University of Southampton

Faculty of Environmental and Life Sciences

<u>School of Health Sciences</u>

"It's more than just eating" - Family carer lived experiences of eating and appetite in people with dementia

by

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Thesis for the degree of <u>Doctorate of Philosophy</u>

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<u>Abstract</u>

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Changes in eating behaviour and appetite are a recognised symptom of dementia, described as difficult to manage and associated with family carer feelings of burden. To date there is little empirical research about family carers experiences of these symptoms and behavioural changes. This exploratory, phenomenological study takes a unique approach to developing new knowledge about eating and appetite in dementia. Ten family carers of a person with dementia participated in in-depth interviews. Interpretative phenomenological analysis was used to develop an understanding from these data of family carers lived experiences of eating and appetite in dementia. Specifically, the study explores meaning of these lived experiences for the family carers themselves, their response to changes in eating behaviour and appetite and their views on or experiences of related resources and support.

The present study found that the essence of such lived experiences are that of daily ethical challenges. This encompasses the complex, ethical decision-making around eating, appetite and food which family carers need to make as ability for shared decision-making declines. Personal meaning of food and eating, the need to keep relatives safe in the context of eating and food related tasks, and the powerful influence of health promotion messaging around diet add to the ethical dimension of responding to changes in eating behaviour and appetite. This study found that family carers have little advice or

information to support them respond to such changes, with variable understanding of the impact of dementia on these functions identified. Eating behaviour and appetite changes in dementia may impact family carer ability to meet their own needs and those of the person with dementia, with implications for continuation of home care.

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Research Thesis: Declaration of Authorship

Print name: Emily Walters

Title of thesis: "It's more than just eating" - Family carer lived experiences of eating and appetite in people with dementia

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Parts of this work have been published as:

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Signature: Date: 3 November 2022

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Definitions and Abbreviations

Abbreviations

ADL	Activities of daily living
BAPEN	The British Association of Parenteral and Enteral Nutrition
BMI	Body mass index
BPSD	Behavioural and psychological symptoms of dementia
ESPEN	The European Society of Parenteral and Enteral Nutrition
GDPR	General Data Protection Regulation
GP	General Practitioner
HCPC	The Health and Social Care Professions
HRA	Health Research Authority
IPA	Interpretative phenomenological analysis
MNA	Mini nutritional assessment tool
MND	Motor neurone disease
MUST	Malnutrition universal screening tool
NICE	National Institute for Health and Care Excellence
PPI	Patient participant involvement
REC	Research Ethics Committee
UK	United Kingdom

Chapter 1   Introduction

Eating is a basic human need stimulated by appetite for food. Our appetite or desire to eat can be influenced by many things with physiological need the most obvious. Appetite, how and when we choose to eat is also affected by the environment, life events, personal beliefs, age and illness. Sometimes changes in appetite and eating can be problematic resulting in disordered eating or malnutrition. These can have serious implications for the health and wellbeing of the individual with wider effects on society as well as health and social care services. Public health messaging attempts to raise awareness of the detrimental effects of these. However, such messaging in the United Kingdom (UK) is predominantly focused on healthy eating with national campaigns to raise awareness and understanding of malnutrition less common, despite also being a public health issue. Such an example is the annual Malnutrition Awareness Week co-founded by the Malnutrition Task Force and The British Association of Parenteral and Enteral Nutrition (BAPEN) since 2018. Whilst public health campaigns can be helpful, additional support from healthcare professionals is sometimes required.

I am a dietitian with special interest in disease-related malnutrition and the management of appetite and changes in eating associated with this. My clinical work to date has focused on supporting individuals with a range of acute and chronic disease, which adversely impact appetite and eating. Due to the symptoms of disease or the iatrogenic effects of treatment many patients I have supported struggle to consume adequate energy, protein and nutrients putting them at risk of malnutrition. Less frequently some experienced insatiable appetite (hyperphagia) as a result of medication such as steroids or a tumour in the part of the brain associated with memory or appetite regulation. My first patient caseload as a newly qualified dietitian included individuals on the older person and dementia wards. It was here that I began to better understand the changes in eating and appetite in people with dementia gaining insight into how difficult these were to manage even within a more controlled clinical setting such as a hospital. As my clinical experience increased, I realised that family carers were also impacted being expected to respond to appetite and eating changes. This was often with limited access to support or advice.

Dementia is a progressive condition with increasing need for support and care (Carter, 2015). It is suggested that most people living with dementia wish to remain living at home but as the disease progresses and care needs increase greater support at home is necessary to enable this (Carter, 2015). Family members will often step in to provide such care yet this role of family carer comes with very little support or training in how to respond to changes in eating or appetite (Carmichael et al., 2008). An Australian study describes how family carers felt they were not supported to provide nutritional care for someone with dementia citing a lack of information around how to manage changes in eating (Ball et al., 2015). From my own observations the situation seems to differ little in the UK. Improved support from healthcare professionals is recommended alongside education for family carers (Ball et al., 2015). However, for this to be effective and useful there is a need to understand what support and information family carers want and need and how best to provide this. This leads to some questions. What is available to support family carers in their response to feeding-related problems, eating behaviour or appetite changes? How do family carers respond to these and what is the meaning of such changes for family carers?

1.1   Study purpose

This study sets out to explore and explain the lived-experiences of family carers of eating and appetite in people with dementia living at home. This is an area of research, which is not well described in the literature. The present study provides new insight and understanding of family carer lived-experiences of eating and appetite in dementia contributing new knowledge. Specifically, this is in relation to the meaning of lived experiences of eating behaviour and appetite in dementia for family carers, their response to changes in eating and appetite and support and advice around this. This new knowledge can be used to inform and debate practice in this important area, contributing to the evidence-base for clinical practice and provision of support, information, advice and care.

The research question, objectives and study design are developed within the context of an interpretivist research paradigm and hermeneutic phenomenological philosophy with consideration of my own researcher position. Through exploration of lived-experiences an

understanding of how family carers respond to eating and appetite in dementia are identified. Family carer perspectives on previous support or resources relating to eating and appetite in dementia are explored alongside family carer views about what would be helpful or supportive in the future. The research question and objectives for the study are as follows.

Research question

What are family carer lived-experiences of appetite and eating in people with dementia living at home?

Study objectives

1) To explore family carer lived experiences of appetite and eating in individuals with dementia living at home
2) To identify meaning of these lived experiences for family carers
3) To explore family carer views and lived experiences of resources and support relating to appetite and eating in dementia
4) To explore strategies employed by family carers in response to appetite and eating in people with dementia
5) To discover how family carers describe appetite and eating in people with dementia

1.2   What is dementia?

Dementia is a chronic or progressive syndrome that affects the brain (World Health Organization, 2020). It can result from several different diseases or an injury that primarily or secondarily affects the brain, the most common form of dementia being Alzheimer's disease (World Health Organization, 2020). Dementia causes death of brain cells and eventual cessation of any associated functions of these cells. This includes parts of the brain involved in appetite regulation as well as areas controlling functional ability to put food into the mouth, chew and swallow. Sensory functions of taste and smell can be impacted effecting desire to eat and enjoyment of food. Dementia can also impact vision making it difficult to prepare food or eat. Memory loss is perhaps the symptom most people associate with dementia and this too can affect eating and appetite. It can be difficult to remember to eat and drink, recall when food was last eaten or recognise

edible food items. As a result, it can become challenging to bring to mind how to prepare food or eat it. These changes can affect the amount and type of food eaten and risk adversely impacting nutritional state.

1.3   The impact of dementia on family carers

Whilst addressing the gap in knowledge is good reason for the present study it is helpful to contextualise this through consideration of the impact of dementia. Dementia affects society, health and social care providers as well as those with the disease and their family members. This is eloquently summarised in the following statement.

> "I can think of no other disease that has such a profound effect on loss of function, loss of independence, and the need for care. I can think of no other disease so deeply dreaded by anyone who wants to age gracefully and with dignity. I can think of no other disease that places such a heavy burden on families, communities, and societies" (Chan, 2015)

Dementia is a significant challenge for the individual, family members and society. The incurable nature of this degenrative condition has resulted in dementia being described as the most feared disease in those aged over 50 years (SAGA, 2016). This is likely due to its degenrative nature, loss of cognition and function, lack of cure and inevitable death. It is ranked within the top ten conditions for healthcare burden in those aged 60 years and older with considerable support from health and social care services required (Prince et al., 2015). It is estimated that over 50 million people worldwide have dementia with 10 milliion new cases annually (World Health Organization, 2020). At least 850,000 people are thought to be living with dementia in the UK with 448,300 older people having a documented diagnosis of dementia in England alone in 2018 (England, 2019, Prince et al., 2014). Alzheimer's disease is the most common form of dementia accounting for between 60-70% of dementia cases worldwide (World Health Organization, 2020). The incidence of dementia is anticipated to continue rising with over 1 million adults predicted to be living in the UK living with dementia by 2021 (Prince et al., 2014).

Understandably, there is much focus within the research community to find a cure, slow down progression of the disease or prevent dementia from occurring but as yet there has

been little success with these ventures. Without a cure, management is currently focused on enabling the individual to live well with dementia. However, the progressive nature of the disease means that increasing amounts of support are required to supervise activities of daily living (ADL) alongside interventions to help manage symptoms and maintain quality of life and wellbeing (National Institue for Health and Social Care, 2015, Allegri et al., 2006). Family members will often find themselves providing such care without which those with dementia would struggle to remain living in their own home and eventually require residential care (Sharma et al., 2016, Allegri et al., 2006). Even with such family support some individuals will eventually need residential care.

1.4 Provision of care

The need for support for people with dementia living at home significantly impacts both formal home-care service providers and family members. It is suggested that family carers will likely remain foremost as a provider of care in dementia community care policy (Nolan et al., 2002). It can be argued that such care for family members differs from care for a child, with most people with dementia living without the need for care prior to their diagnosis. Partners and adult children are faced with a decision about whether they can provide care and if they want to take on this role. Further, there is decision around engagement with formal care services and consideration of residential care if or when they can no longer provide care or wish to continue doing so.

Two-thirds of individuals with dementia in the UK are estimated to live at home with approximately 60% of the total formal home-care services provision being used to support these individuals (Carter, 2015, Thraves, 2014). Although this seems like a significant proportion of such care services the scale of need is such that up to 80% of UK dementia-care is actually provided by family members, the majority of whom are untrained and unpaid for this role (Silva et al., 2013, Droogsma et al., 2013). This translates into an estimated 670,000 people providing family dementia care in the UK alone with this figure likely rising since 2014 (Prince et al., 2014). The financial value of family care is estimated at £19714, £32237 and £33482 per annum for each individual with mild, moderate or severe dementia respectively with these amounts likely increased since 2014 (Prince et al., 2014). Added to this is the recognition that providing care for

someone with dementia is not a brief intervention as increasing levels of care are required as the disease progresses sometimes over 10 years or more (Lewis et al., 2014). Thus, the contribution to dementia care which family carers make is significant. It is difficult to imagine how the current health and social care services in the UK would be able to provide such care either financially or physically highlighting the critical role family members play in dementia care.

1.5   Family carer burden

The impact on family members of providing dementia care can be wide reaching and whilst this can be a rewarding role it can also be extraordinarily difficult. As Dr. Margaret Chan stated there is no other disease which places such a heavy burden on families (Chan, 2015). The concept of burden of caring is commonly used in the literature to describe the negative consequences on family members of providing care. Causes of carer burden are recognised as being multifactorial. For dementia family carers it is suggested that such burden is largely associated with prevalence and severity of one or more of a cluster of recognised behavioral and psychological symptoms of dementia (BPSD) (Cerejeira et al., 2012). This includes changes in eating and appetite which are classified together within the group of BPSD (Cerejeira et al., 2012). The literature describes one of the most commonly observed BSPD by family members as changes in eating and appetite, being associated with a more negative carer experience and higher levels of burden (Allegri et al., 2006, Fauth and Gibbons, 2013, McCann et al., 1994). Family carers who experience higher levels of carer burden are found to have greater distress which negatively impacts their own wellbeing and lifestyle (Cerejeira et al., 2012, Kales et al., 2015).

The concept of carer burden has been criticised due to its simplistic rather than holistic view of family caring yet despite this the term remains steadfastly within the dementia literature (Hellström et al., 2005). With its prominence in the literature the term will be used for the present study and thesis. A definition of carer burden is where the demands on a carer exceed the individual's perceived ability to cope due to the general burden of felt responsibility and weight of caring and emotional distress (van der Lee, 2017). It reflects some of the personal cost of caring which can be experienced (van der Lee, 2017,

Poehlman and Dvorak, 2000). Another description is the "overall impact of physical, psychological, social, and financial demands of caregiving" (George and Gwyther, 1986). Most recently Bachmann (2020) suggests carer burden is the "risks associated to carers resulting from long-term and usually unpaid care for people with dementia." From these definitions carer burden can be described as a stress response provoked by a negative perspective of perceived ability to cope and resources to provide caregiving (Bachmann, 2020). Although the sentiment of these descriptions are the same agreed definition is lacking giving weight to the academic argument against the use of the term (Bastawrous, 2013). It is suggested that stress and role theories are key elements in this concept and could be used to help develop an agreed definition but as yet there is no consensus for this (Bastawrous, 2013).

Despite a lack of singular definition the term carer burden remains commonly used in the literature particularly within the context of carer experience (Bachmann, 2020). However, it presents a negative connotation of being a family carer, which is not unilaterally agreed with as family carers can also find providing care rewarding and satisfying (Hellström et al., 2005). Reaction to becoming a family carer, underlying personality, support, environment and even age or gender can influence perceptions of carers about their role and the degree to which negative feelings such as a sense of burden occur. Being a spouse, female or younger carer, or caring for a male with dementia seems to particularly increase levels of emotional distress and may help identify those at greater risk of feeling burdened (van der Lee, 2017). This is significant as spouses have been identified as the most prevelant group of carers for those with dementia.

