’ (HCW02)

‘Yea straight forward’ (HCW05)

‘It is, a bit of an incentive you are like yea – you get a voucher out of it!’ (HCW02)

#### 6.2.3.2.2. Cognitive participation

This construct explores the work that homecare workers do to build and sustain a community of practice around the podcasts as a learning tool. It also identifies how homecare workers organise themselves to collectively contribute towards a new working practice, and how they attribute value to participating. The focus group themes (*‘usability’ and ‘why we liked it’*) explore why the participants liked the podcast concept, and practical usability.

There was agreement regarding the benefits associated with the portability of the podcasts, and that they could be played on a range of devices including in the car whilst driving between client houses.

‘Yea because of the car, we get like average is about 15 minutes, 10 minutes’ drive time, so you can listen to it while you’re driving and that’s handy.’ (HCW04)

‘It was good, because you can play it. I only listened through my phone because I don’t have anything fancy in my car. You could play it and still go on your phone which was really good.’ (HCW01)

One of the benefits mentioned was that the podcast could be listened to whilst doing other activities such as cooking or driving. The homecare workers did not feel that this was detrimental to their learning experience, particularly because of the variety of topics and speakers involved.

‘Because I had a gap, so I thought right I will listen to one of them because I had a really long gap, so I stuck it on, and it was only on the internet and I thought I won’t be able to go on What’s app as well, but I thought I would try and it worked, so it was really good! You don’t have to just sit.’ (HCW01)

‘It’s just there in the background isn’t it.’ (HCW02)

‘...I was cooking dinner and everything and the kids were going ‘whats that noise?’ it was on, but I could do other things as well.’ (HCW01)

‘...it was because it was short, it wasn’t half an hour of one person, there was different topics. I think it keeps you interested more, so you’re not like ‘ah its taking ages.’ (HCW04)

The ability to be able to listen again to the podcasts when required, was something that was of benefit.

‘And you can also go back over, so if you thought actually I need to listen to that again, you can just go back over it.’ (HCW03)

As was the ease of playing the podcasts. No homecare worker reported technical difficulties; however, the email containing the links had to be re-located when homecare workers wished to listen.

‘I downloaded one, but then you didn’t need to you could just play it.’ (HCW05)

‘Yea I just played it through the phone, yea.’ (HCW04)

'I listened just through the streamer, which is alright...as long as you keep the email but when you got a load of emails and you have to go back to find it.' (HCW03)

Overall, the homecare workers collectively agreed that podcasts used for learning showed promise.

'I think it's perfect for us as carers.' (HCW04)

#### 6.2.3.2.3. Collective action

This construct explains how homecare workers operationalise the podcasts as a new learning tool. The focus group theme aligned with this construct (*'what we learnt'*) explores the information that homecare workers were able to recall from the podcast, and how they would change their approach to providing nutritional care after listening.

Understanding that a client with dementia may experience taste changes, which can affect the amount that they eat and drink, was one area that homecare workers put into practice after listening to the podcasts.

'...or gravy add a bit of sugar and she would eat the whole lot and go: 'ah that was really nice today'. Which I never realised you could do that to, so that was really handy to know. But it definitely helped her eat more savoury foods because her taste buds had completely changed – she either couldn't taste anything, or they tasted like metal, so having the sweetness in it helped her to eat more savoury foods rather than just focusing on pudding.' (HCW03)

Home care workers also stated that they learned about enriching foods to increase the energy content, without increasing the portion size.

'Adding cream to the milk is handy to enrich it. That was a handy one because you have something they will only drink a certain amount of, so

adding some cream to the milk which they won't necessarily know.' (HCW03)

A podcast topic that some of the homecare workers had not considered before was diet liberalisation. They felt that they would not worry quite so much what a client is eating if risk of malnutrition is a concern. They discussed a focus on reducing calories, and concern with excess sugar intake for clients, however realised that this was their own focus, and perhaps not was best for their clients.

'Yea, not to worry about the calories so much. Because I think we are always in day to day life you are always so focused on calorie intake, that it is then really hard to then disregard that and say actually, getting calories into you is better than anything else. So we have to sort of re-write the rule book, and just go 'as long as you are going to eat' that's fine.' (HCW03)

#### 6.2.3.2.4. Reflexive monitoring

Reflexive monitoring describes how homecare workers assess and understand how the podcasts, as a new way of learning, affect them and others around them. The focus group themes that supported this construct (*'what we do'*, *'format and presentation'*, and *'what could be better'*), describe the nutritional care that homecare workers provide to their clients, and their functional assessment of the podcasts.

Home care workers described a range of activities that they carry out for clients, which were related to food provision and nutritional care.

'And some people you actually go and get their shopping for them as well. So you are actually buying their stuff as well.' (HCW01)

'Prompting them as well, we have to remind them to eat and drink as well...I do have to check in one of my clients bins, because she will say she has had something and she hasn't, so I think right I will check the bin and she ain't had that meal tonight.' (HCW04)

'We do meal preps. Whether it's a microwave meal, Wiltshire Farm Foods meal, or Cordon Bleu cooking' (HCW06)

'We are preparing drinks, sometimes thickened...So we are doing the thickened fluids and purees.'(HCW03)

They described that time constraints can present challenges to them being able to do as much as they would like to help clients eat and drink.

'It's not easy because you are on a time limit.' (HCW04)

'Yea so when you have done all your meal preps and you know, and then they want you to sit and have a chat with them, but you have ran out of time so you got to leave them.' (HCW02)

'I would say most lunchtimes are half hour aren't they.' (HCW01)

When asked about the format and presentation of podcasts, the homecare workers reported that they liked having three separate podcasts, and that they felt 30 minutes was a good duration. They also commented that they liked the variety of speakers.

'I found it really helpful having the different speakers for each podcast, so it wasn't just half an hour of one person and then half an hour of another person; it kept your mind focused because it was a different voice, and it's a different subject.' (HCW03)

And I have to say that three lots of half an hour are better as well. Because you can actually finish off and start again. So not lengthy. (HCW06)

'It was because it was short, it wasn't half an hour of one person, there was different topics. I think it keeps you interested more, so you're not like ah its taking ages.' (HCW04)

The homecare workers provided some constructive feedback on how they felt the podcasts could be improved. Adding some supporting information, was one area discussed.

'I mean like, some foods...If you said to me 'an avocado' I wouldn't know what an avocado looks like! So at least I would know what something



would look like so I can get some of that for a customer, she would probably like that.’ (HCW02)

‘Yea you could print it off or something and attach it to their file.’ (HCW04)

Overall, homecare workers reported that the podcasts were straightforward to use and they saw value in incorporating them into their role. They felt that topics that were relevant to their role, beyond nutritional care, would also be helpful to be delivered in this format.

‘...and also doing the podcast but with other things as well, not just nutrition but other topics.’ (HCW02)

‘Health, safety and safeguarding, some sort of all three.’ (HCW06)

Homecare workers saw real value in the focus group discussions, and felt that it would be a good approach to support future podcast learning, as they do not tend to see each other in person that often.

‘You hardly see anyone unless you come into the office for supervision.’ (HCW04)

‘And then everybody can get together at the end.’ (HCW02)

#### 6.2.3.3. Stakeholder feedback

Feedback was received via email from four stakeholders. The emails were copied into Nvivo 12 (QSR International, 2017b), and analysed to produce the themes detailed in Figure 15. A summary of stakeholder feedback against the NPT constructs and themes is shown in Table 10.

Table 10 - Feedback from stakeholders against NPT constructs and themes

<b>NPT Construct</b>	<b>Theme</b>	<b>Stakeholder feedback</b>	<b>Code</b>
<b>Coherence</b>	<i>Taking part in a trial</i>	n/a	
	<i>Initial Thoughts</i>	'Excited, thought it was a great idea'	EM03
		'My only concern would be that it will only be the younger family members that will feel comfortable with podcasts and possibly not the older generation. My mother won't listen to them, despite the fact that she is very IT literate!'	EM04
		'The podcasts felt like a very easy, convenient and manageable way to learn as opposed to sitting down and studying written information.'	EM01
		'An excellent, innovative, interesting method that was worth testing to see if it would help support learning for domiciliary workers.'	EM02
<b>Cognitive Participation</b>	<i>Usability</i>	'I did have a concern about the logistics of driving, listening and absorbing information.'	EM03
		'Easy to connect on my iPhone and laptop.'	
		'Very easy to access from laptop.'	EM04
		'Very easy using mobile phone - just clicked on the link with no problems.'	EM01
	<i>Why we liked it</i>	'I felt the information would be a great help for homecarers – empowering them with the skills and knowledge to provide a high level of homecare to people living with dementia.'	EM03

		<p>'I think podcast are a great way to learn about any topic in a bite sized session and people can go back and listen to them again.'</p> <p>'...the importance of fluid intake and consequences in terms of toilet breaks and potential falls was clear to understand and again some great tips for carers/families.'</p> <p>'Episode 3 was very thoughtful and I was pleased to hear that it started with shopping and social interaction which is so important.'</p>	EM04
		<p>'The content was so interesting and concise that they made learning very enjoyable! Everything included was relevant and carefully thought out.'</p> <p>'There was a fantastic range of guests across the multidisciplinary team and it was fascinating to hear their perspectives and the knowledge and skills they can bring to help a person with dementia with this aspect of their lives.'</p>	EM01
<b>Collective Action</b>	<i>What we learnt</i>	'I do now have a much fuller understanding of the role of a dietitian in caring for a person with dementia.'	EM01
<b>Reflective Monitoring</b>	<i>What we do</i>	n/a	
	<i>What could be better</i>	<p>'I think if homecarers listened to all the podcasts and perhaps had a transcript to refer to they would have a very good understanding of the incidence, risk factors, recognition, prevention and treatment of malnutrition.'</p> <p>'I thought each podcast was too long, perhaps you could have 6 shorter ones. It might then fit better with journeys and concentration span. Not sure if possible to have an index for the podcast so they listen to one section of it.'</p> <p>'I think it would be great to include some homecarers talking about their experiences and how they managed certain scenarios – how they struggled and how they managed or not but giving some realistic outcomes successful or not.'</p>	EM03
		'I think every good podcast (and I listen to a lot) has excellent show notes so that people can click on links and go straight any relevant websites/books/support that is referred to in the podcast.'	EM04

		'I also feel the podcasts have the potential to be broadened to target other healthcare professionals such as doctors, who don't necessarily encounter this kind of knowledge during their training but would find a lot of the information and concepts very relevant and useful.'	EM01
		'Perhaps more real life domiciliary workers with examples of good practice which linked to the expert's message for that podcast.'	EM02
	<i>Format and presentation</i>	'I thought the summary you gave both at the beginning – when you introduced the topic and at the end when you nicely summarised the material covered and key points related to nutrition were effective.'	EM03
		'Tricky in terms of length as too short runs the risk of the topic being rushed, too long and people get bored. For me the length was good.'	EM04
		'Very clear to listen, I didn't have any problems hearing any of the voices. I liked the overview at the beginning of the podcast, so I knew what the topic would be, before I got too far into it.'	
		'The duration was just right for fitting in between tasks during the day making them very manageable to find time to listen to.'	EM01
		'I did think they were too long and aimed to cover too many learning outcomes. More but shorter podcasts with fewer learning outcomes I think would work better. 6 x 15 min or 8 x 10 min episodes would be better.'	EM02
		'One thing that did strike me was that sometimes it was difficult to know as a listener who to really listen too. The information came both from the 'expert' and the interviewer, and I am not sure how clearly some of the information came across – it would be interesting to learn a bit more from expert broadcasters and/or educators. This was probably exacerbated by the length of the podcast.'	

#### 6.2.4. Discussion

This is the first known study that has tested the acceptability and feasibility of using podcasts with homecare workers. The data indicate that podcasts are acceptable as a training method for homecare workers, and may improve knowledge of nutritional care and dementia. The findings warrant further studies to be conducted. *Table 9* in Section 6.2 outlines the objectives for this study, categorised as acceptability, feasibility, and development. The findings will be discussed within the context of these three headings.

##### 6.2.4.1. Acceptability

This study showed that podcasts are acceptable to homecare workers. They enjoyed using the podcasts to learn about nutritional care for people living at home with dementia, because they were novel, versatile and easy-to-use. In particular, they liked that the podcasts were 30 minutes long, which is shorter than a usual face-to-face training session. Traditional lecture formats used in such training sessions, may result in reduced learner retention rates and engagement (Cooper and Richards, 2017). This aligns with the information processing and cognitive load theories discussed in Section 6.1.2. Mobile phones were the preferred device for listening to the podcasts in this study, and the homecare workers reported that they liked the versatility this offered. This reflects the results of an updated audio content consumer survey, which indicates that mobile phones have a share of 79% of the listening hours of podcasts, with 15% of listening hours through laptops (n= 2351) (Rajar Audio Measurement, 2020). The podcasts designed as part of the current study are a form of digital learning, which is becoming more popular within the health care setting. There are benefits to using this novel form of digital learning, however reduced attention span and the negative consequences that distractions have on the brain cognitive

process, should be considered in future studies (Lodge and Harrison, 2019). The presence of a mobile phone was thought to negatively affect memory recall amongst undergraduate university students, due to the increased cognitive load required to deal with interruptions when learning (Tanil and Yong, 2020). This outcome may vary amongst homecare workers; however is a useful consideration when developing mobile learning packages. Homecare workers said that they liked the option of listening to the podcasts whilst doing other activities, such as cooking, driving or shopping in a supermarket. This versatility of podcasts is a benefit, however media-multitasking may also negatively impact cognitive learning processes previously described (Lodge and Harrison, 2019). There are additional benefits that mobile digital technology can offer homecare workers, such as providing them with daily rosters, storing clients' care plans and delivering prompts to help them in their caring role (Samuel, 2012). Further development of podcasts for homecare workers should consider the possible impacts on cognitive processing.

Home care workers and stakeholders felt that there was value in being able to listen to the podcasts in the car whilst driving between clients' houses. Some reported that they were able to put into practice the information they had heard, such as sweetening savoury foods to satisfy taste changes that can occur in people with dementia. This demonstrates active learning, which has been found to be a key feature of effective dementia training for the health and social care workforce (Surr *et al.*, 2017).

Home care workers reported that they had not received any formal training on nutritional care as part of their role. This is a surprising finding, particularly as in the UK, the Social Care Institute for Excellence (SCIE) includes nutritional care

as an imperative component of the Dignity in Care policy (Excellence, 2009). The same issue seems to exist in the care home setting, where the translation of nutritional knowledge into practice is sub-optimal (Beattie *et al.*, 2014; Bunn, Hooper and Welch, 2018; Bunn *et al.*, 2015; Merrell *et al.*, 2012). The reasons for the absence of nutritional training, and application to practice are important to understand further, to ensure any future training interventions are successful. Podcasts which are listened to in the car between client visits, may help translate knowledge into care at the point of delivery, as they are a form of active learning (Bunn, Hooper and Welch, 2018).

Training using any method in acute and community settings, may improve nutrition knowledge, practice, and attitudes of health care staff (Marples, Baldwin and Weekes, 2017). It appears that there may be some benefit associated with providing homecare workers with nutritional care training; but more research is needed to understand what prevents translation of knowledge acquisition into practice.

The homecare workers felt that the process of getting together, to discuss the podcasts was important to them, and should be part of any future training packages. The role of a homecare worker is mostly autonomous, and they remain in contact via mobile phone or occasional visits to the agency office. Effective supervision in social care is associated with job satisfaction, and develops critical thinking skills (when done as a group). It is important that homecare workers are supported in a role that can be emotionally charged (Carpenter *et al.*, 2012). Although supervision is traditionally carried out one-to-one, group sessions may be useful when staff share clients (which is a regular occurrence in homecare) and they meet to discuss any changes or concerns. The

supervisor can use the session to ensure that good practice is shared and followed by the group (Skills for Care, 2020b). Future studies should explore the benefits of combining podcasts with group supervision, and the time demands of conducting such sessions using virtual platforms as well as in person.

#### 6.2.4.2. Feasibility

The feasibility study enabled trial procedures and research processes to be tested for acceptability, rates of recruitment and participant retention, and unforeseen issues surfaced prior to further pilots. There were no issues regarding accessing or playing the podcasts reported by the homecare workers who took part in the trial, even though for some, it was their first experience of using podcasts. No technical issues were raised to the research team for the duration of the trial. Research participant documentation readability may impact on the success of health research studies (Ennis and Wykes, 2016). The readability score of the participant information sheet was calculated at a reader's age of 12-14 years (ReadabilityFormulas.com, 2003), which satisfies recommendations for written healthcare information (Weiss, 2007). The podcasts were straightforward to distribute to homecare workers, and were accessed via email on their mobile phones. Nutritional care podcasts can be distributed to new employees rapidly, compared to scheduling face-to-face, or even computer-based training sessions. This minimises manager involvement, which has been cited as a barrier to implementing e-learning within care homes (Keenan *et al.*, 2020). This mode of delivery may be useful in the social care sector, where high staff turnover is an ongoing issue (Griffiths *et al.*, 2019).

All homecare workers who took part in the trial completed the pre and post-test quizzes and accessed the podcasts. The host platform (Libsyn) was not able to



specify who accessed the podcasts, however the number of times podcasts were downloaded was recorded (see Section 6.2.3). It would be useful in future studies to record which participants download podcasts and when, however this may reduce the ease of access, which could deter participants. The homecare workers said that they enjoyed being able to listen to the podcasts when and how they wanted, and also liked having the ability to listen again. These attributes align with self-directed learning, in which learners are in control of the learning process (Shahrouri, 2016). Self-directed learning in health professions education has been found to be associated with moderate improvement in knowledge compared with traditional teaching methods (Murad *et al.*, 2010). Home care workers may favour the autonomy to manage their own training and development, resulting in an empowered workforce (Kusmaul, Butler and Hageman, 2020).

The recruitment process for the feasibility trial offered useful insight into future intervention studies conducted with homecare workers. The original homecare agency who was involved, were unable to align with the research timescales and the decision was made to find another agency. The aim was to recruit 12-16 participants, but six took part in the study. This still met the minimum number of participants recommended for a feasibility study and focus group as discussed in section 6.2.2.2. The challenges associated with conducting research in care homes have been explored, and the importance of involving stakeholders (such as care home managers and staff) and residents early on in the research process cited as enablers (Lam *et al.*, 2018). Furthermore, healthcare organisations which are involved in research may deliver improved care by association (Boaz *et al.*, 2015). Further research examining the research culture in homecare agencies, and identifying barriers and facilitators, is needed to support the implementation of future interventions.

Every homecare worker completed the trial, with no drop outs. This may have been influenced by offering participants a £10 Amazon voucher for taking part (distributed after the focus group). The homecare workers stated that they liked having an incentive, and that £10 was appropriate. Offering incentives to take part in future studies may prove to be an enabler when working with homecare workers. The issues associated with offering participants incentives, such as increasing risk of coercion, have been widely debated (Head, 2009). However, there are benefits of incentivising, and participants do not necessarily accept higher risks of potential harm if they are offered higher incentives (Largent and Fernandez Lynch, 2017; Singer and Couper, 2008).

One of the study aims was to assess whether listening to the podcasts resulted in homecare workers having increased knowledge of the nutritional factors associated with dementia. When comparing the results of the pre and post-test quiz, the homecare workers got higher scores after listening to the podcasts ( $p=0.023$ ), suggesting knowledge had improved.

The average time spent working for the homecare agency was 13.4 months (range = 6 to 18 months). Data has shown that homecare agencies experience a high turnover of staff, for reasons such as the difficulty of the role, low salaries, and the requirement to travel long distances (Griffiths *et al.*, 2019). The same data indicates that many leavers remain working in the sector, so already have existing knowledge regarding nutritional care, which could explain the results of this study. However, it is recognised that in this feasibility study it was only a small sample size ( $n = 6$ ), and, therefore, insufficiently powered to fully assess this. It would be useful to understand how long participants have worked in the

social care sector as well as for their current employer, when conducting future studies with more participants.