Emotional distress is also an important factor to consider as it is assoiated with how competent a carer feels in their role. A symbiotic relationship has been observed between emotional distress and feelings of carer competency, where reducing emotional distress can improve feelings of competency and vica versa (van der Lee, 2017). The logic of this would imply that improving how competent a carer feels could reduce levels of emotional distress, positively effecting carer burden. Levels of emotional distress may also influence the risk of the individual with dementia being admitted to a nursing home, with implications for personal and social finances, as well as the potential pyschological and emotional impact on the individiaul with dementia, their family and carers (Gaugler et al.,

2009). This implies a connection between carer emotional distress, feelings of competency and burden and need for residential care.

How family carers perceive their own competency in providing care is important in this context. The dominant factors determining carer burden in dementia are reported as feelings of carer competency and the severity of BPSD (Cerejeira et al., 2012, Allegri et al., 2006, van der Lee, 2017). It is easy to understand that if BPSD are severe it will likely be more difficult to provide care which in turn may udermind family carer confidence in their ability to provide this. BPSD will increase in prevelance and severity as the disease progresses, so it is not unexpetected for feelings of burden to also increase over time (van der Lee, 2017). The evidence suggests that to reduce carer burden interventions should focus on enhancing carers' feelings of competency with interventions to help manage BPSD (Poehlman and and Dvorak, 2000). This is highly relevant to the present study. If the right support or information to engender feelings of competency can be provided to family carers about eating and appetite in dementia the associated feelings of distress or burden might be reduced.

A further suggestion for providing family carer support is politically driven ambition to reduce care costs through keeping individuals at home with family care for as long as possible (Nolan et al., 2002). The academic logic is that interventions to reduce carer burden and emotional distress will in turn reduce the cost of care for the state. Providing interventions and resources to reduce BPSD may improve how competent a carer feels in providing care which in turn might contribute to the individual with dementia continuing to live for longer in a home environment (Joling, 2012). Nolan et al., (2002) suggest that this is the motivation for government drive to provide support with a "growing awareness" of the essential contribution, which family members make to dementia care. Unfortunately, the discourse provided by Nolan et al., (2002) twenty years still resonates today scope to improve family carer remaining.

Perhaps a more helpful and even meaningful approach to supporting families with dementia should be consideration of quality of life rather than carer burden. Dementia can adversely impact the quality of life for both the person with dementia and family carers (Bachmann, 2020). It is not difficult to imagine that family carers who perceive a

worse quality of life may find it more necessary to seek residential care for their family member with dementia. The question then is do we understand what families affected by dementia really need and want in terms of support and advice in order to maximise quality and meaning of life for both themselves and the person receiving care? "Striking discrepancies" are described between the perspectives of healthcare professionals and researchers and those with a disability in the context of needs (Bowling, 1995). It is therefore not unreasonable to suggest that similar discrepancies may occur between professional view and family carer perspective of what is needed for support and advice. A key criticism of researchers and healthcare professionals is the use of statistical significance as an indicator of success of an intervention (Nolan, 1998). Such focus on statistical measures risks losing the humanness such as how individuals feel about or following an intervention. Further, a statistically significant finding for an intervention may confer assurance for healthcare professional or researchers that the intervention is successful or beneficial but the outcome measured may not necessarily be beneficial or helpful for those who are in receipt of the intervention. Outcome measures for supportive interventions need to be appropriate and relevant to those receiving the service and not focused on meeting professional or academic criteria (Nolan, 1998, Nolan et al., 2002). It is even suggested that using measures orientated to a professional view and in particular that of carer burden may limit the scope or range of services provided such that services needed by families are then not provided (Nolan et al., 2002). A significant shift in mind set from the professional to service user paradigm is needed alongside an interest in understanding the experiences of those for whom the service is being designed. This is of particular relevance for the present study and a motivator for exploring family carer lived experiences as a first step in the pathway to providing appropriate and beneficial support and advice around eating and appetite in dementia.

It is acknowledged that management of dementia symptoms is not easy for either healthcare professionals or family carers (Allegri et al., 2006). Models of support need to employ partnership between family carers, those with dementia as well as support services to empower family members and those with the disease. This would help services better reflect the needs of those with dementia and their family carers with ambition to positively impact quality of life (Moriarty, 1999). A consequence of such an approach may help family members not only care for the person with dementia at home

for longer but support a better quality of life for all concerned. It is therefore in the interest of us all to ensure that there is appropriate support for family members to provide care for relatives with dementia (George and Ferreira, 2020). Developing understanding of family carer experiences of eating and appetite provides insight to some of reasons family carers experience negative emotions or feelings of inadequacy as a family carer. This could inform strategies to support family carers and help improve the quality and meaning of life for families affected by dementia. This provides good reason to investigate this topic further.

1.6   Attributing behaviour to dementia

It is easy to attribute any behaviour or action by a person with dementia which is perceived as difficult, strange or socially unacceptable as being due to the disease. Whilst this may be the case for some such an approach forgets that people with dementia are individuals. They may always have had behaviour perceived by others as being 'difficult' or had idiosyncratic habits or behaviours described as socially unacceptable or strange including those relating to eating and food. Kitwood (1997) describes the concept of remembering a person with dementia is an individual in a discourse about personhood in dementia care. Here suggestion is made that those providing care may omit to recall the idea of individuality, forgetting that a person with dementia has their own personal, unique responses to experiences (Kitwood, 1997). There is then a risk that some normal behaviours for those with dementia are subsequently considered abnormal by a carer including family carers with their attributing this to dementia (Kitwood, 1997). This may be the case for some of the observed changes in eating or appetite.

An anecdote was shared about a care home resident with dementia who on being given a cup of tea decided to stir it using the arm of his glasses. Care home staff decided this was inappropriate behaviour, attributing it to dementia and removed his glasses. Of course, what is not known is whether this was usual behaviour or perhaps a result of being resourceful in the absence of a teaspoon to stir the drink or perhaps he had always done this. The sad consequence of this action was that this person was further limited in their functional ability by being unable to see properly without glasses. This highlights the issue of not thinking about the individual and instead considering behaviours as inappropriate

needing to be 'managed' rather than perhaps being idiosyncratic. Further this behaviour brought with it minimal risk and it is difficult to understand why the glasses were removed. Changes in behaviour or response may also be the result of environmental factors or the ageing process rather than dementia and need to be considered when making decisions about any response to these. Judgement is needed to balance enabling independence and allowing idiosyncratic behaviour to continue with risk or harm to the individual or others. A difficult and ethically fraught decision-making process.

Individual responses, habits and concept of personhood need to be borne in mind when thinking about BPSD. BPSD reflect the most common symptoms or behaviours associated with dementia namely delusions, hallucinations, agitation, dysphoria (includes depression), anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behaviour, sleep and night-time behaviour change, appetite and eating, the latter two being grouped as one symptom (Cummings, 1997, Cummings, 1994). Of course, an individual can have any of these symptoms or behaviours for a reason other than dementia. This reflects a limitation of the concept of BPSD but as it remains the most common way of classifying and describing symptoms and behaviour attributed to dementia both within clinical practice and the literature the terminology will be used in the present study and thesis. However, mindfulness of the individuality of behaviour or the possibility of other factors causing observed changes will also be maintained throughout.

1.7   What is meant by eating and appetite?

Although implicitly understood clarifying terms associated with eating and appetite is important for context and positioning of the present study.

1.7.1   Appetite

Appetite in the context of eating is desire or need for food with association made between eating food and cessation of hunger (Andermann and Lowell, 2017, Janowitz and Grossman, 1949). Lay language does not often see the use of the word appetite but rather the expression of associated feeling for example describing feeling hungry or feeling full rather than an increase or reduction in appetite. Both slang and regional

words or phrases are used to describe eating and hungry such as 'grub', 'scran' or 'eats.' Awareness of regional words or slang and their meanings is important when exploring lived experiences to help in understanding and interpretation of data. For the present study drinking and thirst are implied when discussing eating and appetite.

1.7.2   Satiety and hunger

Satiety and hunger are key feelings which drive desire to eat or cease eating (Cox et al., 2020). Satiation and satiety are described as 'within meal' and 'between meal' satiety (Bilman et al., 2017). Satiation occurs whilst continuing to eat but feeling full whilst satiety is the point where eating actually stops being the antonym to hunger (Andermann and Lowell, 2017, Janowitz and Grossman 1949). Hunger is the expression of increased appetite and stimuli for wanting to eat due to homeostatic need or hedonistic desire for food (Andermann and Lowell, 2017, Janowitz and Grossman 1949). Homeostatic appetite regulates hunger and satiety in response to physiological needs, energy and nutrient balance. Hedonistic appetite is stimulated by emotions or environment and usually involves eating foods perceived as being highly palatable. The responses to hunger are summarised in the three 'pillars of appetite' namely food seeking behaviour, consumption of food and satiety processes (Sternson and Eiselt, 2017). Satiety processes are stimulated by resolution of hunger through restoration of energy balance and homeostasis or a relief from hedonistic appetite and food craving.

1.7.3   Extremes of appetite

Hyperphagia and anorexia describe opposite ends of the spectrum of appetite and can be experience by people with dementia. Hyperphagia depicts abnormal increase in appetite presenting as insatiable appetite, searching for food, compulsive or binge eating. It can occur when the physiological processes for satiety are not functioning as would be expected and hunger continue regardless of the amount of food consumed. Hyperphagia may result from medication, disease or an over-riding psychological problem. In contrast anorexia is reduced or loss of appetite associated with illness or disease and occurs even if energy stores are depleted with physiological need for food (Andermann and Lowell 2017). In a clinical context the term anorexia does not refer to the eating disorder anorexia nervosa. Rather anorexia due to disease or illness is an adaptive response to

inflammation processes, which modify appetite and metabolism (Burdette et al., 2020). In the early stages of acute illness this can be beneficial helping the body cope with significant metabolic stress (Burdette et al., 2020). However, if sustained for prolonged periods it has detrimental effect on nutritional state, malnutrition and eventual death if nutrition support is not provided. My own experiences as a dietitian have helped me to better understand the difficulties of managing hyperphagia and anorexia. Reduced cognitive ability or executive function compounds the challenges of altered appetite this due to reduced ability to understand or comply with the advice about diet, eating or other interventions. I have observed that ability for family carers to implement or support compliance with this advice in a home setting can be very difficult and emotionally challenging. It is understandable then why extreme appetite changes and attempts to manage these can result in patient and family carer distress.

A less common change in appetite in people with dementia is pica, described as 'persistent ingestion of non-nutritive substances' with desire to eat or drink non-food items such as paper, dirt or soap (Cipriani et al, 2016). Pica can be associated with iron deficiency, malnutrition or pregnancy and may occur in those with mental health or emotional problems. There is risk of poisoning, choking or intestinal obstruction. Management includes checks for nutritional deficiencies, as well as behavioural and psychosocial interventions (Feldman, 1986). It is particularly described in Alzheimer's disease and semantic dementia where disease effects the temporal lobe and semantic memory, that is to say the memory of meaning, understanding and knowledge (Funayama, 2018). When there is impaired cognition or executive function in a person with pica there is a need for supervision and limitation of access to items which could be dangerous if put in the mouth or swallowed. However, within a home setting constant supervision and limiting access to such items is extremely challenging and likely unrealistic without additional support for family carers.

1.7.4   Eating

Eating is described as a group of different but complex behaviour in response to appetite (Spence et al., 2016). Hunger and cravings whether hedonistic or homeostatic influence eating behaviours with anticipation that these will abate once food is consumed (Andermann and Lowell, 2017). Ability to make decisions about response to appetite is

important requiring cognitive and executive function. For example, deciding when and how much to eat when dieting or if to have dessert when feeling full after a large meal. The physical processes of eating also influence eating behaviour and ability to respond to appetite. These are described as the action of putting food into the mouth, mastication and swallowing of food (Spence et al., 2016). Loss of these physical functions will change eating behaviour or result in abnormal eating.

1.7.5 Describing eating and appetite

Cerejeira et al., (2012) adopted an approach of describing eating and appetite quantitatively and qualitatively which may be helpful when exploring eating behaviours and appetite during the present study. Quantitative changes describe altered amounts of food eaten and reflect either an increase or reduction in what is consumed compared to usual consumption (Cerejeira et al., 2012). This may present as individuals requesting food more frequently, searching for food or an insatiable desire for food or conversely missing meals or snacks, consuming smaller portions, declining to eat or refusing food when offered. Qualitative changes in appetite and eating describe altered taste, choice of food and food preferences with individuals' becoming more or less 'fussy' about food, refusing to eat certain foods or an increased desire for a specific food or food group (Cerejeira et al., 2012).

1.8 Personal positioning

I begin this PhD from the perspective of a clinical dietitian working in the NHS with expertise in the identification and management of disease-related malnutrition. Management of this form of malnutrition in those with an incurable condition including dementia can be particularly challenging with ethical and moral dilemmas for clinicians such as myself. From my own experiences in clinical practice, talking with a patient or family members about likely changes in eating and appetite with disease progression towards end-of-life care can be beneficial. Although difficult and often emotionally charged such conversations can help reduce anxiety or distress for all concerned. Reassurance that what is being experienced or observed is 'normal' for a disease course without cure particularly in the latter phase of life can allow focus to move from what is being eaten to supporting enjoyment of eating, the social activities around this and

quality of life. Nutritional goals can become focused on maximising quality of life and supporting chosen activities rather than seeking to achieve often unrealistic nutritional markers or outcomes. Mealtimes can be an opportunity for social interaction rather than anxiety and arguments about what is consumed. Thus, my role as a dietitian in a palliative care and end of life setting is to support both the individual and their family to manage expectations about nutritional state and intake throughout the disease course, advising on appropriate nutritional interventions for the disease stage and where known reflecting patient wishes. Nutritional care then becomes about how to positively contribute to quality of life, enjoyment, pleasure and comfort appropriate for the stage of a disease and patient wishes. Such an approach is supportive of the ambition of many with dementia to live well.