#### 6.2.4.3. Development

Podcasts are becoming increasingly popular, not only because they are easy to listen too, but also straightforward to produce. For the Teatime Talks podcasts, recording was carried out using a portable compact microphone, and all interviews with guests conducted in person. Total recording time, including introduction and summary segments was around nine hours. The podcasts were edited using Audacity® (Mazzoni, 1999-2015), which is freely available software. The content of podcasts was non-specific to geographical location; therefore, could be distributed to other homecare agencies. With virtual conferencing technology, podcasts involving guest speakers could be recorded remotely, which reduces restrictions on travel and time. This would remove the financial burden associated with travel and hardware (portable compact microphone). The developers time and the hosting platform subscription fee (if used) would be the only incurred costs. For this study, podcasts were an efficient and cost-effective method of providing information regarding nutritional care and dementia that can be repeated as often as the listener requires.

Some homecare workers and stakeholders felt that adding a written resource to support the podcast would help with knowledge retention. A common approach to this is for podcast producers to provide 'show notes' alongside the podcast, which provides an in-depth written account of the podcast, with URL links to further useful resources (castos, 2020). Future studies should explore whether the inclusion of show notes supports an increase of knowledge amongst homecare workers.

#### 6.2.4.4. Strengths and limitations

This is the first study to test whether podcasts about the nutritional care of people living at home with dementia, are acceptable and feasible to homecare workers. The findings indicate that podcasts could be a useful training intervention in this group, however, it is acknowledged that it was a convenience sample and the size was small. The study still met the aims of testing whether podcasts are acceptable to homecare workers, and feasible in this setting. The study was conducted at one homecare agency, and participants were selected to take part by a training manager. It is not known whether participants were coerced into taking part in the study, and the recruitment method would require further exploration in future studies involving homecare workers. The findings are likely to be subject to selection bias, and future studies should aim to include a wider demographic of homecare agencies, and all homecare workers invited to take part. The number of participants recruited was suitable for managing the focus group dynamics. Some homecare workers dominated the discussion, and although quieter contributors tended to agree with points made, this may not have necessarily indicated a collective perspective. Finally, this study did not examine whether improved knowledge of nutritional care and dementia resulted in improved nutritional status of clients of the homecare agency. This would be important to explore in future studies.

#### 6.3. Chapter Summary

This study shows that podcasts about nutritional care and dementia are acceptable to homecare workers, and further trials examining the benefits, are feasible in this setting. Knowledge of the nutritional concerns associated with

dementia were shown to improve after listening to the podcasts, and homecare workers reported that they had been able to put learning into action with some clients. Podcasts appear to be easy to access and use for training purposes in this setting. Home care workers were able to listen to the podcasts on a variety of devices, and in various locations; one of these being in the car in between client visits. This promotes active learning, and reduces the need for homecare workers requiring face-to-face training. They can, therefore, spend more time caring for their clients, particularly as the number of people requiring support with care who live at home is increasing.

This study addresses one of the gaps in research highlighted in the scoping review (Chapter 3), which was that there are no intervention studies that have focused on upskilling homecare workers to provide adequate nutritional care. Health care professionals and homecare workers feel that they need more knowledge in this area (Chapter 5), and this study has shown that podcasts may be effective at providing this. Furthermore, by increasing knowledge of nutritional care and dementia amongst homecare workers, they will be able to provide increased support to family carers who are living at home with someone who has dementia (Chapter 4).

This study provides the baseline for developing future, larger-scale studies related to using podcasts as a training tool for homecare workers. Proposals for developing the findings are presented in Chapter 7, following a review of all four studies in the context of the overall aims of the thesis.

#### 6.4. Reflexive Commentary

*Developing the podcasts enabled me to be creative and innovative, which I really enjoyed, as I consider these to be two of my core values. I was able to utilise my*

*professional and academic networks to create meaningful podcast content, which I also enjoyed. It also reinforced the importance of maintaining such networks, particularly when working in an academic environment. It helped that my colleagues shared my passion and enthusiasm for the topic, as many had seen the impact on their patients who have dementia, of poor nutritional care.*

*It is important to acknowledge my position in the development of the podcasts, facilitation of the focus group, and evaluator of the feasibility trial. The homecare workers were aware that I had created the podcasts, and they may have felt uncomfortable providing feedback that was less positive during the focus group with me present. My analysis of the focus group account, and evaluation of the feasibility trial may have been influenced by my affinity for the podcasts. I felt that I had worked hard to produce a prototype intervention that could support others, and this may have affected my objectivity.*

*The qualitative approach used to analyse the focus group transcript was different to my two previous studies, where IPA was used. Thematic analysis was chosen, with normalisation process theory providing the lens through which I analysed and interpreted the data. This has enabled me to experience two popular qualitative analysis methods. During the analysis and writing of the discussion, it struck me that it was somewhat ironic that I was focusing on the cognitive processes associated with learning information from the homecare worker's perspective, when cognitive processing is an integral part of the degradation associated with dementia as a condition. This has highlighted to me the notion of connectedness that I have had through this study with the homecare workers and their clients who have dementia. Finding ways to improve the cognitive processing of information is something that researchers, healthcare*

*professionals, homecare workers, family carers and people living with dementia are striving for.*

*I feel grateful to have been able to meet homecare workers, and to find out more about their role. It was apparent how much responsibility homecare workers have, particularly when working with vulnerable clients, such as those with dementia. They enable someone living at home to meet fundamental needs such as keeping clean, eating and drinking, and moving around the house. I found it surprising that they have minimal training, or qualifications, to enable them to carry out this important role. In my future clinical and research work, I endeavour to champion and support the profession, as they are pivotal to nutritional care of all clients, and not just those living with dementia.*

*The homecare workers who took part in the focus group really enjoyed being together, and discussing issues they had experienced with clients regarding nutritional care. This was interesting, as it made me consider that although technology is useful for providing opportunities for learning, support and supervision in a healthcare role may be better done face-to-face. It is important to find a balance that improves the nutritional care of people living with dementia at home, as well supporting homecare workers.*

## 7. Overall Discussion

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### 7.1. Chapter Overview

This Chapter begins by presenting a review of the aim of the thesis and the four studies conducted. The findings of the studies are summarised, and their contribution to literature discussed. Proposals for future work to develop the findings further are presented, followed by overall conclusions.

### 7.2. Review of aims and findings

This thesis set out to explore how to support people living at home with dementia to eat well, and to develop an intervention to help improve nutritional care. People living with dementia at home are at increased risk of malnutrition, and many rely on family members to ensure that their nutritional needs are met (Chapter 1). This thesis provides an important insight into care within a person's own home, and adds to the current limited empirical evidence available on care in this setting.

The MRC framework for complex interventions was used to guide the development of the intervention (Medical Research Council, 2006). The first step was a scoping review (Chapter 3), which showed that there are gaps in the literature regarding the opinions of how family members and healthcare professionals feel about the provision of nutritional care for someone living at home with dementia. There was also a paucity of studies that explored the effectiveness of nutrition-based training interventions for healthcare professionals and homecare workers who work with this population.

Qualitative studies to address the gaps highlighted in the scoping review, explored the issues and concerns of family carers (Chapter 4), and healthcare professionals and homecare workers (Chapter 5). It was particularly important to



explore the perspectives of family members providing nutritional care, as previous research has identified that they take a lead role in decisions regarding food choice and preparation (Brodaty and Donkin, 2009; Lindeza *et al.*, 2020), and consequently potentially influence nutritional status. The effects of the symptoms of dementia on nutritional status are well documented (Cerejeira, Lagarto and Mukaetova-Ladinska, 2012; Dauncey, 2014), and mean many individuals become malnourished or at increased risk of malnutrition. To prevent malnutrition, evidence-based guidelines recommend that healthcare professionals screen for malnutrition risk at least every three months (Cederholm *et al.*, 2017; NICE, 2017), however it is unlikely that this is happening and the reasons for this were explored.

The first qualitative study presented in this thesis (Chapter 4) found that as family members transition into the role of carer, they make difficult decisions daily (including food and drink choices). They may decide to exclude the person with dementia in activities such as food shopping, which could otherwise be a beneficial and meaningful activity. Dementia-related changes in appetite, food preferences and mealtime habits can lead to disruption and frustration for carers, which can affect their own nutritional intake. Family members feel that it is their duty to take control of food provision, regardless of the type of relationship with the person with dementia. They are conscious about 'doing the right thing' when it comes to providing nutritional care, and some feel uncertain about the food choices they are making, particularly regarding a reliance on convenience foods.

The second qualitative study presented in this thesis (Chapter 5) found that healthcare professionals and homecare workers felt a sense of responsibility to ensure that people living with dementia received adequate care. The family

caregiver was recognised by participants as needing support. However, challenges to the provision of effective nutritional care and support include limited time to spend with individuals, knowledge of appropriate food and drink choices, and decisions to replace carer support with meal delivery to reduce cost. The healthcare professionals and homecare workers in this study recognised that working together as a team can improve care outcomes. Ideas for improvements focus on raising awareness of nutritional needs and developing training aids regarding nutritional care and dementia. The findings reinforced the importance of ensuring healthcare professionals and homecare workers are provided with adequate training with regard to identifying nutritional risks, helping family carers make appropriate food and drink choices, and preventing the risk of malnutrition in the dyad. Future research should focus on the efficacy of interventions to improve nutritional care from the healthcare professional and homecare worker's perspective.

The next step was to integrate these findings to design a suitable intervention to support those with dementia living at home. The findings suggested that a training aid was needed, and the audience with the most contact with this group were homecare workers. Thus, a series of podcasts were developed to provide homecare workers with evidence-based information about how to provide adequate nutritional care (Chapter 6). The acceptability of the podcasts was explored with homecare workers, as well as the feasibility of further intervention trials in the community and social care setting (Chapter 6). The focus group account, pre and post-test quiz results, and stakeholder feedback indicated that podcasts are acceptable as a training method for homecare workers, and may improve knowledge of nutritional care and dementia. The findings warrant further

studies to be conducted, involving more homecare workers across multiple agencies and geographical locations.

### 7.3. Contribution to research field

The research presented in this thesis has advanced the understanding of the nutritional care of people living at home with dementia. It has highlighted the importance of ensuring that their nutritional needs are considered, and that family members, healthcare professionals and homecare workers have the knowledge to provide nutritional care and, thereby, reduce the risk of malnutrition. The nutritional care implications of living with dementia in the own-home setting have not been explored in enough detail in previous studies, compared to care homes and hospitals. This may be partly explained by a lack of focus on social care by dementia researchers, and also a nihilistic view that there is not much that can be done for people with dementia (Marjanovic *et al.*, 2015).

The final study in this thesis (Chapter 6) outlined the development of three podcasts, which were then tested with a group of homecare workers. Using podcasts to deliver nutritional care training with a mobile workforce has not been explored previously. The work conducted as part of this thesis has demonstrated that it is an important area that warrants further exploration and development. The popularity of podcasts is increasing, but it is unknown how healthcare professionals and homecare workers use podcasts to increase knowledge and develop skills. I have supervised an undergraduate student project, which explored how healthcare professionals use podcasts. A large proportion of participants (which included dietitians, paramedics, pharmacists and occupational therapists) reported listening to educational podcasts (60.2%, n=65) for the purposes of continuing professional development. The perceived barriers

to listening to podcasts were also explored, and findings indicate that profession-specific content based on latest evidence would encourage more healthcare professionals to use podcasts. These findings are encouraging, and further research is required to explore the effectiveness of using podcasts as a learning medium.

#### 7.4. Implications for research and practice

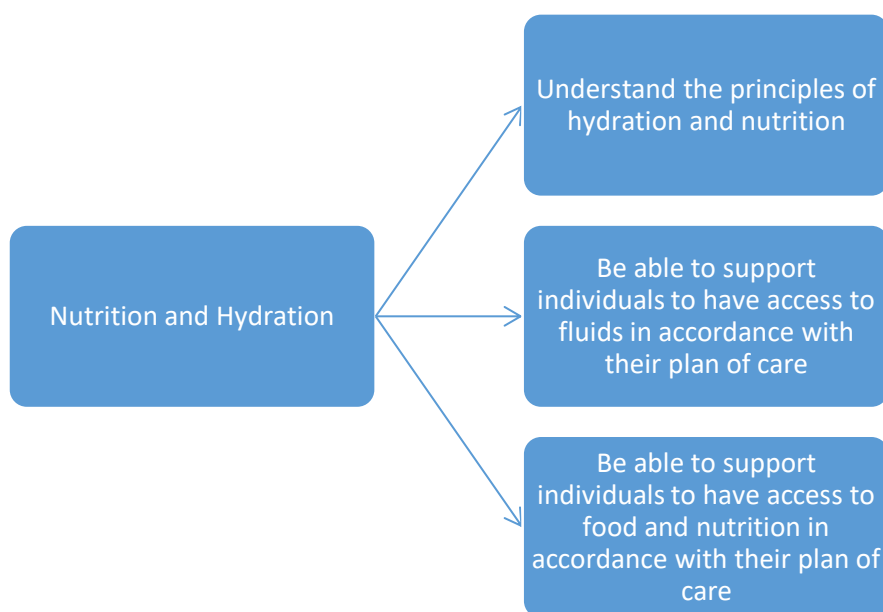
##### 7.4.1. Improving the nutritional care of people living with dementia at home

It is intended that the findings from this thesis will be used to develop podcasts about nutritional care and dementia for use by homecare workers in the UK. Maintaining a focus on nutritional care and dementia is more important now than ever, particularly following the global pandemic of COVID-19 (discussed in section 7.4.1.1).

There are no published requirements stating the level of knowledge homecare workers should have regarding nutritional care for people living with dementia. Homecare agencies are regulated by the Care Quality Commission (CQC) in the UK, and part of the inspection process is to ensure that care agencies meet the fundamental standards. Ensuring that clients have enough to eat and drink to keep them in good health while they receive care is one of these fundamental standards (Care Quality Commission, 2017). It is the responsibility of homecare agencies to provide adequate training to ensure that homecare workers deliver nutritional care that reaches the fundamental standard outlined by the CQC. However, this standard is very broad and homecare workers require more support with understanding the nutritional requirements and consequences of complex conditions their clients may experience, such as dementia (Mole *et al.*, 2019b). The core and mandatory training provided to new homecare employees

is delivered by 'Skills for Care' as an online self-directed package and the learning outcomes related to nutrition and hydration are shown in Figure 16. The learning outcomes are basic, broad, and difficult to measure. Designing learning goals using Bloom's taxonomy, which is widely used in higher education, would encourage learners to develop higher levels of cognitive skills leading to deeper learning and transfer of knowledge (Adams, 2015). Nutrition and hydration learning opportunities should be provided when homecare workers demonstrate a gap in knowledge or understanding, perhaps as part of personal development plans. In addition, they should also receive regular training to ensure they have the skills needed to meet the nutritional requirements of their clients (Lendzionowski *et al.*, 2015).

Figure 16 - Core and mandatory learning outcomes for homecare workers provided by Skills for Care (2020a)



No studies have been conducted to date that identify what the level of knowledge of homecare workers is regarding nutritional care for clients, particularly in terms of identifying clients at risk of malnutrition, and implementing first-line nutritional

support for those that are at risk. At the time of writing, I am supervising a Master's student project at the University of Plymouth, which will explore the current nutritional knowledge of homecare workers, and how confident they feel providing nutritional care to clients with dementia. The findings of this project will provide the information required to apply for further funding for a Delphi study involving key stakeholders, supporting the creation of a benchmark nutritional care standard for community healthcare professionals and homecare workers who work with people living with dementia at home.

It would be of benefit to homecare workers to understand more about the nutrients that are important to older adults (particularly those living with dementia), and some of the symptoms of dementia that can affect how well clients are able to eat and drink. Homecare workers should ensure that meals are appetising, whilst respecting the client's food preferences and any cultural food choices (Excellence, 2009). The homecare workers involved in the feasibility trial (Chapter 6) reported that they learnt new methods of preparing meals that may increase the amount eaten by clients with dementia, such as adding sugar to savoury sauces. The mealtime environment should be optimised by minimising distractions (e.g. turning off televisions), and providing appropriate plates and cutlery (e.g. coloured plates and cups).

#### 7.4.1.1. COVID-19 implications

The World Health Organization declared the outbreak of COVID-19 a pandemic on the 11 March 2020. Since the declaration, the UK has experienced three lockdowns, involving the closure of non-essential services, and people being asked not to leave their homes unless necessary. Having a diagnosis of dementia is thought to be associated with increased susceptibility to COVID-19,

and increased mortality once the virus is contracted (Atkins *et al.*, 2020; Bianchetti *et al.*, 2020; Suárez-González *et al.*, 2020). Over lockdown, services that provided support to people living with dementia and their carers, such as therapy classes and respite day-centres, have had to close, leaving a large number of vulnerable people feeling unsupported (Denning and Lloyd-Williams, 2020). This is likely to have increased the stress and burden felt by family carers as explored in Chapter 4.

Homecare agencies have continued to provide care to clients living at home throughout the pandemic, including those with dementia, and a recruitment campaign was launched to increase the social care workforce (Department of Health and Social Care, 2020c). Furthermore, the 'CARE' logo and brand has been created to provide recognition to those working in the adult social care sector, and positioned alongside the 'NHS' logo for brand equity (*Figure 17*) (Department of Health and Social Care, 2020a). The increased recognition and financial assistance given to homecare agencies will support the social care sector in overcoming the barriers explored in Section 5.5. By positioning homecare workers alongside NHS workers, they are recognised as equally important providers of care towards the health and wellbeing of people living at home. This should include nutritional care, and future research will be required to explore the impact on health outcomes resulting from policy changes and increased government support. Surveys have previously shown that at least 1 in 4 patients were at risk of 'malnutrition' on admission to hospital from their own homes (Russell and Elia, 2014). An updated survey identifying malnutrition risk in the community would identify any impacts resulting from policy changes to social care support. The demand for social care support for vulnerable adults

living at home will only increase following the pandemic, and it is essential that healthcare professionals and family members are adequately supported.

Figure 17 - NHS and new CARE logos



#### 7.4.1.2. Nutritional screening

The James Lind Alliance published the top 10 research priorities for nutritional screening and malnutrition concurrently with this thesis (James Lind Alliance, 2019). The priorities represent what is important to patients, carers, and healthcare professionals, regarding nutritional screening and malnutrition, making researchers aware of the issues that matter most to the people who need to use the research in their everyday lives. Future work to develop podcasts and improve nutritional knowledge and dementia would align with many of the priorities, but particularly those outlined in *Table 11*.



Table 11 - James Lind Alliance research priorities for nutritional screening and malnutrition linked to future work

Priority Number	Priority research area	Future work linked to this thesis
1	How can early intervention be initiated in vulnerable groups to help prevent malnutrition?	Providing nutritional care training for family members and other healthcare professionals who care for those with dementia, to promote early intervention.
2	What is the best way to carry out screening in the community for effective identification of malnutrition?	Increased focus on supporting family carer's with screening for malnutrition risk at point of family member diagnosis of dementia. Exploring role of volunteering agencies in screening.
3	Are people aware of malnutrition, do they know how to prevent it, do they think screening for malnutrition is important?	Further work with family carers' and volunteers who are involved in caring for people with dementia.
9	Can technology and electronic records be used to record and improve nutritional treatments and to convey nutritional advice?	Using podcasts and mobile training applications to provide nutritional care advice to family carer's and healthcare professionals.

The focus should not be aligned to a screening 'tool', but more towards providing family members and other healthcare professionals with support in understanding the nutritional consequences of dementia, and linking to first-line nutritional care guidance. As explored in Chapters 1 and 3, once an individual receives a diagnosis of dementia they are already at risk of malnutrition. More focus on nutritional care as part of the diagnostic process would provide more pre-emptive support.

#### 7.4.2. Podcasts and Mobile Learning (mLearning) for homecare workers

The COVID-19 pandemic has meant that homecare agencies have been advised to avoid all face-to-face training and supervision, using digital solutions only

(Department of Health and Social Care, 2020b). The requirement for digital methods of training has, therefore, increased and is being met through an online platform (Skills for Life), designed to be accessed using a laptop or computer. Society has been forced to communicate using remote technology, and the benefits associated with video conferencing software have been seen for those working from home, and when communicating with relatives and friends. This results in groups being potentially more receptive to using mobile technologies to receive nutritional care guidance.

In my capacity as a university lecturer, I have had to adapt to using remote technology to deliver education and clinical placement experiences to undergraduate student dietitians. Even though I am someone who considers herself comfortable with utilising technology, encouraging students to engage with the technology has been challenging. It has highlighted the importance of providing enough support and instruction when using a new training method with a group of people who may not be as familiar with technology.

For a new way of learning to be successfully embedded in an organisation, focus must be given to all stakeholders, and their level of involvement. Homecare workers may be the end-users. However, managers and funding authorities will also need to accept changes in order for them to be embraced at an organisational level. Normalisation process theory was used in Chapter 6 to understand the multiple components that are involved when homecare workers are asked to listen to podcasts to improve their knowledge of nutritional care. For future work in this area, particularly when implementing interventions to provide training to homecare workers and healthcare professionals, it is advised that normalisation process theory is used to recognise the social and technical

processes involved with adopting change (Richards and Hallberg, 2015, pp. 293-300).

The portability of mobile devices can enable interactions between learners and educational material, fellow learners, and educators in the healthcare professions. Mobile learning may be beneficial as a method of supporting health and social care students during practice placements, by providing opportunities for interprofessional learning, encouraging reflective practice, and integrating theory with practice (Taylor *et al.*, 2010). Mobile learning also provides an environmentally sustainable method of supporting practice placements in healthcare, reducing the reliance on paper-based training portfolios (NHS England and NHS Improvement, 2020). However, devices need to be incorporated institutionally, and learners and educators need additional support to fully comprehend device or app functions. The strategic support of mLearning is likely to require procedural guidance for practice settings and device training and maintenance services (Lall *et al.*, 2019). Future studies will need to investigate the strategic support required to facilitate embedding mLearning as part of practice in a social healthcare setting.

The short nutritional knowledge quiz, and podcasts, were both able to be accessed and completed on a mobile phone. Homecare workers reported that they enjoyed the focus group as part of the feasibility study (Chapter 6), particularly as it was an opportunity to connect with their peers to discuss aspects of their care approach – a form of supervision. With the focus on reducing face-to-face contacts following the COVID-19 pandemic, it is important to explore how effective remote supervision is in the health and social care setting. This may be asynchronous (i.e. learners sharing experiences in a group chat or forum), or

synchronous (i.e. real-time conference calls with voice and/or video). Asynchronous methods may be particularly beneficial, as they do not require homecare workers to take time out from their caring duties to attend.

Remote supervision provided to healthcare professionals regulated by the Health and Care Professions Council has been found to be effective when no other options are available (e.g. due to geographical constraints) (Rothwell *et al.*, 2019). There are limitations to the nature of the supervision, in that clinical practice is difficult to observe and, therefore, may be more beneficial for general discussions regarding training development or career support. Although homecare workers are not regulated by the Health and Care Professions Council, many aspects of their work support that of regulated healthcare professionals such as social workers, occupational therapists, and dietitians. Future work should explore whether remote supervision with homecare workers is as effective as it has been shown to be with other healthcare professionals.

The use of mobile applications to help those living with dementia and those who support them is an emerging area of research. One particular app has focused on the efficacy of music therapy to improve reminiscence of daily activities, associating popular songs with activities such as waking up, getting dressed and eating (Cunningham *et al.*, 2019). Some homecare agencies have started to implement apps for their employees, containing information that would otherwise be available in a paper staff handbook, and cite benefits such as instant cascade of updated information (Bluebird Care, 2017). The apps provide an existing platform on which podcasts and learner support forums can be hosted, and future studies in this area would seek to engage with platform developers. Apps that require users to enter credentials, provide a secure platform where podcasts and

information can be targeted at the desired audience. The platform used to host the podcasts for the feasibility trial (libsyn.com) was designed for wide-scale deployment of podcasts in the public domain to maximise listenership. It did provide easy access to the podcasts for participants; however, did not offer the function to keep podcasts private. Other hosting platforms do offer this capability (e.g. captivate.fm) and may be better suited for hosting podcasts in future trials.

#### 7.4.3. Outcome measures of future studies

When developing further studies, outcome measures need to be carefully considered. Measuring the short-term effects of outcomes (e.g. weight, dietary intake) is less useful in demonstrating effectiveness when caring for people with dementia because these are people with long-term health and care needs. The optimum measure of assessing nutritional status, for populations in general, would rely on a combination of biomarker measurement to assess micronutrient levels, indirect calorimetry analysis to ascertain energy expenditure, and reported nutritional intake (Gupta *et al.*, 2017). This is not practical or suitable for this population. There are ethical considerations associated with taking serum samples and using indirect calorimetry with people living with dementia, who may experience confusion and distress during the assessments.

Using biomarkers may not be an accurate measure, particularly when attempting to assess whether someone is malnourished, due to the interference of inflammatory markers (Bharadwaj *et al.*, 2016). As discussed in section 1.5, dementia is likely to induce an inflammatory response, and increased inflammation markers have been observed in serum samples taken from people with early-stage Alzheimer's disease and dementia with Lewy Bodies (King *et al.*, 2018).

Outcome measures of future studies should focus what is important to those living with dementia, and their carers. Core outcome measures have been explored for interventional research aimed at slowing or preventing the decline of dementia, and although quality of life and activities of daily living were considered (which nutritional status will contribute towards), no specific measures of nutritional status were included in the discussions (Webster *et al.*, 2017). Further work is needed to understand what outcome measures are acceptable for interventional research aimed at improving nutritional care for those living with dementia.

#### 7.5. Strengths and limitations

The strengths and limitations have been outlined for each individual study (sections 3.3.5, 4.3.5, 5.3.5, and 6.2.4.4) and are not repeated here. This section will focus on the overall strengths and weaknesses of the research presented in this thesis.

An empirical research approach has been used throughout, a strength of which is a focus on real-life experience. The context of the own home setting, has provided important insights, which can be used by healthcare professionals and researchers working in this area. This provides high ecological validity, with some aspects being transferable to clinical practice. The research has also shown the diversity and heterogeneity within the own home setting, which is a consideration for future intervention studies.

The decision to use participant diaries and vignettes as part of the qualitative studies (Chapters 4 and 5) strengthened the semi-structured interview findings, allowing a deeper understanding of the caring experiences encountered by family carers, healthcare professionals and homecare workers regarding nutritional

care. Diary completion by family carers, revealed a greater understanding of the challenges faced by carers of people living with dementia, and would be useful in the clinical setting as well as in research (Jayalath, Ashaye and Kvavilashvili, 2016). The vignette used during semi-structured interviews with healthcare professionals and homecare workers, supported the understanding of what participants would 'do' next, and compare value-driven perspectives between professions (Sampson and Johannessen, 2020).

Although the interview studies (Chapters 4 and 5), and feasibility study (Section 6.2) were limited to participants from South West England, the scoping review (Chapter 3) included studies from a range of countries. This ensured that a breadth of available literature was included, as the concerns with adequate nutritional care of those living with dementia at home is not a problem unique to the UK.

Stakeholder input has been a strength of this research, and it was important to involve those who would use the intervention, and be benefited by it (section 2.3). Interpreting and sharing the experiences of family carers, healthcare professionals and homecare workers addressed one of the gaps identified in the scoping review (Chapter 3). Building rapport with stakeholders enabled the exchange of knowledge and ideas; one of the fundamental aspects of PPI (Gibson, Welsman and Britten, 2017).

The limitations associated with the sample size and location of participants in the feasibility study (section 6.2) should be noted. For the purposes of a feasibility study, the sample size was adequate; however, does restrict generalisability of the findings. The challenges with recruitment experienced in this study is reflective of barriers with involving homecare workers in social care research. A

limitation being that there is such variation between social care organisations that the research strategy needs to be adjusted accordingly (Cyhlarova, Clark and Knapp, 2020). Future studies should aim to recruit a greater number of participants from a range of homecare agencies to increase external validity, and this may require more time and resources allocated as part of the recruitment process.

My dual-role as a researcher and registered dietitian has been a strength of this research. The content of the podcasts, were formed largely from evidence-based dietetic guidance; therefore, clinical experience has informed the research from beginning to end (Hawe, 2015). I had an existing network of healthcare professionals who were involved in the creation of the podcasts. It is important to reflect on some of the potential limitations of my position as a clinician-researcher. Clinical queries did arise as part of the family carer interview study, and this could have influenced the participant-researcher relationship. However, I felt comfortable addressing simple and reasonable questions regarding food and diet, as this was an appropriate form of reciprocity for the participant giving their time to take part (Hay-Smith *et al.*, 2016).

#### 7.6. Overall conclusions

Many opportunities exist to help people with dementia to eat well at home, involving family carers, healthcare professionals and homecare workers. Despite this, I have shown that there are few studies exploring the experiences of family members and healthcare professionals in providing nutritional care. This thesis has demonstrated that by providing homecare workers with podcasts containing information regarding nutritional care, knowledge is likely to improve. It has also provided a view of how family carers feel about providing nutritional care to other



family members living at home. Taking on the food shopping and meal preparation can be confusing, and family carers may feel guilty that the options they provide are not the best choices. Family carers may, therefore, struggle with their own nutritional intake. Healthcare professionals and homecare workers feel that they have a responsibility towards ensuring that the people with dementia they care for are adequately nourished, yet they do not feel that they have enough time or knowledge to achieve this.

Adequate nutritional care should be accessible to anyone living with dementia who is struggling with eating and drinking as a result of their symptoms. The research conducted and published as part of this thesis will act as a foundation to encourage healthcare professionals and researchers alike to place more focus on the nutritional needs of people with dementia living at home. After all, it really is 'what you do that makes a difference'.

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## **Appendix A Vignette**

My name is Peter, and Sandra and I have been married for 45 years. She is a retired nurse, was always good at looking after other people – including me! In fact, she has spent our married life looking after me. She used to do all of the shopping, cooking and cleaning until...well until a few years ago when things changed. The memory clinic said she had Alzheimer's disease which is a type of dementia as I understand it. Anyway, her memory got quite bad quite quickly and I have had to take over doing a lot of the things around the house. It hasn't been easy – I had never boiled an egg let alone plan a week of food shopping for two people and a cat (although the cat often eats the same as us as Sandra feeds it her food!).

Sandra does get quite confused – I often find packets of biscuits around the house in some strange places. She was such a good cook, and used to make everything from scratch. I don't cook so well, so I do rely on ready-meals for us both but I do worry whether we are eating the right things. I am still working a few days a week so we have a carer who comes in the mornings and she helps Sandra get up, washed and makes her breakfast and lunch. I worry whether Sandra eats enough, she leaves half of her meals when we eat together, and sometimes doesn't want to eat at all. The carer mentioned the other day that I need to get her some new clothes as her current ones are getting too big. I also worry whether she drinks enough; she forgets to drink cups of tea so I am forever heating them up in the microwave.

I don't like thinking of myself as Sandra's 'carer' as I am her husband. I feel like I have had to quickly change the way I react to things compared to what I used to be like. Back in the day, I wouldn't have had the patience for it, but now, if

Sandra takes a whole pack of oven chips out of the freezer and puts them in fridge so that they defrost and have to be thrown away, I just think 'does it matter'? That is the main thing I have developed throughout this is patience. But you know the worst thing? Up until a few months ago, when Sandra was still able to make cups of tea, she asked me every time how I take my tea. After 45 years of marriage and now she can't remember how I take my tea – that really upset me.



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## **“TEATIME podcast – testing the feasibility of a podcast for homecarers”**

We would like to invite you to participate in a new research study. Before you decide whether or not you would like to take part, it is important for you to understand why the research is being done and what it will involve. This information sheet explains the background and aims of the study. Please take time to read it carefully and discuss it with others if you wish. Please contact us if anything is unclear or if you would like more information. Your participation in this study is voluntary.

### **Why have I been chosen?**

This study will test whether a podcast on nutrition and dementia, aimed at homecarers, is acceptable for future development and further testing. You are employed by a homecare agency and care for clients who have a form of dementia, and may carry out shopping, cooking, meal assistance responsibilities on a daily basis.

This is the first study to see whether using podcasts as a training tool is acceptable to the people they are aimed at; you. We want to see whether listening to these podcasts is acceptable to you and whether it would be worthwhile developing and testing the idea further. By understanding more about what you

think about this prototype podcast series, we can improve it to help you care for clients with dementia.

### **What is a podcast?**

Podcasts are digital audio files which can be listened to on a computer or mobile device, typically available as a series, new instalments of which can be received by subscribers automatically. You usually need a 'podcast' app to listen to podcasts on your phone, such as SoundCloud or Spotify. Most smartphones have a built-in player.

### **What would I have to do if I took part in this study?**

#### **1. Listen to three podcasts**

Listen to three podcasts, which are 20 to 30 minutes in duration. The podcasts cover different topics about nutrition and dementia. You can access them via your mobile phone through a link which will be emailed or texted to you. You can then listen to the podcasts whenever you choose to, perhaps whilst in the car between client visits (if you connect your phone to your car audio system via Bluetooth). You can listen to the podcasts as many times as you like, and stop/start them as required. You will be able to download them to keep on your mobile and listen off line (i.e. you will not need an internet connection).

#### **2. Take part in a focus group**

Take part in a focus group facilitated by Louise Mole, the lead researcher. This will take place at the agency office. It is expected to take no longer than 1 hour, and will be tape recorded. Just before starting, Louise will ask you and your other colleagues who attend to say your names and how many years you have been a

carer. This will ensure that voices can be identified when the recording is being typed up. You will be asked to talk about the three podcasts and what you thought about them. We are also interested in hearing about your other experiences with training about nutritional care and dementia. Louise will invite the group to go into detail about what you thought about the podcasts, and how you think they may be improved.

### 3. Complete a short online quiz before and after listening to the podcasts

A link to a short online quiz will be included in the email you have received inviting you to take part in this study. We would like to see if your knowledge of nutrition and dementia improves after listening to the podcasts. Your results will be kept confidential and not shared with anyone outside the research team. During the focus group, Louise will hand around an electronic tablet and you will be invited to repeat the quiz. The questions will be another opportunity to check knowledge after you have listened to the podcasts.

### **Will any expenses be paid?**

Yes, any travel expenses incurred will be reimbursed. You will also be offered a £10 Amazon gift voucher for your time. Refreshments will be provided.

**Do I have to take part?** No. It is entirely up to you whether or not to take part. If you decide to take part you may choose to withdraw at any time. You will be asked to sign a consent when you arrive to take part in the focus group to say you have had enough information and that you are happy to be part of a recorded discussion.

### **Will my records be confidential?**



Your name and time spent as a homecarer, as well as any client details shared during the focus group will be kept strictly confidential and made anonymous when the recording is typed up. The focus group recording will be destroyed once it is typed up. Electronic information will be stored on a computer which is password protected, in a document file that is also password protected for a maximum of 10 years following the study. All information will be handled in compliance with the Data Protection Act 2018). You will be given a paper copy of your consent form, and a further signed copy will be kept in a locked cupboard at the Peninsula Allied Health Centre at the University of Plymouth.

### **What are the possible benefits of taking part in this study?**

You will have the opportunity to enhance or refresh your knowledge of some aspects of nutrition and dementia, and you will contribute to the development of a training resource tailored specifically to the needs of homecarers. The long-term benefits could inform future research regarding improving the nutritional care of people living at home with dementia.

### **What are the possible disadvantages of taking part in this study?**

There is a risk that discussing some experiences may cause some emotional discomfort or upset. If this occurs Louise will offer you the opportunity to pause for as long as is required, and you will be able to leave the focus group if you wish.

### **Who has reviewed this research study?**

The study has been approved by the School of Health Professions Postgraduate Ethics Subcommittee.

### **How will I hear about the results of the study?**

An abstract of the study article can be sent to participants when available if you request it.

### **Your rights**

Your participation in this study is entirely voluntary. You may withdraw at any time.

If you require any further information about this study or have any questions please contact the lead researcher: [louise.mole@plymouth.ac.uk](mailto:louise.mole@plymouth.ac.uk) or telephone 07814140955. You can also contact the director of studies Mary Hickson: [mary.hickson@plymouth.ac.uk](mailto:mary.hickson@plymouth.ac.uk) or telephone (01752) 587542. Thank you for taking the time to read this information sheet.

## Appendix C Consent form – feasibility study

### “TEATIME podcast – testing the feasibility of a podcast for homecarers”



Lead researcher: Louise Mole, PhD Student, University of Plymouth

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Chief Investigator: Professor Mary Hickson, University of Plymouth

#### Consent Form

#### Please initial box

1. I confirm that I have read and understand the information sheet dated XX/XX/XXXX for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.

☐

2. I understand that I am free to withdraw at any time without giving any reason. I understand that any recorded contributions to the focus group discussion cannot be removed if I decide to withdraw and will still be used in the analysis.

☐

3. I understand that our discussions during the focus group will be audio recorded and that any identifying information recorded will be removed during transcription. The transcription will be kept securely at the University of Plymouth.

☐

**Name of Participant**

**Date**

**Signature**

**Name of Researcher**

**Date**

**Signature**

For further information please contact the researchers

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# ***The nutritional care of people living with dementia at home: a protocol for a scoping study***

**July 2016**

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## **Abstract**

### *Introduction*

The symptoms associated with dementia can result in adverse nutritional consequences, including increasing malnutrition risk. Many people are living with dementia in their own homes, and nutritional needs are often supported by family or friends providing care, and/or formal domiciliary carers. Direct and indirect interventions to improve nutritional status in dementia have been explored, however many of these take place in a care home or hospital setting. We intend to address this gap by reviewing interventions and other literature associated with managing the nutritional status of people living at home with dementia.

### *Methods and Analysis*

It is intended that this scoping study protocol will outline the planned stages prior to conducting a full scoping study using the Arksey and O'malley (2005) six-stage framework to identify existing literature relevant to the nutritional care of people living with dementia in their own homes. Thematic results of the literature search will be combined with the outputs from stakeholder focus groups, and key themes and ideas for future interventions discussed.

### *Ethics and Dissemination*

The scoping study will use robust methodology to search for interventions and other literature focused around managing the nutritional status of people living with dementia in their own homes. A stakeholder group including representatives from patients, carers, and primary healthcare professionals will be involved as part of the final stage of the scoping study process, and appropriate ethical approval will be sought following approval of this protocol. The findings of this scoping study will also be published in a relevant peer reviewed journal for dissemination, and form part of future seminar presentations.

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## 1.0 Background

There are an estimated 850,000 people living with dementia in the UK , and it is forecast that this could increase to over 1 million in 2025 (Prince et al., 2014). The behavioural and psychological symptoms of dementia (BPSD) may be caused by a number of progressive diseases, the two most common being Alzheimer's disease (AD) and Vascular Dementia (VD). The BPSD have been documented (van der Linde et al., 2014) ,however there is acknowledged heterogeneity in symptom presentation amongst individuals as the disease progresses. The average duration of the disease from diagnosis to mortality is around ten years, however it is purported that many people will have been living with dementia for years prior to symptom recognition (Alzheimer's Society, 2016). Two thirds of people with dementia are thought to be living at home, with an estimated 670,000 family and friends taking the role of primary carer (Prince et al., 2014). This role includes meeting the individual's health, emotional and social needs, which will become more complex and demanding as the dementia progresses, and can have profound impacts on the individual and their family (Fauth and Gibbons, 2014).