Anecdotally this type of conversation is less likely to occur for those affected by a dementia diagnosis compared with other incurable diseases, being unable to recall any referral for a person with dementia from a palliative care service nor discussion with at an early enough stage of dementia to enable individual to express their desire for future nutritional care. My experience is that the focus for those with dementia is about living well but nutrition is often not discussed, particularly in the context of an incurable condition or palliative care. My belief is that good palliative care includes discussion of nutrition and eating to enable better support to live well with an incurable disease. Palliative care and living well are therefore not incompatible.

From my own practice, family carers of those with dementia usually only seek help or are referred when nutrition becomes problematic such as appetite changes or eating behaviour being too difficult to cope with or weight change becomes worrisome. Often such changes become increasingly difficult to manage at a time when the person with dementia is no longer able to communicate their wishes or they are considered not to have capacity to make decisions about their care. This is not surprising as it is recognised that changes in eating and appetite are more likely to occur as the disease progresses and in particular the latter stages of disease (Watson and Green, 2006). As a result, the voice of the person with dementia is often lost by the time decisions about nutritional care including support for eating and drinking are made yet this is not the case for all neurodegenerative diseases.

1.9   Nutritional pathways in neurodegenerative diseases

The National Institute for Health and Care Excellence (NICE) provides guidance for pathways of care for different diseases including neurodegenerative diseases such as dementia. Such guidelines are informed by current evidence and consensus of professional opinion and act as a reference for clinical practice. During my initial scoping of the literature for the present study I reviewed the NICE guidance for dementia and was struck by how little information there was relating to nutrition care. I then compared this with NICE guidance for other neurodegenerative diseases and was surprised by the significant difference in nutritional guidance for those with dementia compared with motor neurone disease (MND).

The NICE guidelines for dementia, "Dementia Assessment, Management and Support" makes three statements about nutrition, eating or appetite (National Institue for Health and Care Excellence, 2018).

> 1.10.6 Encourage and support people living with dementia to eat and drink, taking into account nutritional needs
>
> 1.10.7 Consider involving a speech and language therapist if there are concerns about a person's safety when eating and drinking
>
> 1.10.8 Do not routinely use enteral feeding in people living with severe dementia, unless indicated for a potentially reversible comorbidity. NICE has produced a patient decision aid on enteral (tube) feeding for people living with severe dementia.

There is no reference to the support of a dietitian, advice on how to 'take into account' the persons nutritional needs nor guidance on how best to 'encourage and support' eating and drinking.

In contrast the NICE guidelines for MND contains comprehensive guidelines on nutritional care. The guidance states that nutritional care should be considered right from diagnosis and at subsequent multi-disciplinary team reviews (National Institue for Health and Care Excellence, 2016). The nutritional pathway in the guidance describes the inevitable loss of ability to feed independently, chew and safely swallow as the disease progresses (National Institue for Health and Care Excellence, 2016). Recommended care includes

access to dietitians and speech and language therapists with supported discussions around having a gastrostomy feeding tube for when oral nutrition was no longer safe or possible (National Institue for Health and Care Excellence, 2016). The guidance also states that the individual should be able to document if they do not want a gastrostomy feeding tube in an 'Advanced Decision to Refuse Treatment' thus giving them control over future nutritional interventions (National Institue for Health and Care Excellence, 2016). This not only helps to prepare individuals and family members for the impact of MND on ability to eat and drink but provides opportunity for the individual to have choice and control about their nutritional care in the future. From my own observations of practice this level of advice and support around nutritional care, eating and drinking and the opportunity to discuss treatment options as the disease progresses is rarely offered to those impacted by dementia in the UK.

The lack of detail in the NICE guidance around nutritional care and support for eating and drinking in dementia suggests a lack of evidence and limited demonstrated of the significance of appetite and eating changes in dementia. A year prior to the NICE guidance for dementia, the European Society for Clinical Nutrition and Metabolism (ESPEN) guidelines on nutrition in dementia were published but the evidence for these is generally weak (Volkert et al., 2015). This could be why the NICE guidelines do not reflect these recommendations. ESPEN recommends screening for malnutrition risk, resolution of problems resulting in malnutrition and provision of nutrition such as it is "adequate" to address the issue of malnutrition (Volkert et al., 2015). This includes "enough attractive food" in a "pleasant environment" with "adequate nursing support" and the use of oral nutritional supplements (ONS) to improve nutritional status (Volkert et al., 2015). However, the use of ONS is not clear cut in dementia with a systematic review (six randomised controlled trials, three non-randomised trials) concluding that although ONS did improve weight and muscle mass but there was no beneficial effect on cognition and function (Tangvik et al., 2021). Of concern was those with lowest body mass index (BMI) were more likely to compensate for the additional nutrition consumed by reducing dietary intake (Tangvik et al., 2021). Conversely those with higher BMI and at lowest nutritional risk had better functional ability and were more likely to take ONS (Tangvik et al., 2021). Thus, those at most risk were least likely to take ONS or improve overall nutritional intake.

1.10   Vicarious decision-making about eating and feeding in dementia

Food and nutritional care are highly emotive issues resulting in vicarious decision-making being challenging for some family carers. With a lack of guidance around the management of eating and appetite in dementia an increasing need for vicarious decision-making emerges as the disease progresses and capacity for the individual with dementia to make decisions diminishes. Family members, other carers or healthcare professionals have to make decisions for the individual without necessarily knowing or agreeing on what the individual's wishes are. This can result in a sense of burden for the decision-maker questioning if the 'right' decision has been made.

For family carers decision-making becomes an increasingly regular feature as dementia progresses. Decisions about food, eating and drinking are made multiple times each day thinking about what to eat or drink, when to eat, how much to encourage or limit eating, how to encourage drinking, how to cope with "faddy" eating, changes in food preference or refusal to eat or drink and what to do about choking on food or coughing on drinks. Anecdotally it would seem that most family carers carry such decision-making about nutritional care alone with little access to support from healthcare professionals and infrequent access to a dietitian or speech and language therapist for specialist assessment, advice and support. Healthcare professional advice or support relating to nutrition and eating is often only provided in association with formal care such as during a hospital admission, when paid carers are required, nurses provide care in the home or residential care is required. Appropriateness of nutritional interventions may be debated by healthcare professionals and family carers alike. For example, decisions around the use of thickened fluids or particular textures of food to manage swallowing problems or use of prescribable ONS to improve nutritional intake.

When the person with dementia is no longer considered to have capacity to make decisions, vicarious decisions are made in the context of what is deemed to be in a person's 'best interest'. These are particularly difficult decisions to make when the wishes of the individual concerned are not known or have not been documented. Significant difference of opinion between family members and healthcare providers about what is best for the person at the centre of care can occur. My own reflections on the challenges,

which such vicarious decision-making can cause, are captured by the following case report presented by Cantor et al., (2002). The case report describes how a man with Alzheimer's disease was living in residential care and had reached the point where he could no longer feed himself (Cantor et al., 2002). His wife stated that she believed he would not have wanted to be spoon-fed and this was supported by implied statements about care made in his Last Will and Testament. However, the healthcare professionals and carers providing residential care felt they could not be certain about his wishes and that provision of fundamental care, which included nutritional care, should continue. Additionally, the patient did not appear distressed at being spoon-fed yet distress was expressed by those providing care in the residential facility at the thought of stopping spoon-feeding.

This case report identifies distress associated with spoon-feeding being experienced by both family and formal carers and is not unexpected. The literature describes such caregiver distress being associated with the various BSPD which includes changes in eating and appetite (Cerejeira et al., 2012). Without certainty about the patient's wishes and lack of explicit documentation there is understandable caution on the part of those providing formal care around stopping a part of fundamental care. The issue of withholding fundamental care in the form of food and drink is incredibly emotive and ethically fraught with legal ramifications (Justice, 1995). It is therefore not surprising that spoon-feeding was continued for this individual living in a residential care setting. This leads me to speculate about what would have happened if there had been a formal discussion and documentation about nutritional care as part of advanced care planning? What would have happened if this individual had remained at home without formal, paid care? Would the family have not spoon-fed the individual following through on the belief that this is what was wanted? Or would it have been too difficult not to support eating and watch the person die through starvation?

On reflection whose 'best interest' is being treated when I provide advice? This is an uncomfortable thought, as no doubt personal views around the meaning of eating and food subconsciously influence decision-making about the nutritional care recommend. Other influences include those of the multidisciplinary team and family members of the individual being treated. Does this drown out the voice of the individual at the heart of

decision-making? What information is routinely provided about eating and appetite in dementia to families and patients and is this helpful? The weak evidence for NICE and ESPEN guidelines around nutritional care in dementia suggests significant gap in empirical knowledge about eating and appetite in dementia with limited understanding of how family carers respond to changes and the meaning of these for families. Exploring the lived experiences of family carers would provide some foundational insight with scope to benefit practice and family carers.

1.11   Policy context

Policy context of the present study originated with the The Prime Minister's Challenge on Dementia which was a response to growing concerns about the increasing prevelance, associated costs and burden of dementia (Older People and Dementia Team, 2012). The challenge identified four themes: reducing risk of dementia, improving health and care for those affected by dementia, improving awareness of dementia with social action to create dementia friendly communities and dementia focused research (Older People and Dementia Team, 2012). Government monies from this intitiative supported the National Institute of Health Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) Living Well with Dementia Program, which focused on work streams to improve the quality of life of people with dementia and their family caregivers. This funding stream supported the present study and associated Clinical Academic Fellowship and PhD. This sits within the Wessex NIHR CLAHRC collaboration for Ageing and Dementia.

Dementia is a global problem with significant rise in cases predicted 152.8 million people estimated to have the disease by 2019 (GBD 2019 Dementia Forecasting Collaborators, 2022). Public health policy for many countries is focused on reducing modifiable risk factors (high BMI, smoking and high fasting blood glucose) for the disease with a need for planning of health and social care services to provide support and care for those with dementia (GBD 2019 Dementia Forecasting Collaborators, 2022). A more recent UK government policy sets out aspirations for dementia care by 2020 (DOH 2020). This describes the wishes of people with dementia around care including services designed around the needs of both the person with dementia and family carers with 'personal

choice and control over decisions' (DOH, 2020). This is of relevance to the present study where choice and control of eating and provision of nutritional care declines as ability and function is reduced.

1.12   Thesis structure

This thesis comprises 10 chapters. The present chapter introduces the study, background to the study's development and broad context within which it sits alongside the thesis structure. The research question and study aims are also presented. Chapter 2 argues the unique phenomenon of eating behaviour and appetite in those with dementia. This justifies exploration of family carer lived experiences of eating and appetite in dementia as a distinct topic. A hermeneutical approach the literature review of family carer lived experiences of eating and appetite in people with dementia is then presented in chapter three. Knowledge about support and information for family carers in managing this dementia symptom are explored demonstrating limited evidence to support practice in this field justifying the present study. Chapters 4 and 5 present the methodology and method. Chapter 4 includes the theoretical framework and philosophical approach used for the study. This enables development of the method and provides justification for the approach used. Chapter 5 presents the study design, patient and participant involvement (PPI) and ethical considerations. Data collection is via in-depth semi-structured interviews with Interpretative Phenomenological Analysis (IPA) used to enable meaning of family carer experiences to be developed.

Chapters 6, 7, 8 and 9 present details of the participants and findings. Chapter 6 introduces the participants using pen portraits. Description of participants' life worlds is provided supporting the development of the rich, contextual data for interpretation of participant lived experiences of eating and appetite in dementia. Chapter 7 answers the research question and specifically objectives one and two, presenting and discussing new knowledge and understanding of family carer lived experiences of eating behaviour and appetite in dementia. Chapter 8 presents family carer strategies in response to appetite and eating in people with dementia and description of these functions meeting objectives three and four. Chapter 9 meets objective five presenting family carer lived experiences of advice, support and information relating to eating and appetite in dementia, exploring

their preferences for future support and advice. The final chapter considers the implications of this new knowledge for practice, study limitations and recommendations for future research.

1.13   Chapter summary

This first chapter has introduced the study providing context and background from which the research question and objectives have been developed. These inform the focus and purpose of study with thesis structure presented. Chapter 2 makes argument for the unique effect of dementia on eating behaviour and appetite required to establish the unique phenomenon of family carer lived experiences of eating and appetite in people with dementia.

Chapter 2   Eating behaviour, appetite and dementia

This chapter argues the unique phenomenon of the eating behaviour and appetite in dementia justifying exploration of family carer lived experiences of these functions in dementia as a distinct topic. This discourse originates from discussion with a Gerontologist who stated that changes in eating and appetite observed in dementia were no different to those associated with ageing. If this were the case it would be difficult to justify the present study.

To help argue the unique phenomenon of eating behaviour and appetite in dementia a neuro-biological lens is required. However, this does not result in abandonment of the hermeneutic phenomenological lens used for this thesis and study. Such a lens requires interpretation of text from an individual's own perspective with acknowledgment of personal bias (Boell and Cecez-Kecmanovic, 2014, Smythe and Spence, 2012). Similarly, this chapter reflects my own interpretation and understanding of peer reviewed literature or 'text' related to the phenomenon of interest with acknowledgment of my personal bias influencing this. This includes my natural alignment with a neuro-biological lens resulting from my being a qualified dietitian. Thus, although a neuro-biological paradigm is necessary it does not overshadow the core philosophical paradigm used for the present study and thesis.