The nutritional needs of an individual with dementia are an integral consideration of the holistic care provided at all stages of the disease. Maintaining an individual's nutritional status includes preventing unintentional weight loss (fat and muscle), and meeting fluid and micronutrient requirements. The inter-dependant relationship between the decline in nutritional status and cognition has been explored (Lee et al., 2009, Spaccavento et al., 2009), and this decline can begin in the early stages of the disease (before formal diagnosis), which if not addressed can increase the rate of progression to mortality, as well as increasing the risk of clinical vulnerability e.g. risk of falls, infections and pressure sores. Across all care settings, the main symptoms of dementia that can affect nutritional status include: memory decline, loss of motor skills, visuospatial ability, taste changes, changes in appetite, and swallowing problems. The management of these symptoms (and others) will vary dependant on the care setting, and previous systematic reviews have focused on Randomised Controlled Trials (RCT's) carried out across all care settings (residential homes, ward environments and own homes), but including minimal analysis of studies specific



to a 'own home' setting (Bunn et al., 2016, Abdelhamid et al., 2016). Carer surveys have indicated that there is a need for increased primary care support relating to the nutritional needs and consequences associated with dementia in those living at home (Alzheimer's Society, 2012). Domiciliary care may form part of the support that the person with dementia receives, and, therefore, plays a significant role in helping maintain an adequate nutritional status. Best practice guidelines have been published to support managers of domiciliary care agencies (Skills for Care, 2014), however there is limited literature that evaluates the nutritional care that these agencies provide.

This scoping study intends to address this gap, by mapping what is currently known about the nutritional care of people with dementia living at home, including any interventions that may have been trialled or implemented, and the views of patients and carers (family and domiciliary). The scoping study will use the Arksey and O'malley (2005) staged framework which includes identifying the research question, searching for relevant studies, selecting studies, charting the data, and collating, and summarising and reporting the results (Levac et al., 2010). The final element of the framework will also be included, which will involve consulting with key stakeholders to validate findings and facilitate opportunities for knowledge transfer and exchange. The outcomes of this scoping study will inform future research, and assist in the development of interventions in this study area. This approach was chosen, due to its promotion of including a wide range of study types to answer a range of questions related to a broad topic to engender conceptual clarity. This scoping study will not intend to rate the quality of evidence found, however will include descriptive numerical summary analysis, qualitative thematic analysis and interventions will be critically appraised.

The research question for this scoping study is:

- What is known about managing the nutritional status of people with dementia living at home?

Additional sub-questions to be addressed include:

- What interventions have been trialled in this setting to improve or maintain nutritional status?

- What are the difficulties with maintaining and/or preventing decline of nutritional status experienced by people with dementia who live at home?
- What is known about the nutritional consequences of dementia by patients and/or formal and/or informal carers?
- Where would carers of and/or people with dementia living at home (formal and informal) go to seek help regarding difficulties with eating and drinking?

## 2.0 Methods

### 2.1 Objectives

The objective of this scoping review is to examine how the nutritional status of people living at home with dementia is managed, the difficulties associated with enabling this, and the involvement of carers and other healthcare professionals.

Preliminary searches of key databases returned no evidence of existing scoping studies in this field of study. Currently, two review protocols are listed on the Prospero and Cochrane Systematic Review database; one is focused on conducting an 'umbrella' review of current systematic reviews of RCT's, and intends to investigate nutritional interventions for individuals over the age of 80 years living with dementia (however excludes mild cognitive impairment, which could be an indicator for dementia and have nutritional consequences), and the other is concerned with the effects of environmental or behavioural modifications on food and fluid intake and nutritional status in people with dementia across all care settings, and is concerned with patient-related outcomes only (i.e. excludes impact of RCT interventions on carers or other stakeholders) (Burckhardt et al., 2014, Herke et al., 2015).

### 2.2 Inclusion and Exclusion criteria

The scoping study methodology encourages finding a breadth of literature, therefore, the following will be included:

- Any interventions (using any research approach) aimed at maintaining or improving the nutritional status of individuals (no age restriction, male and females) with dementia or mild cognitive decline, who live at home alone, or with formal and/or informal carers.
- Any literature where carer or patient knowledge of nutrition and dementia and awareness of available support has been explored.
- Any literature exploring the nutritional consequences of dementia.

Any literature conducted in nursing/residential care homes, or an acute setting will be excluded, however studies conducted with patients using day-centres or short-term respite care will be included.

There will be no restrictions imposed on the outcomes of studies and quantitative (e.g. body weight, blood markers, and hand grip strength) and qualitative (e.g. themes, concepts, case-studies, perceptions and experiences) outcomes will be included.

### 2.3 Study selection

At least two reviewers will be involved in the initial searching of titles and abstracts, and will meet at regular intervals to corroborate and make iterative refinements to the search strategy. Bibliographic information will be downloaded using EndNote X7.5 (Thomson Reuters, 2016). In case of disagreement a third independent reviewer will contribute to discussions. The preliminary search strategy is detailed in *Appendix A*, and will be adapted as required for searching each database. The following sources will be used to search for literature:

- Database search: Electronic databases will be searched from data of inception to present, and the search syntax will be modified as appropriate for use in the following databases:
  - MEDLINE (OvidSP)
  - The Cochrane Library
  - EMBASE
  - TRIP
  - PsycINFO
  - CINAHL

This scoping study will only include literature published in English, due to the resource implications associated with translating literature written in other languages.

- Citation search: Forward and backward citation searching will be conducted on included articles for further material. In the absence of required information, the first authors of studies will be contacted to request additional related material either unpublished or in press.
- Experts in the field: Experts in the field and corresponding authors of included studies will be contacted to gather further information.
- Grey literature search: To minimise the impact of publication bias, grey literature sources will be searched for unpublished material. Examples of

this type of material include government reports, policy documents, dissertation theses, book chapters and research reports. Searches for grey literature will be conducted in the Health Management Information Consortium (HMIC) and the Social Policy and Practice (SPP) databases, both of which will be accessed via OvidSP. Web of Science will also be searched for further material (e.g. conference proceedings) relevant to this scoping study.

- Search engines will also be used with keywords relating to the research questions to find any further relevant grey literature for inclusion (e.g. guidelines, and surveys).

## 2.4 Extraction Method

Full text reviews will be conducted by at least two independent researchers. A data charting form will be developed to include standard information (e.g. author, year of publication) and further detailed information in order to answer the research questions. This will be subject to iterative amendments as reviews progress to ensure that relevant contextual information is captured. The initial data charting form will be validated by two reviewers to corroborate consistency, as recommended by Daudt et al. (2013).

## 2.5 Quality Assessment

An element of quality appraisal will be involved in this study, however, unlike a systematic review approach all studies will be included in analysis as may contribute to the knowledge base even if they are of questionable quality. Daudt et al. (2013) recommend using a validated tool for the quality assessment and for the present scoping study reviewers will use the Mixed Methods Appraisal Tool (MMAT), as it allows for quick assessment of qualitative, quantitative and mixed method studies in one tool (Souto et al., 2015, Pace et al., 2012).

## 2.6 Presentation of results

Included studies will be synthesised using descriptive numerical summary analysis, and a PRISMA diagram (Moher et al., 2009) will be used to convey the flow of inclusion upon completion of the review. Qualitative thematic analysis

will be used to identify the key themes and topics, which will then be presented in a summarised format.

## 2.7 Stakeholder Consultation

This scoping study will include the final stage of the Arksey and O'malley (2005) framework, which involves consulting with key stakeholders. Preliminary findings from the literature search will be shared in a focus group format, with participants representing patients, informal carers, domiciliary carers and healthcare professionals. The focus group will be recorded for future qualitative analysis and the outcomes integrated with the outcomes of the literature search. Following this, a further stakeholder engagement session will be held with the intention of sharing the emerging themes from the overall scoping study, and promoting opportunities for knowledge transfer and exchange. The positive impacts of patient and participant involvement (PPI) in health and social care research have been identified as enhancing the quality and appropriateness of research (Brett et al., 2014). Levac et al. (2010) state that stakeholder consultation should not be a required component of scoping studies as it adds 'methodological rigour'. The authors of this scoping study acknowledge the complexities of involving focus group participants with dementia, however will accept the inclusion of 'study partners' (often carers) who can act as informants and provide comfort and reassurance to the participant (Black et al., 2014). The findings of this scoping study will also be published in a relevant peer reviewed journal for dissemination, and form part of future seminar presentations.

Appropriate ethical approval will be sought from Plymouth University prior to involving stakeholders.

## 3.0 Conclusion

This document has outlined the protocol for a scoping study which intends to map the existing literature regarding the nutritional status of people with a diagnosis of dementia living at home. Due to the number of people currently living with dementia, and the projected increase in diagnoses by 2025, it is important to increase the knowledge base of the impacts upon nutritional status and appropriate interventions for people residing in their own homes. The output of

this scoping study will inform future research in this area, and provide a broad review of available literature and stakeholder views.

### 3.1 Funding

This research is funded by the National Institute of Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care, South West peninsula (PenCLAHRC). The views expressed are those of the author and not necessarily those of the NHS, the NIHR, or the Department of Health.

### 3.2 Competing Interests

None

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## 5.0 Appendix A – Preliminary Search Strategy (for Medline OVID)

#	Searches	Results
1	exp dementia/	273445
2	dement*.ti,ab.	117843
3	(living adj2 dementia).ti,ab.	903
4	alzheimer*.ti,ab.	143554
5	'mild cognitive impairment'.ti,ab.	15964
6	1 or 2 or 3 or 4 or 5	312065
7	home.ti,ab.	225574
8	'own home'.ti,ab.	1265
9	'patient* home'.ti,ab.	2340
10	'own house'.ti,ab.	107
11	non-institutional*.ti,ab.	2485
12	'sheltered accom*'.ti,ab.	106
13	community.ti,ab.	424379
14	domestic.ti,ab.	65261
15	caregiver.ti,ab.	23712
16	7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15	703818
17	nutrition*.ti,ab.	274361
18	nutrient*.ti,ab.	122154
19	exp Meals/	17411
20	food.ti,ab.	378570
21	meal*.ti,ab.	74422
22	breakfast*.ti,ab.	10922
23	lunch*.ti,ab.	7485
24	dinner*.ti,ab.	4047
25	snack*.ti,ab.	7195
26	eat*.ti,ab.	95461
27	drink*.ti,ab.	144946
28	hydrat*.ti,ab.	54666
29	feeding.ti,ab.	181867
30	tea.ti,ab.	29089
31	diet*.ti,ab.	556751
32	vitamin*.ti,ab.	221385

33	supplement*.ti,ab.	311327
34	ingestion*.ti,ab.	74982
35	cooking*.ti,ab.	12305
36	appetite.ti,ab.	28444
37	17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36	1876303
38	6 and 16 and 37	2139

Search Strategy for EBSCO (and PROQUEST) Databases:

(AB(dement\*) OR TI(dement\*) OR AB(alzheimer\*) OR TI(alzheimer\*) OR AB('mild cognitive impairment') OR TI('mild cognitive impairment')) AND (AB(home) OR TI(home) OR AB('own house') OR TI('own house') OR AB(non-institutionalised) OR TI(non-institutionalised) OR AB('sheltered accom\*') OR TI('sheltered accom\*') OR AB(community) OR TI(community) OR AB(domestic) OR TI(domestic)) AND (AB(nutrition\*) OR TI(nutrition\*) OR AB(nutrient\*) OR TI(nutrient\*) OR AB(food) OR TI(food) OR AB(meal\*) OR TI(meal\*) OR AB(breakfast\*) OR TI(breakfast\*) OR AB(lunch\*) OR TI(lunch\*) OR AB(dinner\*) OR TI(dinner\*) OR AB(snack\*) OR TI(snack\*) OR AB(eat\*) OR TI(eat\*) OR AB(drink\*) OR TI(drink\*) OR AB(hydrat\*) OR TI(hydrat\*) OR AB(feeding) OR TI(feeding) OR AB(tea) OR TI(tea) OR AB(diet\*) OR TI(diet\*) OR AB(vitamin\*) OR TI(vitamin\*) OR AB(supplement\*) OR TI(supplement\*) OR AB(ingestion\*) OR TI(ingestion\*) OR AB(cooking\*) OR TI(cooking\*) OR AB(appetite) OR TI(appetite))

## Appendix E Search Strategy for scoping review

OVID Search Strategy:

#	Searches	Results	Annotations
1	exp dementia/	273445	
2	dement*.ti,ab.	117843	
3	(living adj2 dementia).ti,ab.	903	
4	alzheimer*.ti,ab.	143554	
5	'mild cognitive impairment'.ti,ab.	15964	
6	1 or 2 or 3 or 4 or 5	312065	
7	home.ti,ab.	225574	
8	'own home'.ti,ab.	1265	
9	'patient* home'.ti,ab.	2340	
10	'own house'.ti,ab.	107	
11	non-institutional*.ti,ab.	2485	
12	'sheltered accom*.ti,ab.	106	
13	community.ti,ab.	424379	
14	domestic.ti,ab.	65261	
15	caregiver.ti,ab.	23712	
16	7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15	703818	
17	nutrition*.ti,ab.	274361	
18	nutrient*.ti,ab.	122154	
19	exp Meals/	17411	
20	food.ti,ab.	378570	
21	meal*.ti,ab.	74422	
22	breakfast*.ti,ab.	10922	
23	lunch*.ti,ab.	7485	
24	dinner*.ti,ab.	4047	
25	snack*.ti,ab.	7195	
26	eat*.ti,ab.	95461	
27	drink*.ti,ab.	144946	
28	hydrat*.ti,ab.	54666	
29	feeding.ti,ab.	181867	
30	tea.ti,ab.	29089	
31	diet*.ti,ab.	556751	

32	vitamin*.ti,ab.	221385	
33	supplement*.ti,ab.	311327	
34	ingestion*.ti,ab.	74982	
35	cooking*.ti,ab.	12305	
36	appetite.ti,ab.	28444	
37	17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36	1876303	
38	6 and 16 and 37	2139	

### **EBSCO and ProQuest Search Strategy:**

(AB(dement\*) OR TI(dement\*) OR AB(alzheimer\*) OR TI(alzheimer\*) OR AB('mild cognitive impairment') OR TI('mild cognitive impairment')) AND (AB(home) OR TI(home) OR AB('own house') OR TI('own house') OR AB(non-institutionalised) OR TI(non-institutionalised) OR AB('sheltered accom\*') OR TI('sheltered accom\*') OR AB(community) OR TI(community) OR AB(domestic) OR TI(domestic)) AND (AB(nutrition\*) OR TI(nutrition\*) OR AB(nutrient\*) OR TI(nutrient\*) OR AB(food) OR TI(food) OR AB(meal\*) OR TI(meal\*) OR AB(breakfast\*) OR TI(breakfast\*) OR AB(lunch\*) OR TI(lunch\*) OR AB(dinner\*) OR TI(dinner\*) OR AB(snack\*) OR TI(snack\*) OR AB(eat\*) OR TI(eat\*) OR AB(drink\*) OR TI(drink\*) OR AB(hydrat\*) OR TI(hydrat\*) OR AB(feeding) OR TI(feeding) OR AB(tea) OR TI(tea) OR AB(diet\*) OR TI(diet\*) OR AB(vitamin\*) OR TI(vitamin\*) OR AB(supplement\*) OR TI(supplement\*) OR AB(ingestion\*) OR TI(ingestion\*) OR AB(cooking\*) OR TI(cooking\*) OR AB(appetite) OR TI(appetite))

## Appendix F Summary table of articles included in scoping review

First Author and (Year)	Geographical Area	Sample and Methodology	Size	Aims	Time frame	Recommendations for future research or clinical practice
Ahmed et al., (2014)	Australia	n = 75 Prospective case controlled		Measuring eating habits and hunger/satiety in two frontotemporal syndromes compared with AD and healthy controls.	24 hours	Relationship between disinhibition, alterations in eating and orbitofrontal cortex integrity. Metabolic profile in FTD vs. amyotrophic lateral sclerosis. Actinography to understand caloric intake vs. expenditure.
Andrieu et al., (2001)	France	n = 318 Prospective cohort		Relationship between nutritional status and risk of institutionalisation.	12 months	
Annweiler et al., (2012)	France	n = 125 Prospective cohort		Low serum 25-hydroxyvitamin D (25OHD) concentrations and association with MCI	9 months	Further prospective analyses to include more memory clinics and whether low serum Vitamin D could be prognostic amongst of dementia amongst those with mild cognitive impairment.
Ball et al., (2015)	Australia	n = 14 Descriptive exploratory study semi-structured interviews		To explore the perceptions of family carers of people with dementia, with emphasis on feeding-related challenges, burden of care, and practical strategies.		A need for strategies and services focusing on family carer education.
Bilotta et al., (2010)	Italy	n = 105 Prospective cohort study		Whether caregiver burden can be an independent predictive factor of weight loss at 3 months in those with AD living at home.	3 months	Further longitudinal studies with larger sample sizes and more complete psychological assessments of caregivers.
Bourdel-Marchasson et al., (2001)	France	n = 43 Case control study		Investigating blood markers of oxidative stress and antioxidants in normally nourished elderly people with AD.	1 month	The impact of Vitamin E supplements on weight maintenance and co-morbidity.
Buell et al., (2010)	Massachusetts	n = 318 Cross sectional prospective study		To explore mechanisms through which Vitamin D may be involved in neurocognitive function.	4 years	

Buffa et al., (2010)	Italy	n = 560 Cross sectional study	Bioelectrical Impedance Vector Analysis (BIVA) and its use for screening/monitoring nutrition/hydration in AD.		
Burns et al., (1989)	London	n = 78 Case control study	Investigating the nutritional status of people with dementia in hospital, living at home vs. control.	6 months	
Chi et al., (2015)	Taiwan	n = 104 Cross sectional and correlational	To investigate the prevalence and patterns of and factors associated with hyperphagic behaviour in Taiwanese patients with dementia living at home.	5 months	Health professionals in homecare or in clinics should be educated regarding the prevalence, patterns, and correlates of hyperphagic behaviour.
De Bruin et al., (2010)	Netherlands	n = 53 Comparative cross-sectional study	To compare dietary intakes of older people with dementia receiving day care at regular day care facilities (RDCFs) or at green care farms (GCFs).	19 months	Larger sample sizes, more observations.
De Rouvray et al., (2014)	Central Africa	n = 1016 Cross-sectional study	To determine the nutritional status of elderly African people and to investigate the association between undernutrition and dementia.		Larger sample size.
Droogsma et al., (2013)	Netherlands	n = 312 Retrospective cross-sectional study.	To determine the prevalence of malnutrition and its relation to various factors in community-dwelling elderly with newly diagnosed AD.	10 years	The relationship between daily functioning, nutritional status and AD warrants further investigation.
Droogsma et al., (2014)	Netherlands	n/a Systematic Review	Review of the effect of interventions in community dwelling AD pts with risk of undernutrition.		Future research should focus on establishing risk factors to design targeted interventions.
Droogsma et al., (2015)	Netherlands/Belgium	n/a Review	To summarise existing knowledge about weight loss and undernutrition in community-dwelling AD patients.		