Argument for changes in eating behaviour and appetite being the same for dementia and ageing is rooted in some similarity of description of changes in these functions. This includes anorexia, brain atrophy, changes in neurotransmitter and hormone levels with potential for socio-economic factors negatively impacting eating or a decline in functional ability effecting meal-related tasks. Dementia is a chronic or progressive syndrome affecting the brain with alteration of blood perfusion, atrophy and dysregulation of neurotransmitter and hormones (World Health Organization, 2020). Similarly, ageing can also be associated with brain atrophy and changes in neurotransmitter and hormone levels (Peters, 2006). Such changes as described as impacting cognition and memory in the older person which may impact eating behaviour and appetite (Peters, 2006). In dementia such alterations reduce ability to respond to and interpret olfactory, visual and gustatory stimuli as well as feelings of hunger or satiety (Ismail et al., 2008, Piguet et al.,

2011, Wittekind and Kluge, 2015, Wlodarek D., 2013, Boyce and Shone, 2006). A decline in memory may also impact these functions (Higgs, 2002). Whilst these changes in dementia and ageing appear similar they do not necessarily result from the same root cause. For example, anorexia is described in both older people and those with dementia. However, in dementia these changes are disease and not age-dependent suggesting different causes. Hyperphagia, bizarre eating habits or pica are sometimes observed in those with dementia but do not commonly occur in older people again implying appetite changes in dementia are disease and not age related (Chapman and Nelson, 1994, Woolley et al., 2007).

2.1 An overview of the appetite regulation

Before exploring this topic further, it is helpful to establish some of the fundamental elements of appetite regulation and describe the role of the brain in these. The brain is central to the processes and activities required for eating and appetite. The hypothalamus is known as the appetite centre working alongside the brainstem to maintain homeostasis (Dagher, 2012, Ahima et al., 2008). An 'appetitive network' of four areas of the brain support activities for eating namely the amygdala and hippocampus, the orbitofrontal cortex and ventromedial prefrontal cortex, the striatum and the insula (Dagher, 2012). The insula, frontal operculum, amygdala, the striatum and frontal lobes enable the senses of taste, vision and smell to be detected and interpreted to support decision-making around eating and response to appetite. The insula also supports learning around sensory information and nutritional effects of foods eaten, whilst motivation and reward prediction involves the striatum and brain stem. This simple overview begins to describe the complex involvement of the brain in eating behaviour and appetite thus if damage to the brain occurs there is a risk of change in these functions.

Insight into the brain's role in eating and appetite has improved using neuro-imaging to map brain activity. Experiments have such activity in response to pictures of food, feelings of hunger or infusion of relevant hormones such that it is now accepted that the brain is central to the processes necessary eating and regulation of appetite (Dagher, 2012,

Ahima et al., 2009). Blundell et al., (2010) provides diagrammatic summary of this in Figure 1.

BRAIN

Meal quality	Meal quantity	Nutrient status	Energy balance
•Expectations •Reards and please •Recognition •Associations	•Stretch •Osmotic load •CCK, GLP-1, PYY, Grehlin	•Insulin •Oxidation •Glucose •Amino Acids	•Insulin •Leptin •Adiponectin

Sensation, prior beliefs and associations

Stomach and intestines

Liver and metabolites

Body (fat) mass

Sensory → Cognitive → Post ingestion → Post absorptive

SATIATION → SATIETY

FOOD EATEN

Figure 1 Satiety cascade adapted from Blundell et al., (2010)

These highly complex processes use multiple connections between the brain, endocrine system, metabolic pathways and organs (Bilman et al., 2017, Cipriani et al, 2016). Berthoud et al., (2017) summarises this complexity presenting two distinct functions of the brain – the 'metabolic brain' and the 'cognitive, emotional and executive brain.' These 'brains' are influenced by the external environment including influences such as food intake, food choice and physical activity (Berthoud et al., 2017). The internal environment similarly influences both the metabolic and cognitive, emotional and executive parts of the brain through digestion and absorption of nutrients, the gut-brain axis, metabolism, energy storage, thermogenesis, growth and repair within the body (Berthoud et al., 2017). The metabolic brain is responsible for homeostatic appetite involving a whole-body system. Homeostatic regulation can stimulate feelings of hunger and satiation in response to metabolic need, energy and nutrient balance, growth and repair (Berthoud et

al., 2017). The hypothalamus is central for neural messaging around homeostatic regulation whilst the neurons in the lateral hypothalamic area respond to a range of cues including hormone and nutrient levels, as well as neurotransmitters from other brain centres associated with energy balance, weight and drinking (Cipriani et al., 2016, Brown et al., 2015, Cox et al., 2020). The brain is able to sense changes in energy stores through changes in hormone and neuropeptide levels and stimulate metabolic pathways to modify appetite and maintain energy balance (Ahima, 2009). The anorectic pathway suppresses appetite whilst the orexigenic pathway stimulates it (Marić et al., 2014) (Augustine et al., 2020, Heisler and Lam, 2017) (Cox et al., 2020). The hormones insulin, grehlin and leptin and the neuropeptides cholecystokinin, glucagon-like peptide and peptide YY are key to appetite regulation and metabolic pathways. Cox et al., (2020) describe how these interplay with the brain and the body to stimulate or suppress appetite influencing hunger and satiety signaling, energy expenditure or availability of energy stores and hedonistic responses.

The brain stem and hypothalamus are central to regulation of the orexigenic pathway stimulated by increased grehlin and reduced insulin and leptin levels. Grehlin is secreted by the gastric cells and transported via the circulatory system and vagus nerve stimulating agouti-related peptide neurons and neuropeptide Y neurons in the arcuate nucleus (Heisler and Lam, 2017, Aviello et al., 2020, Augustine et al., 2020). Grehlin also stimulates the amygdala, orbitofrontal cortex, anterior insula, and striatum and may enhance hedonistic appetite (Malik et al, 2011).

The anorectic pathway is triggered as digestion begins. Insulin is secreted from the pancreas in response to rising glucose levels stimulating the anterior cingulate cortex, orbitofrontal cortex, sensorimotor cortex and hypothalamus (Ahima et al., 2009). This triggers a cascade mechanism of hormones and neuropeptides to suppress appetite and stimulate satiation (Zanchia et al., 2017). Secretion of leptin from adipose cells increases in response to energy deficit inhibit secretion of grehlin (Heisler and Lam, 2017, Marić et al., 2014). Leptin is able to cross the blood-brain barrier, stimulating production of the neuropeptide proopiomelanocortin which inhibits agouti-related peptide activity in the hypothalamus arcuate nucleus suppressing appetite (Heisler and Lam, 2017). It also reduces cocaine and amphetamine regulated transcript in the brain and activity of

mesoaccumbal dopamine neurons and the neurons in the ventral tegmental area in the mid-brain to down regulate appetite and feelings of hunger (Andermann and Lowell, 2017). Finally, leptin can inhibit appetite through stimulation of the nucleus tractus solitarius in the brainstem via the vagus nerve (Heisler and Lam, 2017).

There is also direct relationship between the gastrointestinal tract and the brain, referred to as the gut-brain axis which is critical for control of digestion, absorption and appetite (Berthoud et al., 2017). The vagus nerve is central to the gut-brain axis through a feedback mechanism (Breit et al., 2018). As food enters the gastrointestinal tract, hormones and neuropeptides are secreted and sensed by the brain through the circulatory system or vagus nerve (Susuki et al., 2011). The ileal brake slows movement of food through the gastrointestinal tract to aide nutrient digestion and absorption by slowing gastric emptying, increasing gastric distention as well as hormonal and neural signalling to the brain to inhibit hunger (Malijaars et al., 2008) (Andermann and Lowell, 2017). Receptors in the stomach detect distension providing feedback to the brain when the digestive system is at capacity for volume of food or drink (Janowitz and Grossman, 1949, Andermann and Lowell, 2017). As food moves from the stomach into the small intestine the entero-endocrine cells in this area secrete anorectic hormones into the nervous and blood circulatory systems stimulating the brain to down regulate appetite via both the vagus nerve and circulatory system (Andermann and Lowell, 2017, (Bornet et al., 2007). Such anorectic gastrointestinal hormones include amylin and cholecystokinin which communicate primarily with the hippocampus, amygdala, frontal cortex, insula and anterior cingulate cortex (Zanchi et al 2017).

Whilst the metabolic brain primarily regulates homeostatic appetite, the cognitive, emotional and executive brain enables processing and decision-making about how to respond to feelings stimulated by appetite change and ability to select, prepare and eat food. This can be in response to both hedonistic and homeostatic appetite with external cues, learned behaviour and personal belief moderating response to appetite signals and decisions about what, when and how to eat (Andermann and Lowell, 2017). Damage to the areas of the brain involved in metabolic, cognitive, emotional and executive function such as can be found in those with dementia risks impacting appetite regulation or eating behaviour. Thus, the brain is involved in metabolic pathways and appetite regulation as well cognitive, emotional and executive function illustrating the vulnerability of people

with dementia to changes in eating and appetite. This in turn is highly relevant for family members providing care.

2.2   An overview of eating

The process of eating is described by Spence et al., (2016) in the 'Five Phases of Eating' and is helpful in understanding why people with dementia can experience difficulties with this function (Figure 2).
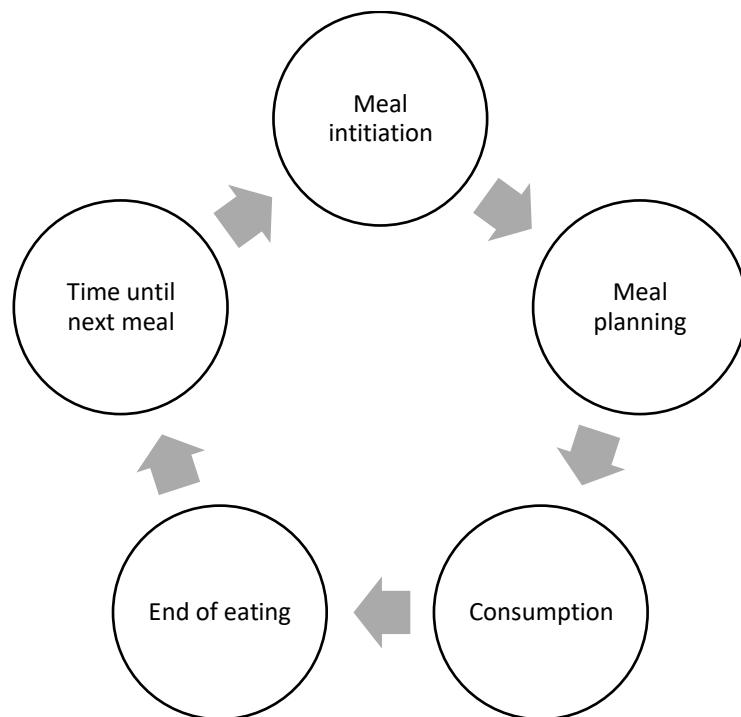
Figure 2 The five phases of eating adapted from Spence et al., (2016)

Memory, executive and cognitive function are required for all phases of eating with physical function important for successful meal-related tasks and consumption of food. Meal initiation is a response to appetite stimuli and external cues whilst memory, sense of time and diurnal rhythm are used to help in the decision-making process around this. Ability to recall prior eating and interpret type of hunger is important for meal planning and decisions about choice of food. Meal planning also requires assessment of concurrent or planned activities, environment, access to food or cooking facilities with decisions around when, where and what to eat. Functional ability to purchase or prepare food is also necessary. Thus, cognitive, executive and emotional function are needed to enable decision-making around meal initiation and planning.

Recognition of food and recall of how to eat is an important component for consumption of food. This requires effective recall of relevant memory and ability to learn from and process memories. Consumption of food necessitates food being placed in the mouth and ability to chew and swallow. Functional ability to consume food particularly involves the Nigrostriatal Dopamine Pathway, the cerebellum, premotor cortex, Brocca's area and the medulla oblongata. The Nigrostriatal Dopamine Pathway runs from the substantia nigra to the caudate and putamen in the basal ganglia and is necessary for motor planning stimulating purposeful movement such as movement of hand to mouth (Vignando et al., 2020). The cerebellum is involved in maintaining posture, balance and control of limbs whilst the premotor cortex helps to guide eye and head movements providing information for orientation. Without these it would be physically difficult to co-ordinate consumption of food unaided. The Broca's area controls movement of facial muscles, the tongue, jaw and throat for mastication of food, formation of a food bolus and ability to initiate a swallow. The medulla oblongata is also critical for safe swallowing.

The end of eating phase reflects satiety and as has been previously described requires memory as well as ability to interpret and act on appetite cues. The time until the next meal is a consideration which can influence the end point of eating. It includes understanding of when food will be next available and planned activities in the interim period which might influence the amount of energy required. The cycle then returns to meal initiation. The complexity of processes required for eating helps in understanding of why eating can be difficult for those with dementia with greater risk of eating-related problems occurring as the disease progresses and damage to the brain increases.

2.3   Motivation and reward

Consideration of pleasure in eating and the role of emotion and reward in appetite is important in the person with dementia. Blundell et al., (2010) present the effect of 'liking' food, anticipated pleasure, internal state and external stimuli on desire for food (Figure 3).

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                                    ┌─────────────────────────────┐
                                    │  Cultural and social context │
                                    │  Previous food experience     │
                                    └─────────────────────────────┘

                  ┌──────────────────────────┐
                  │ Reinforcement and reward  │
                  └──────────────────────────┘
   Change of state

┌──────────────────┐   ┌──────────────┐   ┌──────────────────────────┐
│ INTERNAL STATE   │   │              │   │ EXTERNAL STIMULI          │
│ Physiological and│   │   LIKING     │   │ Learned use context: Time,│
│ psychological    │   │              │   │ frequency, situation,     │
│                  │   │              │   │ appropriateness           │
└──────────────────┘   └──────────────┘   └──────────────────────────┘

   ┌──────────────────┐  ┌──────────────┐  ┌──────────────────┐
   │ Psychophsyiological│ │ Anticipated  │  │ Environmental    │
   │ cues and triggers │  │ pleasure     │  │ cues and triggers │
   └──────────────────┘  └──────────────┘  └──────────────────┘

   Consumption          ┌──────────────────┐
                        │ LEVEL OF DESIRE  │
                        └──────────────────┘
```

Figure 3 The effect of liking on desire and the intermediary influences of psycho physiological state, and external stimuli (learned cues) adapted from Blundell et al., (2010). Black arrows reflect proximate drivers (human activities or actions), grey arrows indicate underlying processes.

Behavioural and emotional response including response to hedonistic appetite for food involves the limbic system (Rajmohan and Mohandas, 2007). The nucleus accumbens is the reward centre and works alongside the mesolimbic dopamine pathway connecting the ventral tegmental area to the nucleus accumbens and mesocortical pathway connecting the ventral tegmental area to the cerebral cortex area of the brain to stimulate reward and motivation (Vignando et al., 2020). Dopamine response involving the brain stem provides a reward value for food consumed with anticipatory dopamine activity when the same food cue occurs (Burdette et al., 2020). In this way dopamine provides both a learning and motivational signal about eating specific foods (Dagher, 2012). The endocannabinoid system also has a significant role in the reward system and

pleasure with stimulation of the endocannabinoid system resulting in food cravings as shown with use of recreational cannabis (Jager and Witkamp, 2014).

Eating food perceived as highly pleasurable driving the dopamine pathways and stimulating the nucleus accumbens resulting in positive emotions. Studies have shown that the higher the perception of a food being pleasant the greater the dopamine release (Vignando et al., 2020). Such associations are highly individual and influenced by how such personal experiences are organised within the brain (Burdette et al., 2020). Negative emotions such as depression commonly induce satiety and loss of appetite but the response of the emotional eater is to eat (Adriaanse et al., 2011). Such eating may result from inability to differentiate homeostatic hunger from the physiological state experienced with negative emotions such as anxiety, distress or depression (Adriaanse et al., 2011). Emotional eaters will have made an association between eating usually highly pleasurable food with a positive effect on the reward system. This is an unconscious association between a negative emotion and eating which can become a learned response and eventually habitual when a particular emotion or difficulty is experienced. Studies have shown that there is a Pavlovian type response in humans with regards to eating and a specific emotion *(*Bongers et al., 2015). Such conditioning can have positive or negative effect on food choice and overall health. For example eating excess amounts of sugar or fat as a result of consuming highly palatable foods in attempt to moderate mood may result in weight gain and obesity *(*Bongers et al., 2015). However, this approach usually only brings short-term changes to mood with potential for longer-term damage to physical health. Kuijer et al., (2015) found that use of food and eating to regulate mood was in fact associated with greater levels of depressive symptoms.

2.4   Eating behaviour and appetite in dementia

With the brain central to regulation of appetite and eating behaviour, changes in these functions are unsurprising in the person with dementia. The nature of changes vary according to type and stage of dementia influencing family carer lived experiences of these functions . Understanding of this provides context for the present study.

2.4.1   Alzheimer's disease

The most common form of dementia in the UK is Alzheimer's disease affecting 62% of those with a dementia diagnosis (Alzheimer's Society, 2014). Around half of individuals with Alzheimer's disease report a reduced appetite as an early presenting symptom with 80% experiencing problems with eating and swallowing at some point in their disease course (Ikeda et al., 2002, Roqué et al., 2013, Kai et al., 2015, Bozeat, 2000). The oral phase and pharyngeal phases of eating can be problematic in any form of dementia causing problems with chewing, forming a food bolus and swallowing (Cipriani et al, 2016). Those with Alzheimer's disease seem to have more difficulties swallowing liquids whilst vascular dementia can result in more difficulties forming a food bolus in the mouth and chewing semi-soft foods as well as increased risk of silent aspirate (Suh et al., 2009). Such differences in eating and swallowing may reflect the different areas of the brain affected by dementia (Suh et al., 2009).

Feta-amyloid plaques[1] and neurofibrial tangles[2] spread in a predictable pattern through the cortex of the brain, resulting in atrophy and reduced or loss of associated functions. Alzheimer's disease commonly affects the hypothalamus thus changes in appetite can be anticipated (Baloyanni et al., 2018). Animal studies have shown that ablation of neuropeptide Y in the hypothalamic arcurate nucleus causes loss of appetite and starvation (Ahima et al., 2009). This suggests damage to this area of the brain impacts appetite regulation and is likely a factor in development of anorexia in dementia. Changes in the cerebral cortex are seen early on in Alzheimer's disease with this part of the brain responsible for higher-order functions such as cognition, memory and planning (Bozeat, 2000). These functions are necessary for response to changes in appetite, accessing food, food preperation, planning when and what to eat and ability to eat. Appetite control and eating are therefore effected if ability to process thoughts or make decisions are diminished (Jager and Witkamp, 2014). It is not surprising to observe as functional decline occurs with disease progression ability to prepare food, put food in the mouth, chew and

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[1] Beta-amyloid plaques form between neurons in the brain, blocking synapse connections and preventing communication between cells, thus inhibiting their ability to function (McKeith, 2002).
[2] Neurofibrial tangles destroy the brain's ability to function normally by preventing nutrients reaching brain cells, causing cell death (McKeith, 2002).

swallow deteriorates with changes in eating behaviours and food preference described (Kai et al., 2015, Ikeda et al., 2002).

2.4.2   Vascular dementia

Vascular dementia effects 17% of individuals with dementia in the UK and may occur concurrently with Alzheimer's disease (Alzheimer's Society, 2014). Reduced blood flow within the brain due to either a blood clot, for example as a result of a cerbral vascular accident or small blood vessel disease occurs notably in the frontal lobes of the brain. The former causes an acute presentation of vascular dementia, whilst small blood vessel disease is progressive, causing a gradual slowing of thinking and processing (Alzheimer's Society, 2014). The area of the brain effected by a clot will be adversely effected whilst diseased frontal lobes will diminish ability for executive and cognitive function. The primary early distinguishing feature of vascular dementia is apathy which can result in a general lack of interest in food and eating. Slowing of thinking and processing can impact ability to engage in decision-making, make a plan or implement this in response to feelings of hunger with organisation and intitiation of tasks in relation to eating becoming problematic.

2.4.3   Dementia with Lewy bodies

Dementia with Lewy bodies[3] is less common with an incidence of 4% of all with dementia in the UK (Alzheimer's Society, 2014). There is a high risk of malnutrition reported due to the consequences of brain atrophy and iatrogenic effects of treatment (Koyama et al., 2016) (McKeith, 2002). 30% of individuals with Lewy bodies dementia have concurrent vascular dementia and 70% have parkinsonism symptoms (Alzheimer's Society, 2014). Unlike other forms of dementia there are features of both Alzheimer's disease and Parkinson's disease, with up to 70% having parkinsonism, including limb rigidity, bradykinesia and gait. This can impact ability to remain independent with feeding and food-related tasks. A differentiating symptom from Alzheimer's disease is the high prevalence of hallucinations reported as the most distressing symptom and a cause of carer burden (Emre, 2007, McKeith, 2002). This may make it difficult for the perosn to eat

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[3] Lewy bodies are abnormally phosphorylated, neurofilament proteins causing loss of neurons in the brain. As in Alzheimer's disease there is also generalised brain atrophy but neurofibrial tangles are rare.

well or accept food. Further distinctive features are the frequent fluctuation of cognition and consciousness and higher levels of depression (40%) than other forms of dementia all of which can negatively impact appetite, eating and ability to consume adequate nutrition (McKeith, 2002, Koyama et al., 2016). Further, the iatrogenic effect of treatment with cholinesterase inhibitors includes nausea, vomiting and anorexia which can negatively effect eating and nutritional state (McKeith, 2002).

Parkinson's dementia can be difficult to diagnose and is usually only done so in those with established Parkinson's disease[4] (Emre, 2007). At diagnosis memory problems are significantly less in Parkinson's dementia (67%) than in Lewy body dementia or Alzheimer's disease (94% and 100% respectively) becoming more noticeable as the disease progresses (Emre, 2007). Brain atrophy is similar to dementia with Lewy bodies but greater than observed in Alzhiemer's disease, with hypoperfusion occuring especially in the cortex area causing greater variablity in the occurrence of BPSD than in other forms of dementia (Emre, 2007).

2.4.4   Frontal temporal dementia

Frontal temporal dementia is rare occurring in only 2% in the UK population of people with dementia (Alzheimer's Society, 2014). Frontotemporal dementia has a high prevalence of appetite changes (Ikeda et al., 2002). It has a predominant presenting symptom of signfiicant increase in appetite with hyperphagia and insatiable appetite (Alzheimer's Society, 2014, McKeith, 2002, Koyama et al., 2016). A preference for sweet foods often accompanies this but as the disease progresses appetite usually declines with reduced appetite a feature in the latter stages of the frontal temporal dementia (Ikeda et al., 2002, Allegri et al., 2006). This form of dementia can be subdivided into semantic dementia and frontal variant frontal temporal dementia with similar symptoms in each but a greater incidence of depression and "mental rigidity" in semantic dementia (Bozeat, 2000). As is already described depression can impact eating and appetite whilst mental rigidity may result in the need for routine or the same foods putting with potential to impact nutritional state.

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[4] Diagnosis requires at least two of the following: reduced attention or memory, executive dysfunction or visou-spatial problems (Emre et al., 2007).

Frontal temporal dementia is characterised by brain atrophy in the limbic region, particularly the frontal and temporal lobes (Bozeat, 2000). The significant appetite changes can be explained by commonly observed degeneration of the hypothalamus with increased levels of circulating leptin and agouti-related peptide stimulating appetite (Alberici et al., 2008, Ahmed et al., 2016). Of interest is that hyperphagia in diseases such as Prader–Willi syndrome or from a traumatic brain injury usually results in significant weight gain (Crenn et al., 2014; Miller et al., 2011). In contrast hyperphagia associated with dementia does not always have the same effect with some even experiencing weight loss despite excessive eating Chi et al., 2015, Smith et al., 1998). This suggests that hyperphagia in dementia could in some way be compensatory or that there are other changes in the physiological pathways.

Behavioural and personality changes are a common feature of frontotemporal dementia,[5] with loss of social awareness often displayed as disinhibition, social withdrawal and lack of conversation (Bozeat, 2000). The predominant symptom group identified by carers is "sterotypic eating behaviour" including ritualised behaviour, clockwatching, sterotyped use of catch-phrases, preoccupation with counting and numbers, changes in food preference towards sweet food and hyperphagia (Bozeat, 2000, Ikeda et al., 2002). Such symptoms can impact eating behaviour, food choice and timing of meals. Such changes may be due to the effects of the disease on the hypothalamus which is responsible for regulation of hunger, thirst, sleep and circadian rhythms (Ahmed et al., 2015).

2.4.5   Impact on nutritional state

Changes in appetite and eating behaviour can significantly impact nutritional state. A major risk factor for malnutrition in dementia are changes in appetite and eating behaviour being implicated in the ability of the person with dementia to live well (Allegri et al., 2006, Roqué et al., 2013, Keene et al., 1998). Malnutrition is a complication of dementia which many family carers will experience being the most common nutritional

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[5] The frontal lobes enable reasoning, problem solving and making judgments, whilst helping control impulses and higher emotions such as empathy, altruism (Bozeat et al., 2000).