Faxen-Irving et al., (2009)	Sweden	n = 204 Randomised Controlled Trial	The effects of omega-3 fatty acid (FA) supplements on weight and appetite in patients with mild to moderate Alzheimer's disease (AD) in relation to inflammatory biomarkers and apolipoprotein E.	12 months	Studies exploring the effects of omega-3 on the gene transcription of albumin.
Ferrario et al., (1996)	Italy	n = 44 Prospective cohort	Nutritional patterns in the elderly with AD and mild cognitive impairment.	12 months	
Fjellstrom et al., (2010)	Sweden	n = 17 Focus group interviews	To examine how people living with AD perceive everyday life aspects of food choice, cooking, food-related work and nutritional concerns.		Both qualitative and quantitative methods are needed with special focus on the themes highlighted in this study.
Gillete-Guyonnet et al., (2000)	France	n = 76 Longitudinal cohort	Descriptors of weight loss in AD.	30 months	
Guerin et al., (2005)	France	n = 395 Prospective study single-centre cohort	To describe progressive and severe weight loss in the course of AD.	1 year	F/up of people with AD should be every 6 months and include assessments of functional, nutritional, and neuro-psychologic status.
Guerin et al., (2009)	France	n = 395 prospective single-centre cohort	To characterise massive weight loss in AD ( $\geq 5$ kg over 6 months) over a number of years.	mean f/up 2.5yrs (full time 6.5yrs)	Links with BPSD need to be explored further, using large cohorts.
Guyonnet et al., (1998)	France	n = 76 Prospective study	Monitoring the incidence and severity of weight loss over time in people with AD living at home.	1 year	Regular monitoring of nutritional status in AD pts as soon as diagnosis is suspected and weight loss prevention programmes to reduce caregiver burden.
Hagnelius et al., (2012)	Sweden	n = 926 Cross-sectional study	Total plasma homocysteine differences in relation to prescribed Vitamin B12 in people with dementia.		Regular monitoring of the nutritional status in elderly geriatric patients is necessary. Healthcare workers need to pay more attention to nutrition and compliance. Use of biomarkers early to identify people at risk.



Hua-Chen et al., (2013)	Taiwan	n = 13 Semi-structured interviews	Family caregivers experience with problematic eating behaviours amongst community-dwelling older adults with dementia.	Hospital based dementia outpatient clinics to engage in disease progression on a regular basis. Care skills of caregivers need to be developed to take these specific behaviours in mind, as well as providing greater psychological assistance.
Ikeda et al., (2002)	UK	n = 91 Questionnaires	Investigating the frequency of changes in eating behaviours and development of eating behaviours in frontotemporal dementia and AD.	The efficacy of SSRIs in other primary eating disorders also argues for the need for larger placebo controlled trials in frontotemporal dementia.
Isaia et al., (2011)	Italy	n = 130 Cross-sectional cohort study	Evaluation of the nutritional characteristics of non-institutionalised people with dementia.	Appropriated evaluation of nutritional status could prevent and treat nutrition related problems in people with dementia living at home.
Johansson et al., (2011)	Sweden	n = 15 Ethnography	Capturing the self-description of managing mealtime tasks by persons with dementia.	It is important for caregivers to create a trustful relationship even before problems arise to be able to support the persons when necessary.
Jyvakorpi et al., (2012)	Finland	n = 202 Randomised controlled trial	Whether an individualised nutritional care intervention has an effect on weight, health, physical functioning, and Quality of Life in those with AD and their spouses living at home.	1 year
Keene & Hope., (1998)	UK	n = 104 Prospective	Investigation of hyperphagia and its	1 year (some

		longitudinal study	elements during the course of dementia.	until death)	
Keller et al., (2007)	Canada	n = 23 Descriptive qualitative semi-structured interviews	Family caregiver's perspectives on mealtimes when caring for someone with dementia.		Some formal education can help change attitudes about the primary goals of mealtimes (eg, connection and pleasure), but innovation, experimentation, and flexibility are needed to identify how best to meet the eating challenges they encounter at mealtimes.
Keller et al., (2008)	Canada	Study 1: n = 14 interviews with formal providers Study 2: n = 74 email survey	Nutrition education needs and resources for dementia care in the community.		Front-line staff require more nutrition education than currently provided.
Kwan et al., (2005)	Hong Kong	n = 81 Pilot prospective study	To identify associated factors for weight changes in AD pts.	6 months	The weight loss associated with AD can be prevented and ameliorated by dietary manipulation and caregiver training. Drugs that can lower plasma TNF concentrations may be beneficial to those subjects with AD who fail to gain weight despite dietary intervention.
Lee et al., (2009)	South Korea	n = 490 Cross sectional study	Comparing differences in nutritional risk between mild cognitive impairment groups and normal cognitive function elderly groups in the community.		Screening for nutritional risk should be included in geriatric evaluations.
Lyngroth et al., (2015)	Norway	n = 213 Cross sectional study	Association between people with dementia and caregivers self-reports of nutritional status.		Self-reporting and proxy-rating seem both applicable for nutritional screening among moderate cognitive impaired. Reduced MMSE and/or failed clock drawing test might predict the risk of undernutrition.
Milward et al., (1999)	Australia	n = 316 Retrospective cross sectional study	The association of coincident anaemia with different dementias in elderly, community-dwelling people.		Larger community-based investigations of the associations between anaemia and dementia are needed.

Miyamoto et al., (2011)	Japan	n = 60 Cross sectional observation study	Examination of whether dementia-related eating difficulties increase probability of weight loss in the elderly with dementia who attend day-centres.	6 months	The relevance of the Eating Behaviour Scale (EBS) and its association with weight loss in this group need to be further assessed in a larger population. Standardised methods of assessing eating behaviours in subjects with dementia should be developed.
Nes et al., (1988)	Norway	n = 16 Cross sectional study	Examination of dietary intakes and blood levels of certain nutrients in a non-institutionalised group with dementia vs. healthy control group.		10 micrograms Vitamin D may be necessary to ensure satisfactory 25-OH-Vitamin D level for persons above 75 yrs.
O'Neill et al., (1990)	Ireland	n = 18 Cross sectional study	Dietary and anthropometric measures in mild to moderate AD in community-dwelling people.		Further studies are needed to determine whether low bodyweight is associated with the aetiology of the disease or whether it is a result of the disease process.
Presse et al., (2008)	Canada	n = 62 Cross sectional study	Dietary Vitamin K intake in community-dwelling people with early-stage AD vs. control group		Future longitudinal studies need to consider Vitamin K and AD, and the role of diet in AD. Dietitians should be mindful of the role of green vegetables in cognitive health.
Puranen et al., (2014)	Finland	n = 99 (caregiving dyads) Cross sectional study	Clarification of the association of the caregiver's sex on the nutrient intake of AD couples.		A need exists for tailored nutritional guidance amongst older individuals and especially among male caregivers. Male caregivers might benefit from cooking courses combined with nutritional guidance.

Puranen et al., (2015)	Finland	n = 40 Field notes and survey	Describing the process and feasibility of a randomised controlled trial of an intervention that provided nutritional guidance to home-dwelling people with AD.	1 year	Assessment-based, tailored nutritional guidance implemented with a personal and positive approach may inspire and empower AD families to make positive changes in their diets.
Riviere et al., (1998)	France	n = 72 case-control study	To compare Vitamins C and E plasma levels in patients with AD and assess Vitamin C intake and nutritional status.		Mechanisms by which AD is associated with low plasma Vitamin C remains to be identified.
Riviere et al., (2001)	Europe	n = 224 Non randomised controlled trial	To determine if a nutritional education program prevents weight loss in AD patients.	1 year	By giving nutritional information and support to families, it is possible to improve the patient's global state of health. It is , therefore, important to assess the nutritional status and to follow the weight in patients, while giving support to caregivers.
Riviere et al., (2002)	Europe	n = 224 Cross-sectional observation study	Investigate the predictors of aversive feeding behaviours in people living with AD at home with a caregiver.	1 year	It is important to develop interventions for caregivers and to assess, manage and treat the caregivers stress in order to prevent nutritional problems. Examining the interactional components of meals within the caregiving dyad is probably one of the best strategies to allow people with dementia to have adequate nutrients, especially in later stages of dementia.
Rullier et al., (2013)	France	n = 56 (caregiving dyads) cross-sectional study	The association of individual characteristics of people with dementia and family caregivers with nutritional status of people with dementia.	6 months	Nutritional deficiencies in dementia should be investigated within the caregiving dyad and the nutritional status of CG should also be assessed.

Salva et al., (2009)	Spain	n = 946 Cluster randomised multi-centre study	Testing a socio- educative and nutritional intervention program to prevent weight loss and loss of function in dementia pts (NutriAlz) - published baseline characteristics	1 year	
Salva et al., (2011)	Spain	n = 946 Cluster randomised multi-centre study	Testing a socio- educative and nutritional intervention program to prevent weight loss and loss of function in dementia pts (NutriAlz).	1 year	Patient specific oriented nutritional intervention and activity programmes.
Scarmeas et al., (2009)	America	n = 1393 Longitudinal follow-up study	Investigation into the adherence to the Mediterranean Diet and incidence of MCI and progression from MCI to AD.	average 4.3 years	Replication in other populations. Biological mechanisms involved still unclear.
Shatenstein et al., (2001)	Canada	n = 2427 Cross-sectional cohort study	Anthropometric differences in an elderly cohort - some who have dementia.		Simple anthropometric indicators would appear to be useful proxy measures for nutritional state, if more detailed info is unavailable. Need for broad- based nutrition research in senior populations to elucidate predictors of poor nutritional status.
Shatenstein et al., (2007)	Canada	n = 72 Longitudinal follow-up study	To follow the natural evolution of dietary and nutrition status among elderly community dwelling adults with AD.	1 year	This population would benefit from systematic dietary assessment and intervention to prevent further deterioration in food consumption and increased nutritional risk.
Shatenstein et al., (2008)	Canada	n = 2 Case Studies	The application of dietary intervention strategies in two participants of a larger study - one successful one unsuccessful. Provides understanding of what works/does not and why.	Full study was for 6 months	Patients should undergo full nutritional assessments as part of the review process at memory/geriatric clinics. Timely intervention is required. Nutrition professionals are needed in the setting where AD patients are treated.

Shatenstein et al., (2016)	Canada	n = 67 (caregiving dyads) Quasi-experimental controlled study	Measuring the effectiveness of a dietary intervention to improve nutritional status in community-dwelling AD patients.	6 months	Diet must be assessed and tracked from diagnosis and the caregiver involved.
Silva et al., (2013)	Canada	n = 33 (caregiving dyads) Semi-structured interviews (telephone)	To identify difficulties in dietary management encountered by caregivers and gather opinions on a nutrition intervention strategy.		A better understanding of the caregiver's experience is essential for the development of nutrition interventions adapted to the needs of older adults with AD.
Smith et al., (1998)	America	n = 439 Longitudinal study	Patterns and associates of hyperphagia in community-based pts with dementia.	18 months	
Soto et al., (2012)	France	n = 414 Prospective cohort study	To explore whether weight loss is a predictor of rapid cognitive decline in people with AD.	4 yrs	Weight assessment is simple to perform in current medical practice.
Suominen et al., (2015)	Finland	n = 99 recruited Randomised controlled trial	The effect of a tailored nutritional guide on nutrition, health-related Quality of Life, and falls in persons with AD.	1 yr	Future studies ought to focus not only to weight loss but also to protein intake and other nutrients in order to maintain good nutritional status. Assessment-based, tailored nutritional guidance should be a significant part of the care of old and frail individuals.
Tombini et al., (2016)	Italy	n = 90 (caregiving dyads) Cross sectional study	Measuring nutritional status using MNA, comparing to caregiver nutritional status, and exploring the influence of different factors on nutrition.		Important to identify early signs of malnutrition in AD pts and caregiver's with a tool such as MNA. Nutrition Education should also be provided.
Tully et al., (2003)	Ireland	n = 193 Case control study	Determining n-3 PUFA status in free-living pts with AD using an established biomarker.		Further research into whether low DHA status in AD causes progression of disease.

Vellas et al., (2005)	France	n = 523 Prospective cohort study	To determine the impact of nutritional status on evolution of AD and on response to AchEI in people with AD living at home.	1 year	
Venci et al., (2015)	America	n = 60 Descriptive, cross-sectional study	To determine water intake and patterns of beverage consumption and contribution to total daily micronutrients and energy in older adults with memory decline.		Incorporating adequate amounts of beverages in meals and snacks may help older adults meet their nutrient recommendations.
Winograd et al., (1991)	America	n = 64 Cross sectional study	Nutritional intake in patients with senile dementia of the Alzheimer type.		
Wlodarek et al., (2013)	Poland	n = 160 Cross sectional study	Assessment of the quality of diet of AD individuals living at home, Nursing Home vs. control.		Suitable nutritional intervention may have general positive impact on the diet of the elderly.
Wolf-Klein et al., (1995)	New York	n = 21 Cross sectional study	Measuring the resting energy expenditure in people with AD in different settings.		Further studies are needed to elucidate the mechanisms leading to potential altered body composition in pts with AD. For clinical practice authors recommend additional 200kcal/kg/day in addition to estimated energy requirements preferably as a snack.

## Appendix G Ethics committee approval letter for qualitative studies



5<sup>th</sup> July 2017

### CONFIDENTIAL

Louise Wilkinson  
FF01, UPC Marjon Campus  
Plymouth University  
Peninsula Allied Health Centre  
Derriford Road  
Plymouth  
PL6 8BH

Dear Louise,

### Application for Approval by Faculty Research Ethics Committee

**Reference Number:** 16/17-778

**Application Title:** An exploration of family carer, domiciliary carer and healthcare professional experiences and perceptions of the nutritional care of people living with dementia at home: a qualitative study

Many thanks for sending us the final amendments to your research project and ethics application. I am pleased to inform you that the Committee has granted approval to you to conduct this research.

This approval is for the duration of the project as stated on the application form (30<sup>th</sup> May 2017 to 31<sup>st</sup> December 2017), after which you will be required to seek extension of existing approval.

Please note that should any MAJOR changes to your research design occur which effect the ethics of procedures involved you must inform the Committee. Please contact Sarah Jones (email [hhsethics@plymouth.ac.uk](mailto:hhsethics@plymouth.ac.uk)).

Yours sincerely,

**Professor Paul H Artes, PhD MCOptom**  
Professor of Eye and Vision Sciences  
Co-Chair, Research Ethics Committee -  
Faculty of Health & Human Sciences and  
Peninsula Schools of Medicine & Dentistry

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Professor Paul H Artes, PhD  
Co-Chair, Faculty HHS REB



Version 1.2 Last updated : 26/05/2017

“Exploring the family carer experience of the nutritional care of people living with dementia at home.”

We would like to invite you to participate in a new research study. Before you decide whether or not you would like to take part, it is important you understand why the research is being done and what it will involve. This information sheet explains the background and aims of the study. Please take time to read it carefully and discuss it with others if you wish. Please contact us if anything is unclear or if you would like more information. Your participation in this study is voluntary.

### **Why have I been chosen?**

You have been chosen because this study is interested in the experiences of people who provide nutritional care to family members with dementia living at home. You live with, or visit a relative who has a form of dementia, and you may carry out shopping, cooking, meal assistance responsibilities on a regular basis.

Few studies have examined the experiences of family members who provide care to another family member(s) living at home with dementia with regards to nutrition. By understanding more about the experiences of family carers, we can develop and test ways to support people with dementia and their carers.

### **What would I have to do if I took part in this study?**

1. Have a face-to-face meeting with Louise at your home or another location. Opportunity to ask questions about the study, sign consent forms and receive diary instructions.
2. Keep a diary for 2 weeks to record any positive or negative experiences regarding eating and drinking.
3. Second face-to-face meeting with Louise two weeks later for audio recorded research conversation.
4. Keeping a diary  
Once you have decided you wish to take part, Louise will arrange a suitable date and time to meet you in person to discuss the study in more detail and provide instructions regarding keeping a diary. Louise will ask you to complete a diary to help you remember things you may wish to talk about during the conversation. . The diary does not have to be completed every day – just when something happens involving shopping, cooking, eating and drinking that you feel you want to record. It may be a nice experience, or something that worries you. You can use paper or a notebook, or a computer to record your diary. Louise will ask you to have the diary available when she meets you to refer to, and if you are happy, she will take the diary away to include the information in her analysis.

#### 5. Research Conversation

This will take place at a location that is convenient to you, and can be at your own home if preferred. This date will be at least two weeks after the time you decide to take part. This is expected to take no longer than 60 minutes, and will be audio recorded. Just before starting, Louise will ask you a few questions about you and the person that you care for (e.g. relationship to person with dementia, age etc.). You will be asked to talk about your experience as a carer for someone with dementia, particularly regarding providing nutritional care (shopping, cooking, eating and drinking etc.). We are interested in hearing about your experiences, and Louise may ask you to go into some detail regarding how you felt during the experience.

The research team would also like to combine some of the experiences discussed, with other participants' information to create a 'case-study' which will be used during future interviews with healthcare professionals and domiciliary carers. This will not contain any traceable information.

#### **Will any expenses be paid?**

Yes, any travel expenses incurred will be reimbursed.

**Do I have to take part?** No. It is entirely up to you whether or not to take part. If you decide to take part you may choose to withdraw at any time, and any information will be destroyed at your request. You will be asked to sign a consent form before starting the study, and then give verbal consent once the tape recorder has been turned on.

#### **Will my records be confidential?**

All information collected about you during the course of this research will be kept strictly confidential and anonymous. We will avoid mentioning your name or other identifying information during the recorded interview for this reason but should this happen when the recorded interview is transcribed, any identifying information will be removed. The recording will then be deleted. Electronic information will be stored on a computer which is password protected, in a document file that is also password protected for a maximum of 10 years following the study. All information will be handled in compliance with the Data Protection Act (HM Government, 1998). You will be given a paper copy of your consent form, and a further signed copy will be kept in a locked cupboard at the Peninsula Allied Health Centre at Plymouth University.

#### **What are the possible benefits of taking part in this study?**

There are no immediate benefits to individuals who take part in the study. However, in the long-term this research could help improve the nutritional care of people living at home with dementia.

#### **What are the possible disadvantages of taking part in this study?**

There is risk that discussing some experiences may cause some emotional discomfort or upset. In the event of this occurring, the researcher will offer you the opportunity to pause for as long as is required, and you will be able to stop if you wish. Louise will advise you to speak with your GP, or another family member for support. If anything is discussed during the interview that is detrimental or dangerous or highlights safeguarding concerns, Louise has a duty to report this.

**Who has reviewed this research study?**

The study has received approval from the Plymouth University Faculty of Health and Human Sciences Research Ethics Committee.

**How will I hear about the results of the study?**

A summary of the study article can be sent to you when available. Louise will ask you if you wish to receive this.

**Your rights**

Your participation in this study is entirely voluntary. You may withdraw at any time.

If you require any further information about this study or have any questions please contact Louise Mole: [louise.mole@plymouth.ac.uk](mailto:louise.mole@plymouth.ac.uk) or telephone 07814140955, or Mary Hickson: [mary.hickson@plymouth.ac.uk](mailto:mary.hickson@plymouth.ac.uk) or telephone (01752) 587542. Thank you for taking the time to read this information sheet.

## Appendix I Consent form for family carers

**RESEARCH  
WITH  
PLYMOUTH  
UNIVERSITY**

**“Exploring the family carer  
experience of the nutritional care of  
people living with dementia at  
home.”**

Lead researcher: Louise Mole, PhD Student, Plymouth University

Chief Investigator: Professor Mary Hickson, Plymouth University

### Consent Form

Please initial box

1. I confirm that I have read and understand the information sheet dated 26/05/2017 for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.
2. I understand that I am free to withdraw at any time without giving any reason, and that my information can be destroyed at my request.
3. I agree to take part in this study.

☐☐☐

_____ Name of Participant	_____ Date	_____ Signature
_____ Name of Researcher	_____ Date	_____ Signature

For further information please contact the researchers

Email: [louise.mole@plymouth.ac.uk](mailto:louise.mole@plymouth.ac.uk)

Telephone: 07814140955

Email: [mary.hickson@plymouth.ac.uk](mailto:mary.hickson@plymouth.ac.uk)

Telephone: (01752) 587542

## Appendix J Interview Schedule family carers

*This semi-structured interview will consist of a series of open-ended questions. However, these questions will depend upon how much detail the participant wants to give. Due to the sensitive nature of this topic, participants will take some direction over this interview and some questions may be missed out or expanded upon. Minor amendments may be made as the interview progresses as issues may arise that the researcher had not considered.*

### Introduction

Thank you for taking part in this research study, I really do appreciate the time you have given. Before we begin, I want to make it clear that if you wish to skip any question(s), or if you want to stop, all you have to do is say; you don't need to give any explanation for doing so. I may also jot down a few notes throughout if that is ok? I may also ask you to clarify or expand on things you say as we go through; this is so that I fully understand the detail of what you are sharing with me.

Are you happy for us to begin?

### Baseline information

Please can you tell me what your relationship is to the person that you care for?

Are you happy to tell me your age?

How long have you lived with the person you are providing care for?

**Now I would like to ask a bit more about the person who you care for...**

What type of dementia does the person you are caring for have? (e.g. Alzheimer's Disease)

How long have they been living with dementia?

### Interview

1. Can you tell me about the type of care you provide to your <parent/spouse>?

**Possible prompts:** what do you help with? What are they able to do themselves? What help do you have from others (if any)?

2. Can you tell me how you provide nutritional care to you <parent/spouse>? Nutritional care can include making decisions about food shopping, cooking, help with eating meals, and thinking about weight.

**Possible prompts:** what happens? What is involved? What about drinking?

3. Can you tell me about a recent time when you have provided support with nutrition to your <parent/spouse>?

**Possible prompts:** what happened? How did you feel? What help/support did you receive?

4. Can you describe to me how things may have changed with how your <parent/spouse> eats and drinks since their diagnosis?

**Possible prompts:** what is different? Any appetite changes? Weight changes? How about where they eat (i.e. at a table or on lap)? How do you know? How does it make you feel?

5. Can you tell me how you feel you cope with providing nutritional care to <parent/spouse>?

**Possible prompts:** How have you adjusted? What/who helps you? What information/support were you given?

6. Can you describe the things that you think about most when considering nutritional care?

**Possible prompts:** How can you improve the care? What/who would help? What particularly concerns you? e.g knowledge, financial constraints etc.

7. **END** We have come to the end now, thank you for sharing your experiences with me today, is there anything else that you feel relevant to add that I may not have asked you?

## Appendix K Diary template

[illegible]

## Appendix L Participant Information Sheet – Healthcare Professionals

Version 1.3 Last updated : 13/11/2017



Participant Information Sheet – Healthcare professionals and domiciliary carers

“Exploring the domiciliary carer and healthcare professional experience of the nutritional care of people living with dementia at home.”

We would like to invite you to participate in a new research study. Before you decide whether or not you would like to take part, it is important you understand why the research is being done and what it will involve. This information sheet explains the background and aims of the study. Please take time to read it carefully and discuss it with others if you wish. Please contact us if anything is unclear or if you would like more information. Your participation in this study is voluntary.

### **Why have I been chosen?**

You have been chosen because this study is interested in the experiences of healthcare professionals and domiciliary carers who work with people living with dementia at home (and their family members).

Few studies have examined the experiences of healthcare professionals and domiciliary carers who provide care to people living with dementia at home with regards to nutrition. With the number of people living with dementia at home increasing, it is important that support is available to ensure that the nutritional status of the individual with dementia is maintained. By understanding more about the experiences of family carers, we can develop and test ways to support people with dementia and their carers.

### **What would I have to do if I took part in this study?**

Your involvement would include taking part in a research interview with Louise Mole, a registered dietitian and the lead researcher. This will take place at a location that is convenient to you, and can be at your own home if preferred. The interview is expected to take no longer than 60 minutes, and will be audio recorded to allow analysis. During the interview, Louise will ask you to talk about your experience as a healthcare professional or domiciliary carer who has been or is involved in working with people with dementia, particularly regarding providing nutritional care (shopping, cooking, eating and drinking or a therapeutic intervention). We are interested in hearing about your experiences, and you may be asked to go into some detail regarding how you felt during these experiences.

### **Will any expenses be paid?**

Yes, any travel expenses incurred will be reimbursed.

**Do I have to take part?** No. It is entirely up to you whether or not to take part. If you decide to take part you may choose to withdraw at any time, and any information will be destroyed at your request. You will be asked to sign a consent



form before starting the study, and then give verbal consent at the beginning of the interview once the tape recorder has been turned on.

### **Will my records be confidential?**

All information collected about you during the course of this research will be kept strictly confidential and anonymous. We will avoid mentioning your name or other identifying information during the recorded interview for this reason but should this happen when the recorded interview is transcribed, any identifying information will be removed. The recording will then be deleted. Electronic information will be stored on a computer which is password protected, in a document file that is also password protected for a maximum of 10 years following the study. All information will be handled in compliance with the Data Protection Act (HM Government, 1998). You will be given a paper copy of your consent form, and a further signed copy will be kept in a locked cupboard at the Peninsula Allied Health Centre at Plymouth University.

### **What are the possible benefits of taking part in this study?**

There are no immediate benefits to individuals who take part in the study. However, in the long-term this research could improve the nutritional care of people living at home with dementia.

### **What are the possible disadvantages of taking part in this study?**

There is a risk that discussing some experiences may cause some emotional discomfort or upset. In the event of this occurring during the interview, the researcher will offer you the opportunity to pause for as long as is required, and you will be able to stop the interview if you wish. Louise will advise you to discuss any issues with your manager or another colleague. If anything is discussed during the interview that is detrimental or dangerous to the patient or highlights safeguarding concerns, Louise has a duty to report this.

### **Who has reviewed this research study?**

The study has received approval from the Plymouth University Faculty of Health and Human Sciences Research Ethics Committee.

### **How will I hear about the results of the study?**

A summary of the study article can be sent to participants when available. Louise will ask you if you wish to receive this at the interview.

### **Your rights**

Your participation in this study is entirely voluntary. You may withdraw at any time.

### **Contact for further information**

If you require any further information about this study or have any questions please contact Louise Mole: [louise.mole@plymouth.ac.uk](mailto:louise.mole@plymouth.ac.uk) or telephone 07814140955, or Mary Hickson: [mary.hickson@plymouth.ac.uk](mailto:mary.hickson@plymouth.ac.uk) or telephone (01752) 587542.

Thank you for taking the time to read this information sheet.

## Appendix M Consent form healthcare professionals

**RESEARCH  
WITH  
PLYMOUTH  
UNIVERSITY**

**“Exploring the domiciliary carer  
and healthcare professional  
experience of the nutritional care of  
people living with dementia at  
home.”**

Lead researcher: Louise Mole, PhD Student, Plymouth University

Chief Investigator: Professor Mary Hickson, Plymouth University

### Consent Form

Please initial box

1. I confirm that I have read and understand the information sheet dated 13/11/2017 for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.
2. I understand that I am free to withdraw at any time without giving any reason, and that my information can be destroyed at my request.
3. I agree to take part in this study.

☐☐☐

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**Name of Participant**

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**Date**

---

**Signature**

---

**Name of Researcher**

---

**Date**

---

**Signature**

For further information please contact the researchers

Email: [louise.mole@plymouth.ac.uk](mailto:louise.mole@plymouth.ac.uk)

Telephone: 07738001028

Email: [marv.hickson@plymouth.ac.uk](mailto:marv.hickson@plymouth.ac.uk)

Telephone: (01752) 587542

## Appendix N Interview schedule healthcare professionals

### Interview Schedule

*This semi-structured interview will consist of a series of open-ended questions. However, these questions will depend upon how much detail the participant wants to give. Due to the sensitive nature of this topic, participants will take some direction over this interview and some questions may be missed out or expanded upon. Minor amendments may be made as the interview progresses as issues may arise that the researcher had not considered.*

#### Introduction

Thank you for taking part in this interview, I really do appreciate the time you have given. Before we begin, I want to make it clear that if you wish to skip any question(s) during the interview; or if you want to stop the interview, all you have to do is say; you don't need to give any explanation for doing so. I may also jot down a few notes if that is ok? I may also ask you to clarify or expand on things you say as we go through, this is to make sure I fully understand your experience.

Are you happy for us to begin?

#### Baseline information

Please can you confirm your profession?

How long have you been in this profession?

#### Interview

1. Can you tell me about your role, and how you come into contact with people living with dementia at home?

**Possible prompts:** What do you do? What is involved as part of your initial/follow-up assessment?

2. What would you say are your main responsibilities regarding the care of people living with dementia at home?

**Possible prompts:** What is involved? What support do you have from other professionals?

**I am now going to read you a short case-study and will ask you some questions afterwards ....<read vignette>**

3. Can you describe your feelings regarding Sandra and Peter's situation?

**Possible prompts:** How did it make you feel? How do you feel it fits into your role? What could have been done differently?

4. Can you tell me about your experiences with working with family carers when it comes to nutritional care?

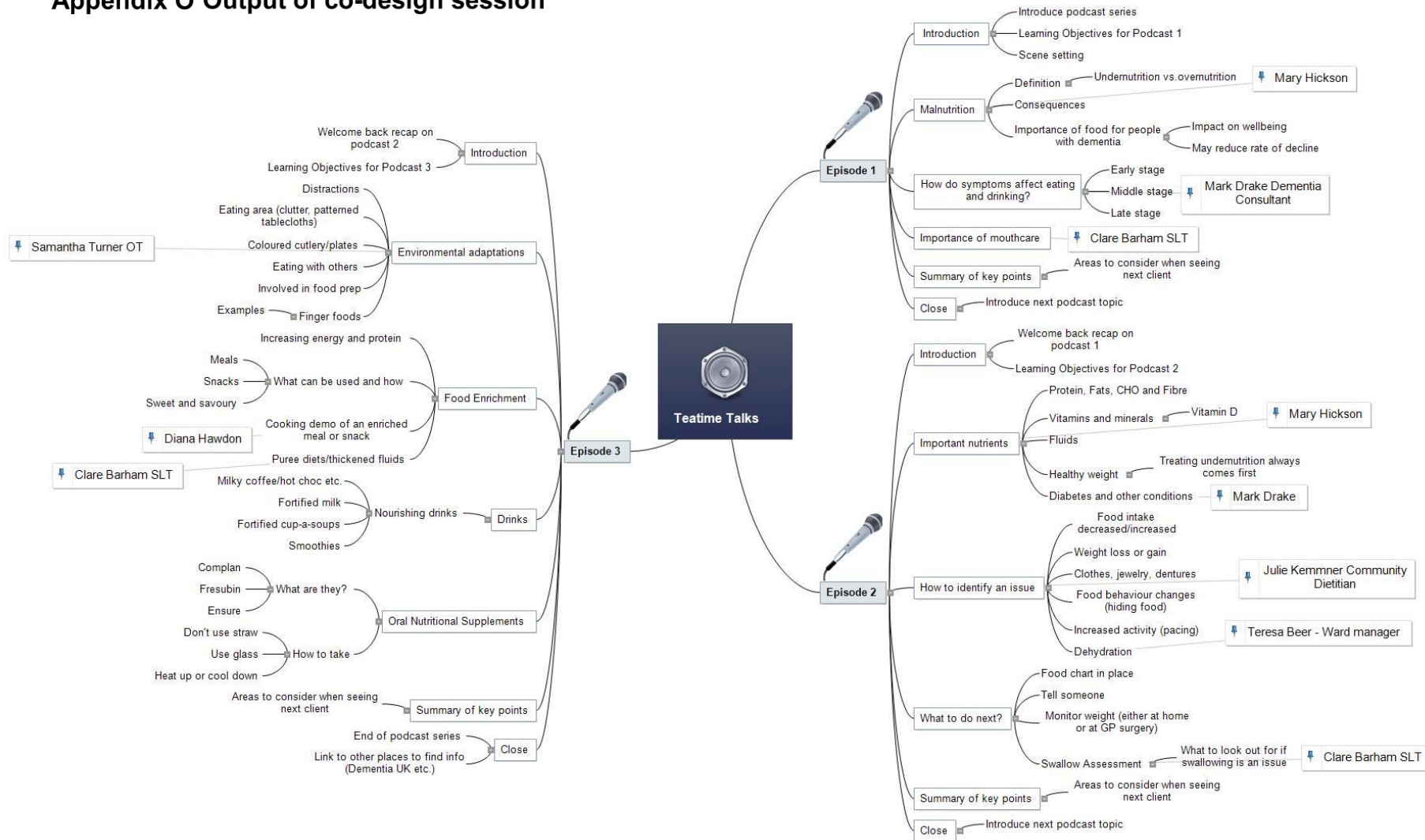
**Possible prompts:** what happens? What is your involvement? What do you feel helps/hinders the family caregiver?

5. Can you tell me about how you think nutritional care could be improved for those living at home with dementia?

**Possible prompts:** what might be the enablers/barriers to doing this? How would this affect your role? What impact do you think it would have on the person with dementia/the family caregiver?

6. **END** We have come to the end now, thank you for sharing your experiences with me today, is there anything else that you feel relevant to add that I may not have asked you?

## Appendix O Output of co-design session



## **Appendix P Example podcast scripts**

Please note that the recorded podcasts do not follow these scripts entirely – however they provide an overview of the content and topics included.

### **Podcast 1**

#### **Introduction**

<intro music, volume down overlay>

“Hello, and welcome to the first episode of Teatime Talk with me, Louise Mole. I’m so glad that you are listening today to find out all about how dementia may affect your clients when they eat and drink. Over the next few episodes, we will be finding out more about what nutrients are important for people with dementia, how to identify if someone is at risk of malnutrition and what you can do to help. We have lots of experts joining us to help. In this episode, we will be understanding what malnutrition is, and what it means for someone living with dementia. We will be hearing from a Specialist Consultant about some of the symptoms of dementia that affect someone’s ability to eat and drink enough. A speech and language therapist, will be discussing mouth care and why it is particularly important for someone with dementia.

By the end of this episode, you will be able to define malnutrition and list some of the causes and consequences. You will be able to identify some symptoms of dementia that can affect how well your clients can eat and drink. Finally, you will understand the importance of mouth care for someone with dementia, and be able to put this into practice, perhaps with a client this week?

So, whether you are in the car listening today or sat down with a cup of tea let’s get started...”

<music interlude, volume up>

#### **Malnutrition**

I am joined by Mary Hickson, a professor and dietitian who has a particular interest in the nutritional concerns of older adults.

“What is malnutrition? It is defined in the dictionary as a lack of proper nutrition, caused by not having enough to eat, not eating enough of the right things, or the body being unable to use or process the food that someone does eat.

Malnutrition can be over or undernourished but usually means a deficiency in calories, protein, vitamins and minerals. It is currently under recognised and, therefore, under treated. We think that malnutrition affects around 3 million

people in the UK, with 93% of these living in the community, either in a care home or their own home.

Someone can become at risk of malnutrition if their requirements for nutrients increase, due to an infection, wound, or perhaps diarrhoea and vomiting. They may also be at risk if they don't eat and drink enough. There are many reasons why someone may not eat or drink as much as they used to. They may feel unwell, or have become less active. They may have problems with chewing food, or swallowing properly. They may have problems with eyesight that can affect preparing and eating food. They may be struggling financially, or may have depression. If their environment has changed, such as they have moved to another home or recently lost a loved one this can have an impact.

All of these potential causes of malnutrition can happen to someone without dementia, but we know that having dementia increases the likelihood of someone becoming malnourished. This is why it is important for us to make sure that someone with dementia is able to enjoy eating and drinking for as long as possible, as it improves their quality of life and may reduce the rate of the decline of dementia.

When someone becomes malnourished they will become more dependent on care providers, family members and medical professionals. They will need to visit the GP more often, and perhaps have more prescription medications. Many will be admitted to hospital, and may not ever return to their own home, but to a care home instead. Some may struggle so much that they don't leave hospital at all.

I spoke to Mr Mark Drake, a dementia consultant, to find out more about what symptoms of dementia can affect someone's ability to eat and drink enough.

*I am with Mark Drake, a consultant who specialises in geriatric medicine and sees many patients with dementia. Thank you for joining us Mark.*

*Mark, will you talk us through what symptoms of dementia can affect how well someone can eat and drink?*

It is worth remembering that there are many different types of dementia, and some types do have specific symptoms that can affect eating and drinking. There are many that are general across all types, which we will cover in this episode.

### Early stages

- A person is usually living in the community at this stage, unless they are in a care home already
- May be depressed following diagnoses
- Weight loss OR weight gain at this stage
- Lose interest in activities e.g. meal times
- Unwilling to try new things or adapt to change e.g. unfamiliar foods

- Find it harder to make decisions, showing poor judgement e.g. affecting shopping, cooking
- Forgetting conversations or events e.g. forgetting meal times or that they have already eaten

#### Middle stages

- Forgetful or difficulty making choices “I will just have what you are having”  
Difficulty making choices e.g. menu
- Forgetting how to eat. Over chewing food or holding it in the mouth. Meals take longer
- Confused. Wandering off. Poor concentration at mealtimes
- Behave in way that is unusual. Behaviours that challenge e.g. rejecting food, spitting it out
- Difficulty with perception. Fearing food has been poisoned, increased anxiety at mealtimes
- A reduced sense of smell can reduce sense of taste in turn. Unusual food combinations
- Need frequent reminders to eat, or how to eat and then they eat very slowing
- In early and middle stage dementia you can get poor appetite weight loss or over eating and weight gain

#### Later stages

- Dysphagia
- May develop changes in taste and food preferences. Unusual food choice or habits e.g. only eat sweet foods, or only fluids
- Very pronounced loss of memory and inability to recognise surrounding and objects including food items. Many will lose ability to feed themselves and will require help
- Indifference to food and environment. Refusal to open mouth, turning the head away
- Gradual loss of speech and the ability to communicate
- Weight loss towards later stages can become more rapid.
- To PEG or not to PEG? (Ticinesi et al., 2016) Alternative feeding methods are NOT indicated in late stage dementia – no evidence to demonstrate that they prolong life and can increase risk of early mortality. – Difficult for family and loved ones...unless they had before dementia for other conditions.

*And what about medications? Can they affect appetite?*

Yes, some people will experience side effects from certain medications whether these have been prescribed for the symptoms of the dementia or other conditions. Many of my patients are taking a long list of medications, so just that in itself can result in someone going off food sometimes.

Thank you so much Mark, we will let you get back to work now!



It is important for us all to clean our teeth to ensure that have healthy mouths. I spoke to a speech and language therapist about how mouth care can be affected for someone who has dementia.

## **Importance of mouth care**

*First and foremost Clare – tell us about what a speech and language therapist does?*

*Thanks. Why is mouth care important?*

Good oral health is important for health and wellbeing. Many older adults have dentures which will need additional care. This shouldn't be any different for someone who has dementia. Poor oral health can result in conditions like oral thrush which is likely to affect how well someone can eat and drink.

*How can dementia affect mouth care in the early stages?*

- Someone in the early stages of dementia should carry out their own mouth care for as long as possible, but they may need to be reminded to do it.
- The carer can give them the brush and toothpaste and show them what to do. The person may find it easier to use an electric toothbrush or a toothbrush with an adapted handle to improve their grip.
- It is very important to establish a daily care routine in the early stages of dementia.