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problem in dementia with an incidence between 14% to 40% (Koyama et al., 2016, Droogsma et al., 2013, Jesus, 2012, Roqué et al., 2013). Two thirds (65.4%) of community-dwelling individuals with dementia are at risk of or have malnutrition effecting those with hyperphagia as well as anorexia (Beattie et al., 2014, Smith et al., 1998). The variation in malnutrition prevalence reflects differing diagnostic methods, stage and form of dementia and presence of appetite changes being more prevalent in the latter stages of disease. Malnutrition risk is used by some healthcare professionals to predict decline in function and cognition in dementia however, there is a lack of evidence to demonstrate causal relationship (Ogawa, 2014, Slava et al., 2009, Koyama et al., 2016). There is also suggestion that the rate of dementia progression is associated with nutritional state but again this is likely relational rather than causal (Koyama et al., 2016). Malnutrition is problematic adversely impacting function, morbidity and mortality impairing recovery from illness, increasing risk of complications and increasing the need for healthcare thus effecting family carer lived-experiences (Stratton et al., 2018). There is no evidence to suggest that the effects of malnutrition in dementia differ from other conditions.

2.4.6   Impact of hyperphagia

Hyperphagia causes insatiable appetite with detrimental impact on both the person with dementia and their family carer. It presents a dilemma for carers as to whether to offer food being requested or searched for or to control consumption by hiding or locking away food or denying requests (Grossman, 2007). Hyperphagia is therefore a potential contributor to family carer burden. It is described as being an interim symptom lasting for an average of fourteen months which suggestion that it occurs about five years after a dementia diagnosis although this is not the case for all forms of dementia (Keene and Hope, 1998, Tsang et al., 2010). This may be the time when those with dementia are able to live alone in their own home yet this complication increases the risk of choking, vomiting or even weight gain if unrestricted eating is allowed (Keene and Hope, 1998, Tsang et al., 2010).

It can be very challenging for family carers to manage eating behaviour with hyperphagia with repeated requests for food, reporting of hunger, stealing of food, continuous eating, eating quickly, swallowing without chewing or overfilling the mouth with food (Hope et al., 1997). This may result in socially unacceptable eating behaviour with impact on

socialisation. Gender and traditional or expected roles may contribute to the incidence of hyperphagia as evidenced by a Taiwanese study. In this society a woman's vocation is traditionally to keep house with findings of greater incidence of hyperphagia if a women provided dementia care (Chi et al., 2015). Educational level of the person with dementia seemed to play no role in incidence of hyperphagia within a Western culture but was a significant factor in those in Taiwan and may relate to the relationship of habitualised etiquette and education in Taiwan embedding eating behaviour in the long-term memory (Chi et al., 2015, Smith et al., 1998). Thus, habitualised eating behaviour and gender roles may be implicated in risk of hyperphagia. Despite these findings similarities were found between Eastern and Western cultures in relation to hyperphagic eating behaviour in dementia with continual eating if food is accessible, repeated requests for meals and seeking of food commonly described (Chi et al., 2015, Bathgate et al., 2001, Ikeda et al., 2002).

2.4.7 Memory

The ability to store and maintain memories is important for many aspects of eating and appetite. Both short and long term memory can be affected by dementia, with subsequent recollection unlikely and repeated questioning about the same issue occurring (Alzheimer's Society, 2021). Recall of recent eating using recalled information influences subsequent food intake with a role in decision-making about beginning and ending eating (Higgs, 2002). The hippocampus located in the temporal lobe is necessary for short-term memory and memory formation and is particularly damaged by Alzheimer's disease. The right temporal lobe is necessary for visual memory and recognition of objects including items which are edible food and objects associated with food preparation and eating. The amygdala makes association between memories and emotions and may be used to develop feelings of pleasure or dislike of certain foods. The cortex is involved in long-term memory development and important for storing learnt information about how to prepare food, how to eat it and socially acceptable behaviour associated with eating and mealtimes.

Loss of memory function makes it difficult to process and store new memories. Memory impairment may impact response to appetite change with inability to recall how much food was previously consumed resulting in difficultly in making decisions around future

food consumption (Higgs, 2005). It can also result in forgetting to eat or experiencing a reduced desire to eat and may exacerbate malnutrition risk (Plotkin and Taani, 2020). The right temporal lobe is necessary for visual memory and critical for recognition of objects including what items are food and edible forms of these. Ability to recall function and how to use items which support eating and cooking such as utensils, cups, ovens and pans is also required for safe, independent eating (Higgs, 2005). A loss of conceptual knowledge is particularly noted in those with semantic dementia with damage to the anterior temporal lobes (Snowden et al, 2018). Such loss makes it challenging to name and understand words with loss of meaning of objects including recognition of edible food items as well as objects supporting eating and food preparation.

An example of the impact of memory loss on eating and appetite is presented in a study of two adults with normal cognitive function and hypothalamus but bilateral damage to the temporal lobes resulting in complete amnesia (Rozin et al., 1998). Sequential offering of additional meals at mealtimes was made with assessment of hunger on ceasing eating. A control without amnesia was offered the same opportunities for additional meals. Those with amnesia accepted and consumed up to three meals whilst the control declined all additional meals eating only one. Hunger ratings in those with amnesia did not reliably show reduction after eating however the number of bites per meal increased with subsequent meals and a feeling of tightness in the stomach was described by one of the individuals resulting in decline of a third meal. This suggests that even when there is inability to recall prior eating there is awareness of physical sensation or discomfort from eating large amounts of food and change in eating pattern or eventual cessation of eating. The study demonstrates that memory has a significant role in eating and the amount of food consumed. Therefore, those with dementia who are experiencing this symptom are more vulnerable to changes in their response to appetite.

2.4.8 External cues

Feelings of hunger and eating can occur in response to external cues that is to say what we see, where we are and whom we are with. Inability to respond to or understand sensory information or a decline in senses such as impaired vision, taste or smell can influence response to appetite and food choice. Apicius, described as a first century Roman food lover is reported to have said that "we eat first with our eyes" with food a

proven stimulus for the brain and appetite pathways (Spence et al., 2016). 'Visual hunger' describes the influence of what is seen and interpretation of this on appetite (Spence et al., 2016). Pictures of food can stimulate the cephalic phase of eating and appetite-related hormones even without physiological hunger (Duszka et al., 2020, Spence et al., 2016). Response to such sensory stimulation activates neurogenic signaling pathways from the cerebral cortex, amygdala and hypothalamus through the vagus nerve to stimulate the parasympathetic nervous system of the stomach where secretions are then increased in anticipation of food. A positive response to external cues is compounded by stimulation of the senses and the cephalic phase of eating (Smeets et al., 2010, Wijlens et al 2012). This response has to be managed and decisions made about whether to eat or not and what to eat. Interpreting external stimuli can help in this decision-making with assessment of how food looks, smells or tastes as well as other factors such as health needs, the timing of the next meal or other activities (Ahima et al., 2009).

Diminished ability to interpret and recall sensory stimuli such as may be experienced by those with dementia can negatively affect appetite and increase the risk of eating contaminated or poorly cooked food. Palatability of food is learnt through association of certain smells and can help in decisions around food safety. This can help prevent ingestion of poisonous, contaminated or rotten food. The olfactory cortex and the preform cortex are involved in the perception of smell as well as learning around olfactory stimuli (Wijlens et al, 2012). Interpretation of visual clues is similarly learnt and also used to help make decisions around eating. The occipital lobes are necessary for vision whilst the nearby parietal lobes are used to help interpret this information for decisions around eating. Response to taste is also important in terms of pleasure and protection from food which is unsafe to eat. Neuropeptides including substance P, cholecystokinin and opioids convey information from the taste receptors in the tongue and oral cavity via the nucleus tractus solitarius and parabrachial nucleus in the brainstem to various parts of the brain including the insula, thalamus, lateral frontal cerebral cortex, central nucleus of the amygdala and lateral hypothalamus (Ahima et al., 2009, Dagher, 2012).

2.5   Appetite and eating behaviour associated with ageing

The main nutrition concern associated with ageing is malnutrition risk resulting from anorexia. This is explained by changes in physiology, appetite and body composition associated with ageing described in the geriatric syndrome of the 'anorexia of ageing' where a decline in food intake is associated with age (Morley, 2017, Chapman et al., 2002, Martone et al., 2013). Anorexia is seen by some as a natural process associated with ageing (Morley and Silver, 1988, Plotkin and Taani, 2020). Landi et al., (2016) describe three major mechanisms contributing to the anorexia of ageing:

- Reduced hunger and altered satiety control mechanism
- Age-related gastrointestinal motility changes
- "Other factors" including functional, cognitive and social issues.

These factors are also of relevance to those with dementia with altered regulation of appetite, diminished cognitive and functional ability and influence of social issues on eating behaviour and appetite. However, lifestyle choices and greater cognitive effort through engaging in new skills or learning can help to reduce the effects of ageing on the brain whilst there is little evidence that this happens in those with dementia (Peters, 2006).

2.5.1   Physiological changes of ageing

In their comprehensive review, Roberts and Rosenberg (2006) evidence how energy regulation is altered in older people due to impaired autonomic function, decline in olfactory and gustatory senses, hormone and metabolic factors such as altered glucose homeostasis (Roberts and Rosenberg, 2006). Circulating levels of glucose, insulin and glucagon can remain high contributing to sustained satiety. Appetite is further affected by delayed gastric emptying perhaps due to impaired autonomic nervous function or less effective detection of gut hormones. Increased levels of cholecystokinin, neuropeptide YY, leptin and insulin and reduced levels of grehlin and neuropeptide Y impact ability to regulate hunger (Landi et al., 2016). This description is not dissimilar to that observed in dementia however these occur in the person with dementia regardless of age. There is also suggestion that ageing changes the hypothalamus with decline in neuroendocrine

function however the impact seems less significant that that observed in dementia (Martone et al., 2013, Rehman and Masson, 2001).

Particular association had been made between ageing and cholecystokinin with animal studies suggesting causal effect of excessive satiety (Morley and Silver, 1988). This is mirrored in human studies where differences in calorie intake between older and younger adults were identified in response to a low dose infusion of cholecystokinin (Landi et al., 2016). Ageing may increase physiological sensitivity to the effect of cholecystokinin, slowing the rate of gastric emptying and small intestine motility promoting earlier satiety (Landi et al., 2016). A further study compared the response of older and younger adults to a high fat meal and demonstrated differences in glucagon-like peptide-1 and grehlin secretion (Di Francesco et al., 2010). This may in part explain reduced appetite associated with ageing. The role of grehlin is however unclear with some studies showing a reduction in grehlin with age whilst others argue that its role in the anorexia of ageing is not significant (Martone et al., 2013, Morley, 2017).

Chronic, low-grade inflammation is associated with ageing and may influence appetite (Martone et al., 2013). Inflammatory processes are a recognised part of many illnesses and diseases including those with dementia with adverse effect on appetite and risk of disease-related malnutrition (Cederholm et al., 2015). However, markers of inflammation including interleukin 1 and 6 and tumour necrosis factor can also be raised in older individuals without underlying disease or illness (Landi et al., 2016). Association is made with chronic low-grade inflammation and changes in the brain structure (Leonard, 2007). The physiological changes and consequences of these would likely be similar in the person with dementia and the older person. An increase in pro-inflammatory factors such as interleukins 1 and 6 and tumour necrosis factor inhibit neuropeptide Y and pro-opiomelanocortin neurons resulting in leptin production, anorectic signaling and appetite suppression (Martone et al., 2013, Landi et al., 2016). This suggests that chronic inflammation is a likely part of the ageing process (Landi et al., 2016). Gastric emptying and small intestinal motility are also affected by pro-inflammatory factors causing early post-prandial satiety and possibly contributing to spontaneous gastroesophageal reflux causing discomfort and a reluctance to continue eating (Landi et al., 2016, Morley, 2017, Martone et al., 2013). Early satiety can also result from physiological changes allowing earlier antral filling of the stomach promoting cholecystokinin and anorectic pathways

(Donini et al., 2003). Aside from physiological changes there are other factors which may affect appetite and eating in the older person including sensory impairment, problems with memory, a decline in function, psychological and socio-economic factors and disease or side effects of treatment.

2.5.2 Impact on nutritional state

Although a decline in eating and appetite may be associated with ageing, the process of ageing may not be the cause. It is acknowledged that eating and appetite can be problematic with age with up to 25% of elderly men and 30% of elderly women experiencing anorexia (Martone et al., 2013). The result of anorexia can be significant associated with worse health outcomes, malnutrition, sarcopenia and frailty (Landi et al., 2016). In turn malnutrition can result in impaired muscle function, immune dysfunction, anaemia, reduced cognitive function, poor health, delayed recovery from surgery and increased morbidity and mortality (Donini et al., 2003). Higher prevalence of anorexia is described in those requiring residential care or hospitalisation suggesting risk is increased as a result of an underlying condition, disability or illness (Martone et al., 2013). This may be the result of inflammatory processes associated with illness which supress appetite (Cederholm et al., 2015). Illness or disease can also increase nutritional requirements whilst medication can impact absorption of nutrients or cause gastrointestinal symptoms such as nausea, diarrhoea or constipation negatively effecting appetite (Donini et al., 2003).

Physiological changes associated with age may be causal in a decline in muscle and adipose tissue and contribute to unintentional weight loss (Chapman et al., 2002). A reduction in growth hormone and IGF-1 may contribute although reduced activity, disease, illness or poor nutritional intake are likely influential on body composition changes (Rehman and Masson, 2001). Muscle loss is common after the age of seventy and increases the risk of frailty, a condition described as being interconnected with anorexia (Martone et al., 2013). Loss of muscle is also associated with sarcopenia[6] (Morley, 2017). It can occur concurrently with low BMI or obesity, the latter described as

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[6] Sarcopenia is defined as a decline in function due to loss of muscle mass and is often associated with ageing (Morley, 2017)

sarcopenic obesity. Further, sarcopenia can be aggravated by low grade production of inflammatory cytokines observed in both chronic disease and ageing (Morley, 2017). Sarcopenia and frailty increase the risk of morbidity and mortality and impact functional ability to shop for and prepare food or eat (Plotkin and Taani, 2020).

Malnutrition may result from disease, illness or socio-economic factors rather than ageing itself. Older people are described as being at higher risk of malnutrition particularly if in residential care or hospitalised. The European consensus definition of malnutrition describes how physical and psychological function are impacted (Cederholm et al., 2015).[7] Unintentional weight loss and malnutrition risk in older people is a significant cause of morbidity and mortality (Chapman et al., 2002). It can be contrasted with the apparent protective effect of obesity in older people particularly during illness described as the obesity paradox (Morley, 2017). However, there are risks with obesity in older age, increasing the risk of type 2 diabetes, cardiovascular disease, certain cancers and dementia. Such risks have become more widely recognised during the COVID-19 pandemic suggesting that a healthy body weight and good nutritional state are important regardless of age.

2.5.3 Memory, cognitive and executive function

Changes in memory, cognitive ability and executive function are recognised symptoms of dementia but also described in the older person. Changes in memory due to ageing may result from slower processing speed and easier distraction and are usually temporary short-term issues such as forgetting a name or item, which unlike in those with dementia is later recalled (Haradaa et al., 2013). Dementia causes cognitive function and memory to deteriorate further than could be anticipated as a result of ageing (World Health Organization, 2020). The cognitive decline associated with ageing may effect conceptual reasoning, concentration and processing speed the latter being particularly related to cognition and motor response (Haradaa et al., 2013). This is recognised as the 'slowing down' associated with ageing but does not result in loss of ability in contrast to the

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[7]The definition of malnutrition is a state resulting from a lack of uptake or intake of nutrition leading to altered body composition (decreased fat free and body cell mass) leading to diminished physical and mental function and impaired outcome from disease (Cederholm et al., 2015)

person with dementia. More time may be required to undertake routine activities or to process information before making a decision whilst those with dementia have more than a 'slowing down' effect with significant decline in executive and cognitive function, orientation, communication and behaviour and emotional control (World Health Organization, 2020). Thus, there is significant difference between memory, executive and cognitive functional change in the older person and the person with dementia.

2.5.4 Sensory impairment older people

Whilst changes in taste and smell make significant contribution to the palatability and enjoyment of eating there is suggestion that decline in these senses only have a minor role in reduced appetite associated with ageing (Morley, 2017). Atrophy of taste receptor cells particularly those involved in salty and sweet tastes can occur whilst a decline in saliva secretion can impact how well food interacts with taste receptor cells on the tongue (Landi et al., 2016). Loss of smell, disease, medication or smoking can also affect taste. Olfactory and visual cues help to stimulate appetite and the cephalic phase of eating. A decline in ability to detect these cues through impaired vision or loss of smell can affect response to appetite cues. Further, loss of taste and smell can result in less inclination to eat whilst impaired vision may make preparation of food and eating challenging.

2.5.5 Other factors ageing

Socio-economic factors are known to impact eating, appetite and nutritional state particularly in the older person as well as the person with dementia. Reduced income resulting from retirement or inability to work due to ill health alongside social isolation are significant factors to consider. Financial state and poverty are associated with poor diet and risk of malnutrition whilst depression can result in isolation and poor appetite (Volkert et al., 2010, Donini et al., 2003). Social isolation may be more common in older people due to bereavement, children becoming adults and moving away, poverty or reduced physical ability to go out, drive or lack of public transport. Obtaining adequate food can be difficult when there is poverty or poor functional ability to buy food or prepare it. Bofill (2004) presents a quote from a participant which strikes to the heart of the matter, "to eat alone is the saddest thing in the world." Loneliness and isolation are

described as risk factors for malnutrition particularly in the older population and a predictor of anorexia (Ramic et al., 2011). A controlled study of 200 older people ($\geq$ 65 years) found that living alone was associated with an increased risk of poor appetite, self-reported food problems and poverty (Ramic et al., 2011). Depression is one of the most common psychological disorders in older people (Landi et al., 2016). It can increase anorectic signaling and often associated with loss of appetite (Morley, 2017, Landi et al., 2016). Of interest is that older people appear to experience greater appetite and weight loss when depressed compared with younger adults and this may contribute to the pathogenesis of anorexia of aging (Landi et al., 2016, Martone et al., 2013). Further, anhedonia around eating is observed in the elderly exacerbating anorexia (Jager and Witkamp, 2014).

Older people are more likely to have polypharmacy with medication a possible cause of poor appetite or weight loss. For example proton pump inhibitors delay gastric emptying whilst some drugs can have side effects of nausea, constipation or dry mouth influencing the desire and ease of eating (Landi et al., 2016). Functional ability may become impaired with age due to muscle loss causing weakness, pain or diseases such as osteoporosis or arthritis. These may adversely affect activities of daily living associated with food and eating such as shopping, preparing food and cooking. Ageing can also be associated with decreased chewing efficiency often due to edentulism. Poor dentition or ill-fitting dentures are likely to affect the type and quality of food with preference for foods which are easier to eat however foods which require less. Limitations brought about by poor dentition influence food choice, range of foods consumed and even amount of food eaten, increasing the risk of nutritional deficiencies and malnutrition (Landi et al., 2016).

2.6 The unique effect of dementia on eating behaviour and appetite

From the evidence to date multiple factors can influence eating behaviour and appetite in people with dementia. Whilst there is some similarity with the changes of these functions associated with ageing, changes in dementia are not age dependent and are not reversible. The factors are summarised in Figure 4 and are helpful to consider when exploring family-carer lived experiences of these functions.

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┌──────────────────────────────────────────┐
│           Socio-economic factors          │
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│           Environmental factors           │
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│           Change in communication         │
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│          Decline in physcial function     │
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│          Concurrent disease or illness    │
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│          Iatrogenic effect of medication  │
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│       Concurrent mental health problems   │
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│               Memory decline              │
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│           Loss of executive function      │
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│            Loss of cognitive ability      │
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│          Damage to the hypothalamus       │
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│     Loss of diurnal rhythm and sense of time │
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│             Anorexia of ageing            │
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Factors influencing eating and appetite
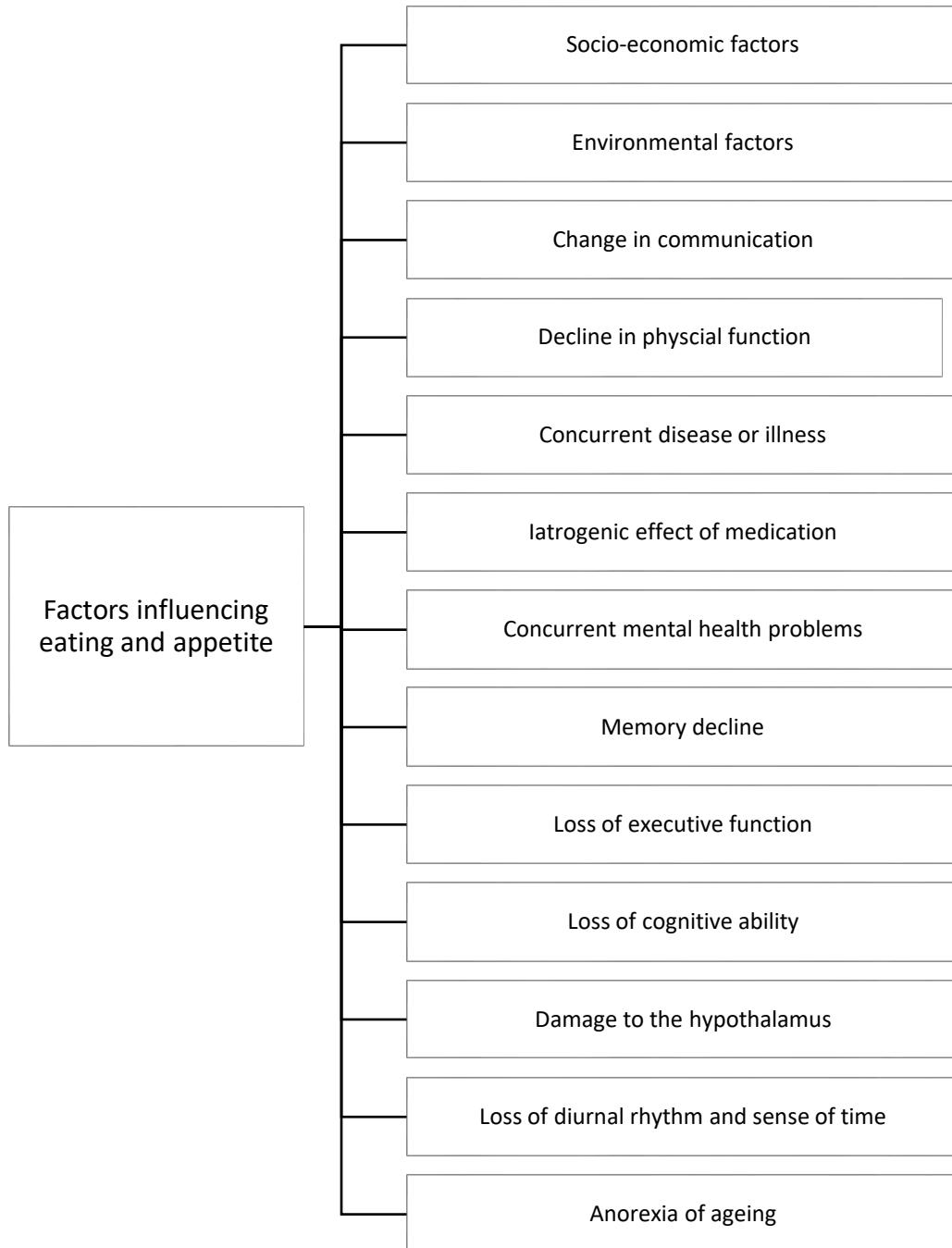
Figure 4 Potential reasons for changes in eating behaviour and appetite in dementia

When compared with older people those with Alzheimer's disease were found to have a significantly higher prevalence of eating and swallowing changes (81.4% vs 26.7%) suggesting that dementia has a specific effect on these functions (Kai et al., 2015).

Social isolation or lack of support can impact the eating and nutritional quality of diet being observed in both the older population and people with dementia. Yet it may be

more difficult for a person with dementia to either access or cope with social interactions and related activities (Plotkin and Taani, 2020). Unlike ageing dementia can effect language, speech, thought processing and comprehension making it harder to communicate a symptom such as pain or other problem which may impact eating or appetite or the ability to communicate hunger or thirst (Plotkin and Taani, 2020). Additionally, those with dementia may be ignored or not heard, being dismissed as not having capacity or cognitive ability to contribute to decisions about eating or requests for food or drink.

Increasing support to eat and drink is required with disease progression including help with feeding, food preparation and meal planning and support to manage altered taste, smell and swallowing (Roqué et al., 2013, Aliani et al., 2013, Luzzi, 2007). Palatability of food, pleasure from eating, safe eating and food choice all rely on sensory information being recognised and interpreted to inform decisions and learning about food choices. Unlike in ageing these are significantly impacted as dementia progresses. Conscious awareness of food cues including hunger and external stimuli are required but loss of memory and ability to interpret these can reduce ability to respond (Dagher, 2012). Behavioural changes such as pacing and inability to sit still can cause significant challenges as can loss of diurnal rhythm and usual eating patterns. This may require adaptation of eating patterns and introduction of strategies such as snacks which can be consumed at different times of day or whilst walking.

Certain drugs used to treat dementia can have side effects which effect appetite (Wilson et al., 2007, Utumi et al., 2011, Sequeira, 2001). An association between antipsychotic medication and hyperphagia has been identified increasing risk of food craving and binge eating (Chi et al., 2015). Cholinesterase inhibitors, drugs which are sometimes used to slow the progression of dementia, can cause nausea, vomiting and anorexia compounding any eating problems (McKeith, 2002).

2.7 The unique phenomenon of appetite and eating behaviour changes in dementia

Eating behaviour and appetite are highly complex processes with the brain central to

their regulation through behaviour and physiological processes (Burdette et al., 2020). Such regulation and control can be impacted through damage to the brain such as occurs with dementia resulting in a disease specific effect on eating behaviour and appetite. These can occur concurrently with changes associated with ageing, socio-economic and environment factors or concurrent disease adding complexity to the understanding and management of eating behaviours and appetite in dementia.

An uncommon reason for loss of appetite or reduced intake during older age is an eating disorder such as anorexia nervosa or bulimia. Such late-life eating disorders may result from changes in body fat and muscle and body dissatisfaction due to ageing with pressure felt to remain slim (Luca et al., 2015). Development of an eating disorder may result from hormonal changes such as experienced during the menopause or stress around life events (Luca et al., 2015). Triggers for late-life eating disorders are therefore not dissimilar to those for younger people however a higher risk of complications is described in the older age group (Luca et al., 2015).

The risk of anorexia in the older person is therefore described resulting in risk of malnutrition, frailty and sarcopenia. However, not all agree that anorexia is a 'normal part of ageing' with Plotkin and Taani (2020) arguing that a decline in food consumption results from other factors including those related to socio-economic issues, physical, psychological, health or dentition problems, medical treatment and polypharmacy, culture or religious beliefs (Ramic et al., 2011, Donini et al., 2005). Changes in eating and appetite in older people are therefore individualistic and sometimes complex (Cipriani et al 2016).

In contrast to the appetite and eating behaviours associated with dementia, it is suggested that anorexia in the older person can be managed and even prevented. Whilst loss of appetite may result from the ageing process, it is important to be mindful of other causes for this in older people. Risk factors for the anorexia of ageing are described by Landi et al., (2016) as presented in Figure 5.
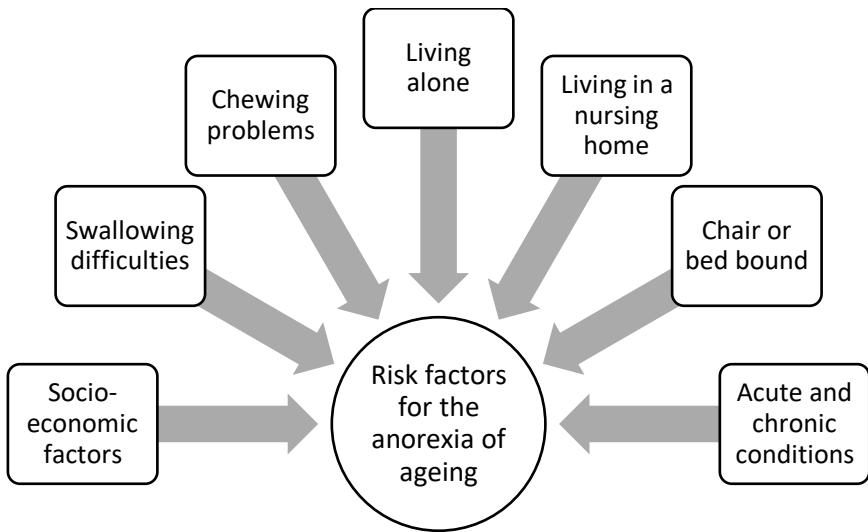