*What about in the later stages?*

- As dementia progresses, the person may lose the ability to clean their teeth, stop understanding that their teeth need to be kept clean, or lose interest in doing so. Carers may need to take over this task.
- Someone may be taking nutritional supplements which can be sugary and so may need their teeth brushing more often.

*How can someone assist with mouth care?*

- The technique will vary depending on the individual concerned.
- Generally, the easiest way is for the person with dementia to sit on a straight-backed chair with the carer standing behind. The carer supports the person against their body, cradling their head with one arm.
- They can then brush the person's teeth using a dry toothbrush and a pea-sized amount of toothpaste.

Thank you for sharing your tips with us Clare.

## **Summary**

Let's re-cap on what we have covered in this episode:

- Malnutrition is a serious clinical condition that is more likely to affect someone with dementia.

- It is difficult to get all the nutrients the body needs if food intake is very poor, which can happen for many reasons.
- The symptoms of dementia may affect how much someone eats and drinks, and these will vary as the dementia progresses. They will also vary from person to person.
- Good mouth care is important for someone with dementia at all stages.

What will you do differently next time you see a client with dementia? Do they have some of the symptoms Jane mentioned? Are they able to look after their teeth properly or do they need more help?

## **Close**

Thank you for listening to Teatime Talks. Tune in to Episode 2, where we will find out more about the nutrients that are particularly important for someone with dementia, hear from a specialist dietitian about how you can spot if someone is at risk of malnutrition, and what you can do if they are. Have a great day!

## **Podcast 2**

### **Introduction**

<intro music, volume down overlay>

“Hello, and welcome to the second episode of Teatime Talks with me, Louise Mole. In this episode, we will be finding out what nutrients are important for someone with dementia, and which ones may need monitoring. We will be joined by a specialist dietitian, to learn how to identify if someone may be at risk of malnutrition and what to do if they are. We welcome back Clare, a SLT to tell us more about swallowing issues and what you can do if you are concerned a client may have a problem swallowing.

By the end of this episode, you will be able to list some nutrients that are important and why. You will be able to assess your clients to check if they may be at risk of malnutrition, and know what to do if they are. Finally, you will be able to identify if someone has an issue swallowing and what to do.

So, whether you are in the car listening today or sat down with a cup of tea let's get started...”

<music interlude, volume up>

### **Important nutrients**

I am joined by Mary Hickson, a professor and dietitian who has an interest in the nutritional concerns of older adults.

We are going to talk about some of the nutrients that are important for your clients, why they are important, and some examples of foods that are good sources. We can't cover off all vitamins and minerals, so have focused on a few that you will hopefully recognise.

PROTEIN is needed for the maintenance and repair of body tissues. You need extra protein if you have any form of surgery or major illness or if you have had sores, ulcers or burns. Sources of protein are found in all meat, poultry, fish, pulses such as peas, beans and lentils, nuts, soya products, eggs, cheese and milk.

FATS provide the most concentrated form of energy in the diet. Fats are found in plant foods and animal foods, and high fat foods such as butter, margarine, oils and full fat dairy products for example can be used to add calories to the diet if energy intake are low.

CARBOHYDRATES are starches and sugars. Starch is found in cereals, pulses, grains and potatoes, and sugars are found both naturally in fruits, vegetables and dairy foods and as added sugar in cakes, biscuits, drinks, confectionery, syrups, jams and sauces. Carbohydrates are the main source of energy in the diet and sugars can make food palatable as well as adding extra calories when appetite is reduced.

FIBRE is not a nutrient but is important in the prevention of constipation. Sources of dietary fibre include cereal foods such as bread, breakfast cereals (particularly wholegrain ones), peas, beans, lentils, fruits and vegetables. Dried fruit is also a good source of fibre.

VITAMIN D is needed for healthy bones and to maintain muscle strength. Lack of vitamin D contributes to bone disorders, leading to fractures (including hip fractures) and bone pain. Most people make vitamin D in their skin when exposed to summer sunlight. Older people who stay indoors, or remain fully clothed when outdoors, are unlikely to make sufficient vitamin D in their skin and are likely to need a vitamin d supplement. 10 micrograms of vitamin D3 is the government recommendation for most adults living in the UK. Useful dietary sources of Vitamin D include fortified breakfast, fortified margarine, cereals, oily fish: sardines, pilchards, canned and fresh salmon, herring, tuna, eggs, liver and liver pate.

IRON is an essential part of haemoglobin, which transports oxygen in the red blood cells. A deficiency in iron will cause anaemia which is characterised by tiredness, pallor and loss of vitality as well as depression. Low iron status is also associated with lowered resistance to infection. Sources of iron include liver and kidney, red meat, some fish such as sardines and tuna, bread, pulses, breakfast

cereals, peas, beans and lentils, fried fruit and green vegetables. Iron from animal sources such as meat and fish is easily absorbed by the body.

CALCIUM is needed for maintaining bones as well as for the transmission of nerve impulses and muscle actions and for many other body functions. Sources of calcium include milk and milk products such as cheese and yoghurt, and milk-based drinks and sauces, custards and puddings, foods made with flour, tinned fish eaten with bones, tofu, egg yolk, pulses such as peas, beans and lentils.

WATER is essential for life. As a major component of the body, it has many functions including transporting nutrients and compounds in blood, removing waste products that are passed in the urine and acting as a lubricant and shock absorber in joints. If you don't consume enough water you will become dehydrated. Elderly people are vulnerable to dehydration and they may have difficulties accessing drinks. Fear of incontinence may also mean that some elderly people restrict their fluid intake. Regular drinks should be encouraged; tea and coffee are a good way of getting elderly to drink. Elderly dehydrated people are at particular risk of urine infections and falls and should monitor how much they drink in hot weather.

### **More on dehydration...Teresa Beer a ward sister told me how to spot the signs of dehydration...**

Early signs of dehydration include:

- Thirst sensation;
- Dry mouth;
- Headaches;
- Reduced concentration;
- Darker, more concentrated urine.
- If fluid intake is not increased the symptoms will worsen and moderate dehydration will develop.

Signs of moderate dehydration

- Reduced urine output, increasingly darker colour and stronger odour (Mentes, 2006);
- Increasingly dry mouth, cracked lips;
- Dry eyes due to reduction in tears;
- Lethargy and increased sleepiness;
- Mild or increased confusion;
- Irritability and agitation;
- Worsening constipation;
- Dizziness due to postural hypotension (drop of systolic BP by 20mmHg), often resulting in falls;
- Sunken eyes;
- Unexpected reduction in wound exudate;

- Reduced skin elasticity/turgor.
- If not recognised and corrected through increased oral fluid intake, the circulating volume will become so low that the patient will eventually develop hypovolaemic shock caused by acute dehydration.

Signs of acute dehydration

- Low systolic blood pressure (100mmHg or less);
- Rapid, thready pulse;
- Increased respiration rate;
- Cold extremities;
- Reduced capillary refill time due to peripheral shut down;
- Hyper or hypo delirium (agitation and severe confusion or conversely increased sleepiness and reduced responsiveness);
- Reduced conscious level;
- Greatly reduced urine output (oliguria).

**...I asked a specialist dietitian, Julie Kemmner how to identify if someone is at risk of malnutrition.**

*Hi Julie! Can you tell us a bit about what a community dietitian does?*

*In episode one, we heard about what malnutrition is and the causes and consequences. So why do we need to worry about whether people who have dementia are at risk?*

- If someone with dementia may be at risk of becoming malnourished, it is all of our responsibility as health and care professionals to look out for signs and act appropriately to prevent things from getting worse.
- This is particularly important for people who are living at home, perhaps on their own, and may only see a homecarer every day or few days. They may not see their GP for months at a time.
- So we really rely on homecarers to be able to spot if someone may be having issues, whether with eating and drinking enough or losing too much weight.

*How can we do it?*

- It is really straightforward to check if someone is at risk of malnutrition. Health care professionals use a tool you may have heard of called 'MUST' which stands for 'Malnutrition Universal Screening Tool'. This takes into account current weight and height, recent weight loss and any clinical conditions. However, it isn't always easy to get a weight for clients living at home, and the most important thing is that people with dementia who are at risk are identified even if a weight can't be taken.
- You can ask the person (or any relatives) if they are concerned about being underweight. You can also ask if they have lost weight (unintentionally) in the past 3-6 months. This may be difficult for someone with dementia to answer though.

- If you have been visiting the client regularly, you may notice that their clothes or rings may have become looser. If they wear a belt, have they had to tighten it? If they wear dentures, are they loose? These are all signs that the person has lost weight.
- Has the person lost their appetite recently or interest in eating? Have you noticed that the food in their fridge hasn't been touched? We know that this is a common symptom of dementia.

*What do we do if they are at risk?*

- There are number of things you can do straight away. You will want to ensure that your concerns are documented on your paperwork, and raised to your manager and any family members.
- If you are really concerned than you should also let the clients GP know.
- It would be a good idea to put a food record chart in place, to keep an eye on how much food your client is eating and what types of food. This will be helpful for you to understand if they are struggling.
- If appetite is a problem, you can try offering smaller, more frequent meals and snacks that are higher in calories.
- You can also offer some higher calorie drinks, like full-fat milk or even supplement drinks like Complan that can be bought from a supermarket or pharmacy.
- Are they struggling with kitchen equipment to prepare meals for themselves? You may need to refer to an occupational therapist who will be able to help with adapted cutlery and kitchen equipment.

*Thank you Julie! We are going to talk more about what can be done to help someone who may be at risk of malnutrition in episode 3.*

As well as what Julie recommended, you may be concerned about a client's ability to swallow. I asked Clare Barham, an SLT, more about this....

### **Swallow assessment with Clare**

*Welcome back Clare – for those who haven't tuned into episode 1, remind us what a speech and language therapist does?*

*And....what is your favourite food and why?*

*Why should we worry whether someone with dementia's swallow isn't working properly?*

- Can lead to aspiration pneumonia which is very serious. This is when fluid or food enters the lungs instead of the oesophagus which can happen if the muscles which control how we swallow are not working like they should.
- It can also mean someone stops eating and drinking, or this declines. This, as we know now, will lead to the person losing weight and potentially becoming malnourished.

*How can you tell if someone with dementia has a problem with swallowing?*

- Do they look like they are having trouble swallowing? Or do they tell you they do?
- Are they holding food or drink in their mouth for a longer time than usual before attempting to swallow? Some people with dementia forget how to chew food or how to swallow.
- Does their voice sound 'wet' after they have swallowed a drink (??how long after)
- Do they cough and splutter every time they take a drink?
- Are they avoiding eating and drinking at all and is this unusual for them?

*What should we do if there is a problem?*

- How to carry out a simple swallow assessment?
- Let the client's GP know, and they can arrange for a community speech and language therapist to carry out a full swallow assessment
- Based on the outcome, the person may be advised to follow a different textured diet and/or thickened drinks.

Thank you for sharing your tips with us Clare.

## **Summary**

Let's re-cap on what we have covered in this episode:

- Ensuring that someone with dementia gets enough of the nutrients that they need is important.
- This makes sure that they are able to maintain strength, energy, healthy bowels, healthy bones and prevent other illnesses.
- It is easy to identify if someone is at risk of malnutrition by checking if they are eating enough, and whether they have recently lost weight.
- If they are at risk, it is important to monitor what they are eating, and consider speaking to the GP.
- Swallow issues can occur for people with dementia, and need to be managed appropriately.

What will you do differently next time you see a client with dementia? Will you check if they are eating enough, or whether they have lost weight recently? Are they eating a variety of foods? If they are not eating very well, check that they are able to swallow food and drinks ok.

## **Close**

Thank you for listening to Teatime Talks. Tune in to Episode 3, which is all about changes that you can make to help someone with dementia eat and drink a bit more, including some ideas for meals and snacks. We even get into the kitchen to cook a meal with a chef!

Have a great day!

## Podcast 3

### Introduction

<intro music, volume down overlay>

“Hello, and welcome to the third episode of Teatime Talks with me, Louise Mole. In this episode, we will be learning more about what we can do to help make it easier for someone living at home with dementia to eat and drink. We are going to ‘talk food’ with a dietitian and chef and discover more about drinks, including some supplements that your clients may be taking. We welcome back Clare, a SLT to tell us more about what to do if someone has been recommended to have a different textured diet or thickened drinks.

By the end of this episode, you will be able to list some changes that you could make to someone’s surroundings to try and encourage them to eat or drink more. You will be able to suggest small changes to foods, drinks and snacks if they need enriching with more calories. You will have a better understanding of oral nutritional supplements and how they can be taken.

So, whether you are in the car listening today or sat down with a cup of tea let’s get started...”

<music interlude, volume up>

### Environmental Adaptations

I chatted to Sam Turner, who is an occupational therapist, about what we can do to help make it easier and more comfortable for someone with dementia to eat and drink....

*Hi Sam, thanks for joining us today! Before we begin, can you tell us what an occupational therapist does?*

*How may an occupational therapist get involved with someone living with dementia at home?*

- An Occupational Therapist would support an individual with dementia to maintain their health and wellbeing within their home environment by supporting engagement in meaningful occupations for example being able to prepare themselves a meal, do their ironing, walk their dog or spend time with their grandchildren.
- Most people with dementia wish to remain in their own homes for as long as possible, especially as this environment will be familiar to them and support their ability to manage routine and habits. As a person’s dementia progresses they may find everyday tasks more difficult. Using equipment



and making adaptations to the home environment can help someone to continue to do things for themselves for longer.

- Important to consider how important food and mealtimes may have been to the individual. Especially if food provision for the household was one of their roles or part of a meaningful social activity. They can still enjoy this task, but may just need a bit more help and support.

*Let's talk more about eating and drinking. What can be done to help someone with dementia continue shopping for, preparing and eating food at home?*

- Going shopping with a care-giver, also some supermarkets have started protected time and slow-tills which may help someone with dementia. Using the same supermarket at the same time per week with a similar shopping list of items can support a person with dementia to be able to manage this task.
- Online shopping and food delivery may be a good option for some however this requires a certain level of ability with technology and more importantly remember that food shopping can be an enjoyable activity as well as one of the main social elements of an individual's week.
- Ready-meal delivery such as Wiltshire Farm Foods may be suitable, but shouldn't be a default option for everyone. Safety aspects of preparing a ready-made meal such as using the oven or microwave would need to be considered if this approach was being used.
- Difficulties with movement and co-ordination may impair a person's ability to cook for themselves. There is kitchen equipment available to make cooking easier and safer. One example is a kettle tipper – a frame which allows hot water to be poured safely, at a constant rate and without the need to lift the kettle. Or a hot water level indicator which beeps when the water is at the appropriate level. Other kitchen equipment includes grip extensions for controls on ovens and other appliances such as large handled / electric tin openers (which ordinarily may be hard for a person with dementia to adjust to using), height-adjustable cupboards and other adapted kitchen tools.
- The person may benefit from equipment such as cutlery with large, contoured handles that are easier to grip, and non-spill cups with (often two) large handles or fittings for long or non-return straws. (These are straws that do not let liquid travel back down, making it easier to drink.)
- In relation to the cognitive decline that a person with dementia can have other environmental adaptations and equipment can help such as a talking clock, automatic cut off function on an oven, automated reminders for eating, orientation computers and home smart devices to support daily routine. Visual prompts such as signs on cupboards/electrical devices are beneficial to remind individual's the contents and how to use oven/microwave.

- Other than physical interventions that can help, some people benefit if they can eat meals with others instead of on their own. This increases the social and safety element of this occupation.
- Some studies have shown the benefit of playing soothing music at mealtimes to create a relaxed environment.
- Involving the person in the preparation of meals may also help, as the sounds and smells will stimulate the senses and help the person understand that it is mealtime.
- It is also key to be aware that an Occupational Therapist can work with people with dementia and their carers to support ways in which that person can continue to engagement in occupations that are meaningful to them in a safe and independent manner, so activities you may think could not be completed possibly could.

*What should a carer do if they think a client is struggling or reducing their level of independence with food related activities?*

- Make sure there is no immediate safety risk, for example if they are starting to struggle pouring boiling water from a kettle or leaving a gas hob on.
- A GP or other healthcare professional should be able to refer to an occupational therapist who can visit the person and carry out an assessment within their home environment. They can then make recommendations and provide equipment or adaptations as necessary ensuring that the person.

Thank you for joining us today Sam!

### **Food enrichment**

*We are in a kitchen today, and I am joined by Diana Hawdon who is a food and nutrition advisor for the soil association, a dietitian and used to work as a chef! Mary Hickson also joins us again.*

*So Diana, what are we cooking today?*

We are going to make a Spanish omelette! It is super quick to make, does not cost too much and is a great way to use up leftovers. It is also a great meal for someone who may need to increase their calories and protein intake.

*That sounds delicious! We have the ingredients prepared here can you talk us through them?*

In this version I am using a chopped rasher of bacon, 2 new potatoes cooked (but use tinned to save time!), 1 tablespoon of tinned or frozen sweetcorn, 1 tomato cut into slices, 2 eggs, 1 tablespoon of mixed dried herbs, ½ teaspoon of Worcestershire sauce, 10g (which is roughly around a small matchbox size) cheddar cheese grated.

[Diana to cook Spanish omelette talking through what she is doing, Diana can delegate tasks to Louise and Mary – such as beating the egg mixture, crushing the potatoes.]

[I think we will record the entire food prep, however may edit some bits out depending on time – when we record we will do some bits without spoken word to record the ‘cooking sounds’]

*So whilst the omelette is cooking Diana, let’s talk a bit more about what homecarers can do to enrich someone’s diet who is living with dementia at home.*

Talk through the foods that can be enriched to increase energy and protein for someone who may have a small appetite:

- Milk
- Custard
- Milk puddings
- Porridge
- Mashed potatoes
- Soup
- Sponge pudding
- Ice cream
- Vegetables
- Gravy

Cream is a good addition – clotted cream contains the most calories. If someone is managing a pint of whole milk a day (cereal/porridge, milky tea/coffees, cheese sauces, puddings) – adding 4 tablespoons milk powder will add 200 kcals and has 40g protein (vs. 18.7g in normal pint).

Nourishing drinks include fruit juice, soup (not packet soup made with water), milk and milky drinks.

Finger foods – if someone is struggling using cutlery, finger foods can be easier for them to handle. Examples are things like mini sausages, sausage rolls, fish fingers, quiche, toast, biscuits, crumpets, pizza slices, and potato wedges.

So the Spanish omelette is done and looks and smells amazing! Let’s have a taste! I asked Clare Barham, an SLT, more about this....

### **Textured diets and thickened drinks**

*Welcome back Clare – for those who haven’t tuned into episode 1 or 2 yet, remind us what a speech and language therapist does?*

*Why might someone with dementia need to have different textured food or drinks?*

- They may struggle with certain textured foods and drinks due to their swallow function not working as it should. This could be because they

have forgotten how to swallow or chew food safely, or it may be that the muscles are not working as they need to.

- Some people with dementia may pouch food in their cheeks and forget it is there. Inhaling pouched food (bolus) is a common cause of choking.
- By altering the texture of the food they eat, or the thickness of drinks it can help make sure that they have time to swallow and don't choke.

*What are the different types of diets and drinks?*

- Scale from normal textured food to liquid, same with fluids from normal to thick.

*Is there anything we can do to help, or need to be aware of?*

- If someone needs to have thickener added to drinks, it is important to.....
- Quick tips if someone needs help with eating.
- Watch out for foods like ice-cream as they are solid but then melt really quickly in the mouth.
- <Lou>
  - Puree meals can be roasting hot when they are first heated, but then can cool down really quickly. A cold puree meal isn't going to be very palatable, so depending how long the person needs to eat their meal, splitting it in half before heating may be a good idea.
  - Puree meals can be enriched to add calories and protein. Butter, cream and milk can be added to foods and cheese to mashed potato. Just ensure that what you are adding doesn't affect the overall texture too much. Sometimes puree meals can be bland so adding seasonings may help.
  - If the meal comes like a ready meal, you can always dish it up onto a plate to make it look more appetising.

*What about using straws?*

- It does depend on the individual, and as long as someone's swallow is working as it should straws may help them stay hydrated. However, if someone's swallow isn't working very well straws can be an issue as they shoot the liquid straight to the back of the throat, bypassing the first stage of the swallow. This can increase the risk of the liquid going into the lungs. You can buy straws with valves on which reduce the rate of flow of the liquid.
- <Lou>
  - I would also add, that if someone is taking oral nutritional supplements, they don't have to be taken using the straw that is often attached to the bottle. It is often better to pour the supplement into a suitable cup or glass.

## **Summary**

Let's re-cap on what we have covered in this episode:

- There are lots of things we can do to help someone with dementia eat and drink enough.
- One way is to make the surroundings relaxed for them, and perhaps get them involved in food preparation.
- Choosing higher calorie meals and snacks can also help as well as adding foods like milk, cheese and cream.
- If someone is recommended a different textured diet or thickened fluids there are ways to make these more appetising.
- Using straws may cause some people with dementia problems, open cups are generally best.

What will you do differently next time you see a client with dementia?

### **Close**

Thank you for listening to Teatime Talks. I hope that the podcasts have been helpful, and encourage you to think more about how you can help someone who you care for eat and drink enough. Nutritional care is all of our responsibility, especially for our clients with dementia who may struggle more.

Have a great day!

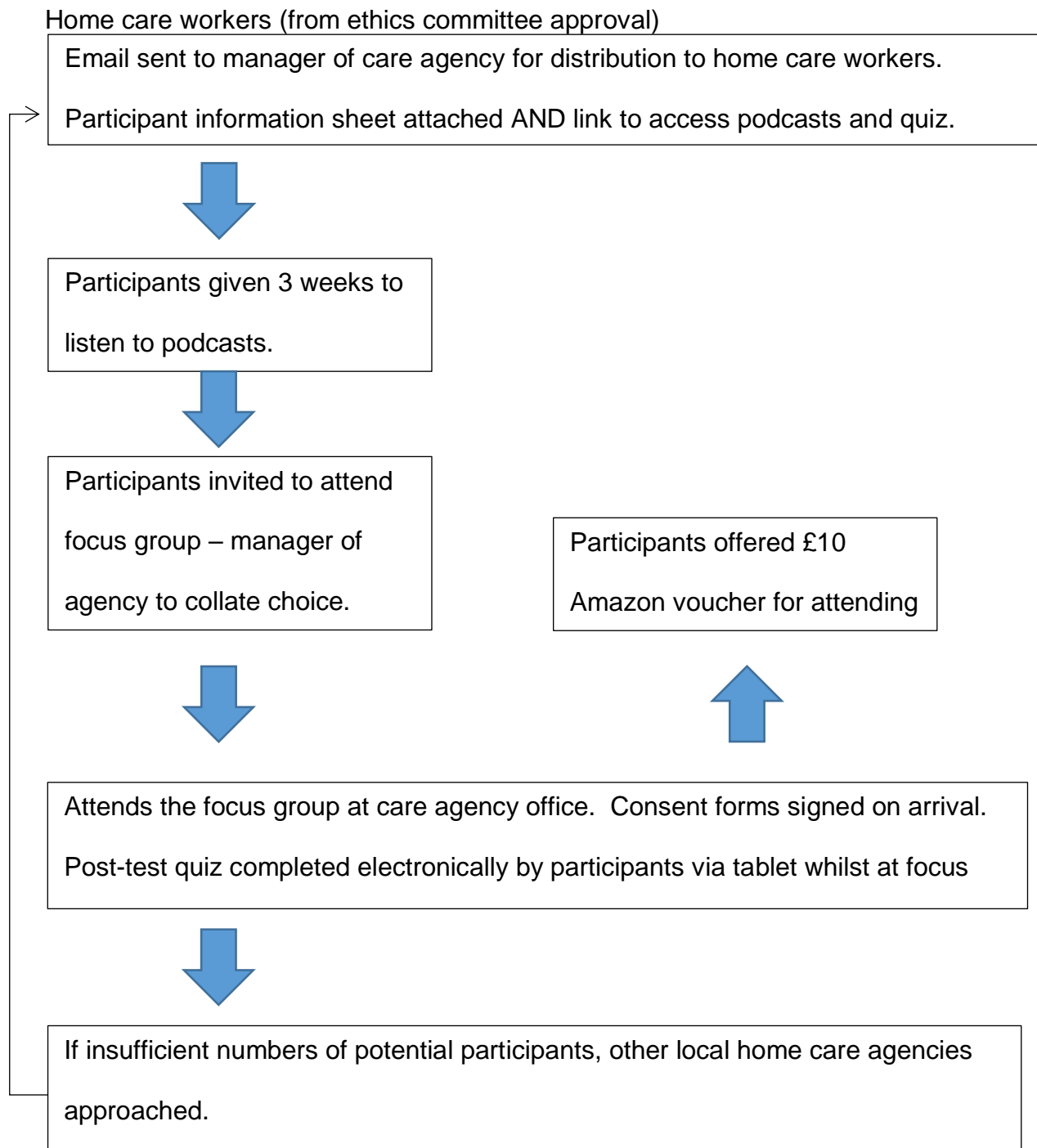
## Appendix Q Teatime Talks podcasts

The podcasts can be accessed here:

[https://liveplymouthac-my.sharepoint.com/:f:/g/personal/louise\\_mole\\_plymouth\\_ac\\_uk/ErOE1nYmcf1Aq7iJ26P2jYUBVchSou-UabcJm47pfziYKg?e=jsvENq](https://liveplymouthac-my.sharepoint.com/:f:/g/personal/louise_mole_plymouth_ac_uk/ErOE1nYmcf1Aq7iJ26P2jYUBVchSou-UabcJm47pfziYKg?e=jsvENq)

Password to access: 'time4tea'

## Appendix R Study Procedure



## **Appendix S Participant email invite template**

*This will be adapted for other agencies if target recruitment is not achieved*

Subject: Improving the nutritional care of people living at home with dementia

Dear homecare assistant

Would you like to know more about nutrition and ways to improve your clients' diets?

I have created a new podcast series which is designed especially for homecarers to help them learn more about nutrition, called TEATIME talks. I would like to know what you think about the podcasts and whether they are useful, so I am inviting you to take part in this study.

All you would have to do is to listen to the three podcasts, then come to a focus group and discuss what you think about them with me and your colleagues. **You will be given a £10 Amazon voucher** for completing the study, when you come to the focus group. Refreshments will also be provided and any travel expenses will be reimbursed.

Before you listen to the podcasts, we'll ask you to complete a short online quiz to test your nutrition knowledge (we will ask you to do this again at the end so we can see what you have learnt).

You can listen to the podcasts whenever is convenient for you (please use the link below to access them). They are specifically designed so you can listen to them in the car in between client visits

The focus groups will take no longer than 1 hour and will take place at the Bluebird office in Torbay.



I attach a copy of the participant information sheet, which contains more information. Printed copies of the participant information sheet are also available to collect from the office. I will ask you to sign a consent form when you come to the focus group to say you have got all the information need and you are happy to take part.

Your information (or any client information you share during the focus group) will be kept confidential and not shared with anyone outside the research team.

I am a researcher at the University of Plymouth and this project is supervised by Professor Mary Hickson ([mary.hickson@plymouth.ac.uk](mailto:mary.hickson@plymouth.ac.uk)).

I hope that you will consider taking part in this study. If you have any queries please do not hesitate to contact me or Mary.

Best Wishes

Louise Mole, Mobile number: 07814140955

## Appendix T Podcast User Guide

### TEATIME podcast – User Guide

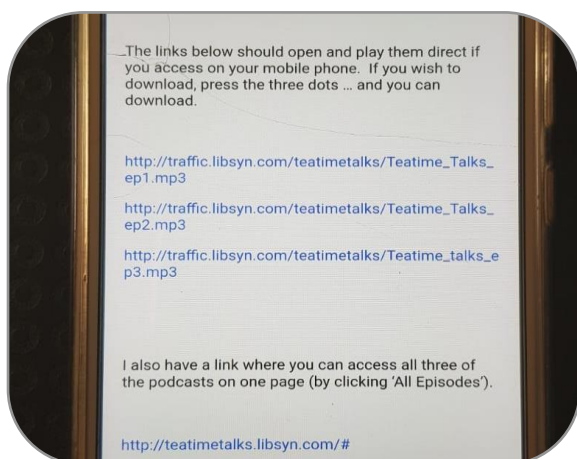


UNIVERSITY OF  
PLYMOUTH

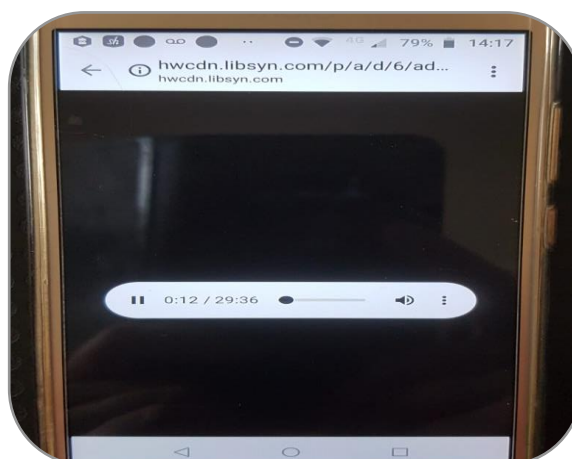
**This user guide will help you access and listen the Teatime podcasts using your mobile phone. If you experience further technical issues please contact Louise Mole on 07814140955.**

Date: 30/09/2019

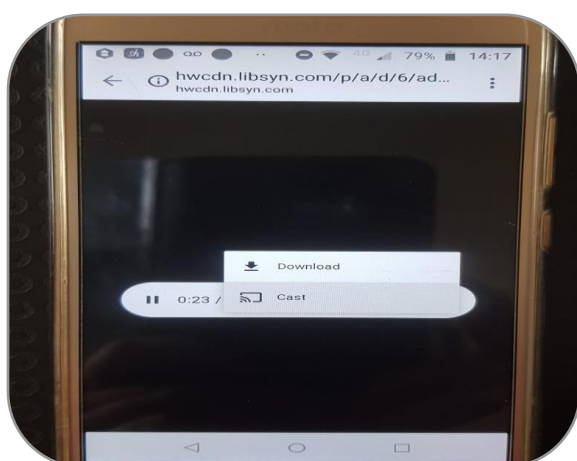
Version 1.0



Access the email containing the podcast links or the SMS text



Click the first podcasts link, which will open in a new window and will start playing straight away. You can perform simple actions such as pausing the podcast and playing again.



You have the option to download the podcasts (each is around 50MB) to your phone. To do this click the three dots to the right of the web player. Click 'download' and the podcast will appear in your downloaded files as: 'Teatime\_Talks\_ep1.mp3'.



You can now play the podcast using another media player app. Most mobile phones have one built-in. If you connect you phone to your car radio using bluetooth you can listen this way.

## Appendix U Recruitment Log

	Participant Name	Participant code for analysis	Participant Job Role	Date of focus group	Contact No./Email address	Consent form completed?	Pre-test quiz completed?	Post-test quiz completed?	Amazon voucher given
1									
2									
3									
4									
5									
6									
7									
8									
9									

## Appendix V Ethics Approval for feasibility study



19<sup>th</sup> September 2019

Louise Mole  
University of Plymouth  
School of Health Professions  
Faculty of Health: Medicine, Dentistry & Human Sciences  
FF01, Peninsula Allied Health Centre  
Derriford Road  
Plymouth  
PL6 8BH

Dear Louise,

**Application for Approval by Faculty Research Ethics and Integrity Committee**

**Reference Number:** 18/19-1148

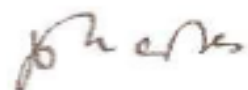
**Application Title:** Training for EATing and drinking In DeMENTia (TEATIME): testing the feasibility of a podcast for home carers.

The Committee has granted ethical approval to conduct this research.

This approval is for 12 months (i.e. until 18<sup>th</sup> September 2020). If you wish to continue beyond this date, you will need to seek an extension.

Please note that if you wish to make any MAJOR changes to your research you must inform the Committee. Please contact the Faculty Research Administrator, Maurice Bottomley (email [hhsethics@plymouth.ac.uk](mailto:hhsethics@plymouth.ac.uk)).

Yours sincerely



Professor Paul H Artes, PhD MCOptom  
Professor of Eye and Vision Sciences  
Co-Chair, Research Ethics and Integrity Committee -  
Faculty of Health: Medicine, Dentistry & Human Sciences

## **Appendix W Pre and post-test quiz**

**Full Name:**

**Time spent as a homecarer:**

**Q1) Which of the following may result in someone with dementia and living at home being at increased risk of malnutrition? (select all that apply)**

- A1) A chest infection
- A2) A recent bout of diarrhoea and vomiting
- A3) Problems with eyesight
- A4) Recently receiving a diagnosis of dementia
- A5) Not sure

[A1, A2, A3, A4 are CORRECT]

**Q2) Which of these statements are true: (select ONE answer)**

- A1) The number of people at risk of malnutrition is greatest in hospitals.
- A2) The number of people at risk of malnutrition is greatest in the community (care homes and own homes)
- A3) Not sure

[A2 is CORRECT]

**Q3) Select all answers that apply to the following 'In the later stages of dementia, someone may':**

A1) lose interest in food

A2) forget how to chew food

A3) need help eating and drinking

A4) have to be fed via a feeding tube

A5) only want to eat sweet foods

A6) Not sure

[A1, A2, A3, A5 is CORRECT]

**Q4) Which nutrient is responsible for ensuring that the gut is kept healthy?  
(select ONE answer):**

A1) Carbohydrates

A2) Protein

A3) Fibre

A4) Fats

A5) Not sure

[A3 is CORRECT]

**Q5) Which of the following statements are correct? (select ONE answer):**

A1) A poor swallow function can lead to aspiration pneumonia

A2) If someone has dementia they will struggle to swallow properly

A3) If someone starts eating with a spoon instead of a fork they have a swallowing problem.

A4) Not sure

[A1 is CORRECT]

**Q6) Which of the following may help someone with dementia eat and drink better? (select ALL that apply):**

A1) Putting on some music they find relaxing whilst they are eating a meal

A2) Adding straws to all of their drinks

A3) Feeding them to get it done quicker

A4) Sitting with them whilst they eat

A5) Not sure

[A1 and A4 are CORRECT]

**Q7) Clotted cream contains more calories than double cream, True or False?**

A1) True

A2) False

A3) Not sure

[A1 is CORRECT]

**Q8) Ice cream is a suitable food for someone who has been recommended to have puree meals and/or thickened fluids – true or false?**

A1) True

A2) False

A3) Not sure

[A2 is CORRECT]

**Q9) Which of the following foods are good sources of protein? (Select ALL that apply):**

A1) Milk

A2) Nuts

A3) Bananas

A4) Steak

A5) Lentils

A6) Avocados

A7) Not sure

[A1, A2, A4, A5 are CORRECT]



**Q10) People living at home with dementia shouldn't drink too many fluids as they may fall if they need to use the toilet more frequently – true or false?**

**(Select ONE answer):**

A1) True

A2) False

A3) Not sure

[A2 is CORRECT]

## **Appendix X Focus group schedule**

### **Introduction**

Thank you for taking part in this focus group, I really do appreciate the time you have all given. I am Louise Mole, and am researching how nutritional care can be improved for people living at home with dementia. The purpose of today is an opportunity for you to share your thoughts regarding the podcasts that you have listened to over the past few weeks. Your identity, and anyone else we discuss today will be kept confidential.

I have a few questions which I will ask, and then we can have an open discussion. There are no 'right or wrong' answers, everyone's contribution is valid. It is also fine to disagree, but please respect other's points of view. An open discussion is great, but please don't interrupt or have side conversations. If you remember, it would be helpful to say your name each time you want to talk (so we know who is who when listening back to the recording).

I will be tape recording the discussion today; is anyone uncomfortable with me doing this? It would also be helpful for confidentiality if you only use first names and avoid naming any clients. If that happens by accident we will make sure it is removed when the recording is transcribed, so don't worry too much. My colleague, <student name> will also be taking notes throughout.

I'm going to start the recording now. Let's do some quick introductions around the table starting on my left. Please can you tell us your first name, how long you have worked at <agency name> and your favourite food.

**[Coherence is about sense making.]**

- 1. What did you think when you first heard about the podcasts?*
- 2. What kind of help with eating and drinking did you provide to your clients before the podcasts?*
- 3. How do the podcasts differ from previous training?*
- 4. Do you think that identifying malnutrition is part of your role? Why do you say that?*
- 5. How do the podcasts fit with your role and day-to-day work at Helping Hands?*

***[Cognitive Participation is about engagement/‘buy in’]***

- 1. How easy was it to find the time to listen to the podcasts?*
- 2. How much effort was it to listen to the podcasts?*
- 3. Did you manage to listen to them during your working day or did you listen to them at other times? (what other times and why?)*

***[Collective action is about actions and interactions that are required to use the intervention]***

- 1. How did the podcasts fit within your working day?*
- 2. How easy was it to access and listen to the podcasts?*
- 3. What were you able to do differently, if anything, with clients after listening to the podcasts?*
- 4. Were you able to trust the information that the podcasts were providing?*

***[Reflexive monitoring is about appraisal and evaluation]***

- 1. How effective and worthwhile do you feel the podcasts are as a way to learn about nutrition and dementia?*
- 2. What did you think was missing from the podcasts?*
- 3. What did you think of the format of the podcasts? (Was the duration right? Was the mix of presenting styles right?)*
- 4. What would improve the podcasts?*

**Useful probing phrases**

Can you tell me more about that?

Can you give me an example?

**END** We have come to the end now, thank you for sharing your experiences with me today, is there anything else that you feel relevant to add that I may not have asked you?

## Appendix Y Email to stakeholder group

Hi!

I was wondering if you had been able to listen to the Teatime talks podcasts yet? It would be really appreciated if you were able to provide some brief feedback on what you thought of them. The trial with homecare workers is underway, however the numbers are small and I would really like to get as much feedback as possible, especially as we hope to build this into applying for funding to develop them further. Feedback will be anonymised in any write-up.

Link to podcast 1: [http://traffic.libsyn.com/teatimetalks/Teatime Talks\\_ep1.mp3](http://traffic.libsyn.com/teatimetalks/Teatime_Talks_ep1.mp3)

Link to podcast 2: [http://traffic.libsyn.com/teatimetalks/Teatime Talks\\_ep2.mp3](http://traffic.libsyn.com/teatimetalks/Teatime_Talks_ep2.mp3)

Link to podcast 3: [http://traffic.libsyn.com/teatimetalks/Teatime talks\\_ep3.mp3](http://traffic.libsyn.com/teatimetalks/Teatime_talks_ep3.mp3)

Please be critical – it is important that you are so that we can aim to make the podcasts the best they can be! ☺ I have listed a few short questions below you can type underneath when you reply. **It would be great if you were able to get your feedback to me before you break up for Christmas.**

If you would prefer to provide feedback over the phone (or in person) please let me know and I will arrange a suitable date and time.

Thank you so much once again!

Q1) What did you think when you first heard about the nutrition and dementia podcast idea?

Q2) How easy was it to access and listen to the podcasts?

Q3) How effective do you feel the podcasts are as a way to learn about nutrition and dementia?

Q4) What did you think was missing from the podcasts?

Q5) What did you think of the format of the podcasts? (Was the duration right? Was the mix of presenting styles right?)

Q6) What would improve the podcasts?

Kind Regards

**Louise Mole**