Figure 5 Risk factors for anorexia of ageing adapted from Landi et al., (2016)

Identifying those at risk enables treatment or even prevention of anorexia using 'multi-stimulus interventions' of food manipulation, environmental adaptation, medication, medical diagnosis and a range of other treatments (Figure 6) (Landi et al., 2016).

Food manipulation
- Enhance food texture, palatability and flavour
- Ensure variety of diet
- Provide feeding assistance

Environmental adaptation
- Prevent social isolation
- Endorse conviviality

Medication
- Pharmacological review to idenfity drugs impacting appetite or weight

Medical diagnosis
- Swallowing disorders
- Dyspepsia
- Malabsoprtion
- Neurological causes
- Endocrine disorders
- Psychiatric disorders
- Respiratory or cardiovascular diseases

Specific treatments
- Limited evidence for use of oral nutritional supplements to treat the anorexia of ageing
- Aim for a daily intake of 1.0 - 1.2g protein per kilogram body weight per day
- Drugs to improve appetite are of limited benefit

Figure 6 Interventions to treat or prevent anorexia of ageing adapted Landi et al., (2016)

Such interventions may be useful to consider in the care of the person with dementia as well as the older person. However, unlike the person with dementia the person experiencing the consequences of ageing has potential for improvement in or even prevention of anorexia in the future. This has significant implications for the family carer of a person with dementia, demonstrating the complexity and challenges of eating and appetite in dementia when compared with the changes observed as a consequence of ageing. Further, whilst there is potential for improvement in eating or appetite in the older person there is little hope of this in those with dementia due to the progressive nature of the disease and as described in Chapter 3 there is little empirical evidence to show meaningful change in eating or appetite as a result of interventions.

2.8   Chapter summary

This second chapter has provided evidence to support the unique effect of dementia on appetite and eating behaviour. The essential role of the brain for these functions is established with differentiation between the effects of ageing and those of dementia on these functions. A complex picture of the potential causes of changes to eating and appetite in dementia is presented. These are further complicated by co-morbidities, socio-economic factors and in older people with dementia the effects of ageing. Appetite and eating changes in dementia are also associated with caregiver burden and implicated in the ability to live well with dementia (Allegri et al., 2006, Roqué et al., 2013, Keene et al., 1998). These have significant implications for family carers providing care for a person with dementia being more complex to manage than those observed in the older person. Exploration of understanding about family carer lived experiences of eating and appetite will be provided in Chapter 3.

Chapter 3   Review of family carer lived experiences of eating behaviour and appetite in dementia

Chapter three presents a review of existing research relating to family carer experiences of eating behaviour and appetite in dementia. Following accepted rationale for literature reviews a survey of existing knowledge has been undertaken to contribute to the development of understanding of the topic of interest and identify knowledge gaps (Baumeister and Leary, 1997, Jahan et al., 2016). Identifying what is already known is an essential step in research enabling development of novel research questions and avoidance of repetition of research (Levy and Ellis, 2006, Boell and Cecez-Kecmanovic, 2014). Thus, a literature review supports an ethical approach to research practice. A hermeneutic framework is used aligning with the philosophical positioning for the present study and this thesis.

3.1   Defining terminology

Although the term family carer is implicit in meaning it is important to clarify meaning for the present study. Family carer is defined as anyone who is involved with and gives significant support to another person informally, regardless of whether or not accomodation is shared (Carers Trust, 2016). This may include a spouse, partner, sibling, child, other relative or friend. Family carers provide informal care without any remuneration and usually without any training for the role (Carretero et al., 2009). Such care is provided within a domestic setting where the dependent person resides. Family carers can provide a diverse range of tasks including personal care, domestic tasks such as cooking or cleaning and even emotional support (Carretero et al., 2009).

3.2   Hermeneutical philosophy and the literature review

This review uses a hermeneutic framework providing a congruent philosophical approach with this thesis and the present study. Hermeneutics is an approach used for interpretation and understanding of text and therefore appropriate for a literature review (Boell and Cecez-Kecmanovic, 2014). A hermeneutical phenomenological perspective argues that interpretation of text can only be made from the researcher's position.

Therefore, an original text such as a published paper is not considered absolute truth but a reflection of the researcher's interpretation of data, researcher bias, interests and context (Smythe and Spence, 2012). At the very least unconscious bias occurs and it is not possible to separate the 'researcher self' from this (Smythe and Spence, 2012). Thus, a hermeneutical paradigm acknowledges, accepts and embraces this inevitability (Smythe and Spence, 2012). With such acceptance comes recognition that there can be no right, wrong or correct understanding rather only researcher interpretation of data to gain a deeper understanding (Boell and Cecez-Kecmanovic, 2014). A literature review using a hermeneutical approach will therefore not just present 'articulated knowledge' but seeks to 'provoke thinking' to expand and develop understanding rather than identify ultimate knowledge or truth (Smythe and Spence, 2012).

Boell and Cecez-Kecmanovic (2014) describe the process of a hermeneutic framework as iterative rather than linear. Literature is identified throughout the research period as opposed to being a one-time event, adding to knowledge and depth of understanding over time (Boell and Cecez-Kecmanovic, 2014). This reflects my own learning and development of knowledge in relation to the present study. The hermeneutic framework has two major hermeneutic circles, one for searching and acquiring papers and the other to describe, analyse and interpret data (Figure 7).
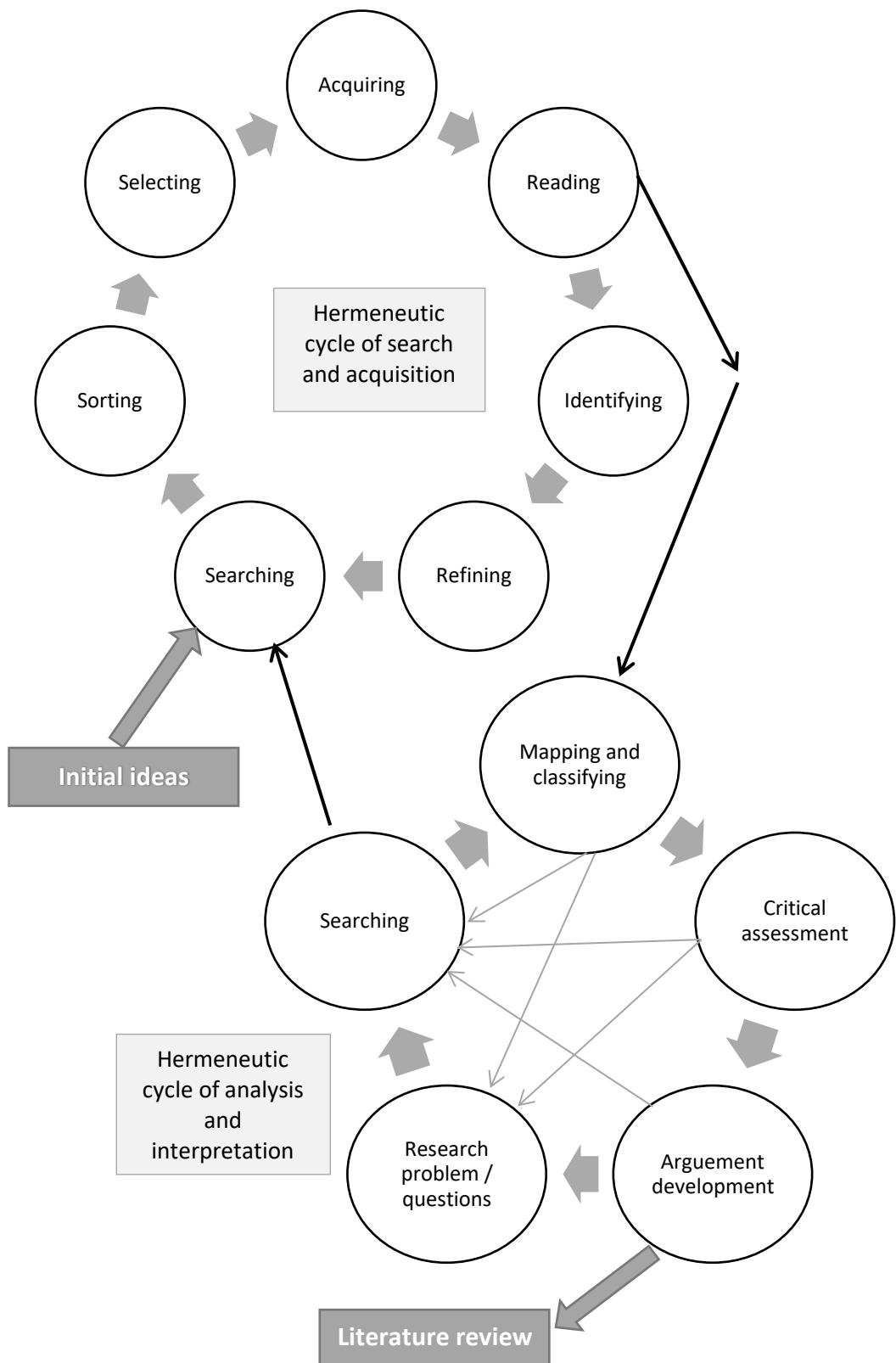
Figure 7 A hermeneutic framework for the literature review process consisting of two major
hermeneutic circles: Search and acquisition, analysis and interpretation, adapted
from Boell and Cecez-Kecmanovic (2014)

Figure 7 illustrates the iterative process going back and forth between papers as they are identified and read, mapping and assessing data such new questions arise and ideas evolve (Smythe and Spence, 2012). This enables refinement of further questions, being an iterative process supporting development of understanding of the overall context of family carer lived experiences of eating behaviour and appetite in dementia. Contextual understanding stimulated my own thinking, raising questions and ideas to help refine further searching. Parts and the whole of a phenomenon are used in hermeneutical philosophy to develop understanding. Thus, for this literature review interpretation of the data (parts) utilises prior knowledge about the context (whole) and understanding of the context (whole) comes from interpretation of the data (part) (Boell and Cecez-Kecmanovic, 2014). In this way findings from a hermeneutically orientated literature review are continually revised and developed. The end point of this process is the end of the research journey (Boell and Cecez-Kecmanovic, 2014). A pragmatic decision to stop the present review was informed by the point at which the final thesis was being written up with searching ending December 31st 2020.

3.3 The literature review journey

The review began with wanting to know more about family carer experiences of eating behaviour and appetite in dementia. Within a hermeneutic framework reading is central to identifying potential sources of literature and helped inform my search strategy. Boell and Cecez-Kecmanovic (2014) describe how early reading and exploration of the literature helps the researcher 'engage with' and find 'their own way through the literature.' This was exactly my experience. Initial scoping yielded little relevant data specifically about family carer experiences of eating behaviour and appetite in dementia. Searching became more intuitive looking for literature associated with the topic to help me develop understanding and knowledge. To support analytical reading and the classifying process context, research setting, participants and method alongside the relevant concepts presented were identified. Data and any particular strengths and weaknesses were also sought.

Databases searched included CINAHL, Medline, AMED, Embase, PsycINFO, the Cochrane Library and Web of Science alongside Internet searches for peer reviewed papers and the grey literature. Initial search terms included: experience / lived-experience, family

carer/caregiver, informal carer/caregiver, spouse, partner, sibling, adult child, dementia, Alzheimer's disease, appetite , eating and eating behaviour. Whilst there was very little explicitly focused on family carer experiences of appetite or eating behaviour in dementia there were data about related topics providing insight into this. The initial scoping identified the European Society for Enteral and Parenteral Nutrition's (ESPEN) guidelines on nutrition in dementia with 26 nutritional recommendations made for an older person with dementia with evidence largely coming from studies in hospital or residential care settings or involving clinical staff (Volkert et al., 2015). However, the evidence for most of the recommendations was low or very low yet the recommendations made by the expert panel were frequently classed as strong. This included the recommendation for educating carers to "ensure basic knowledge on nutritional problems related to dementia and possible strategies to intervene" (Volkert et al., 2015).

The first relevant study identified was by Keller et al., (2010), where grounded theory was used to elicit meaning and experience of mealtimes for those with dementia and their family members. Mealtimes were found to provide a way of 'being connected' and important for family relationships (Keller et al., 2010). This work was influential for the present study highlighting the importance of eating behaviour and appetite in dementia not only in the physical sense of maintaining good nutrition and health but the psychological and social context of eating and inference of this for quality of life. It also highlighted the need to expand search terms in order to identify relevant papers. As such new terms were added and included meals, mealtimes, food, food/meal preparation, meal-related tasks, food shopping, food safety, diet, nutrition education. With a shift in understanding of the terminology required to identify potentially useful data searching became more productive.

This literature review identified five themes of knowledge and understanding about family carer experiences of eating and appetite in dementia:

- Theme 1: Changes in eating behaviour and appetite
- Theme 2: Mealtimes are more than eating and nutrition
- Theme 3: The quest for knowledge and support around nutrition and eating

- Theme 4: Resourcefulness, decision-making and resilience in relation to eating behaviour
- Theme 5: The effect of eating behaviour on family carers wellbeing

3.4   Theme 1: Changes in eating behaviour and appetite

Changes in eating behaviour and appetite in dementia are well documented being categorised by Keller et al., (2016), Ikeda et al., (2020) and Kai (2015). Keller et al., (2016) describe poor appetite, reduced taste and smell, apathy, depression, ability to self-feeding or prepare food, dependence on others, dysphagia and problems recognising food when in the mouth. Others group these together as appetite change, food preferences, eating habits, swallowing disturbances and 'other' symptoms such as eating non-food items or vomiting (Kai et al., 2015, Ikeda et al., 2002). In contrast Ball et al., (2015) categorised family carer discussions about eating-related behavioural issues in dementia as physiological, cognitive, emotional and functional/behavioural reflecting potential reasons for these as opposed to describing changes. This provides a different perspective and may be important to consider when providing support or advice for family carers. How family carers express changes in eating behaviour or appetite in dementia is not well described with the literature using terminology favoured by healthcare professionals or researchers. This is important to understand as terminology used will have implications for effectiveness of supporting information and communication between healthcare professionals and family carers.

There is little exploring family carers' understanding of changes in eating behaviour and appetite in those with dementia. Two studies suggest that family carers do recognise changes in eating behaviour, food preferences, issues with rejecting food and problems relating to hydration as they occur (Watson et al., 2003; Ball et al., 2015). However, there was limited awareness of nutrition-related issues in dementia prior to this Watson et al., 2003; Ball et al., 2015). Further, family carers were interested in and valued discussing with peers' experiences of changes in eating behaviour in dementia in preference to nutritional strategies (Ball et al., 2015). This contrasts with prior research which commonly focuses on description of changes and strategies or interventions to manage these (Lui and Thomas, 2014; Li et al., 2020; Herke et al., 2018).

3.5   Theme 2: Mealtimes are more than eating and nutrition

Mealtimes for family carers of people with dementia are more than just a time to eat or provision of nutrition. They are complex events and as described by Larson et al., (2006) are 'meaning laden activities.' Keller et al., (2015) identified for family carers mealtimes and related tasks were a way of being connected and honouring identity of the person with dementia whilst showing how they adapted to an evolving life.

3.5.1   Mealtimes and social connection

Keller et al., (2006) identified that mealtimes can offer opportunity for conversations and social engagement. They present a time for social connections with some families describing mealtimes or other opportunities to eat together as a high point of the day. Whilst there are several papers relating to this topic most are from Keller's group in Canada. The first published in 2006 describes twenty-three family carer experiences of mealtimes, their view of changes in eating behaviour, concerns and any strategies to manage these changes (Keller et al., 2006). Social aspects of mealtimes were significant being a time to connect with the person with dementia (Keller et al., 2006). This included working together on meal-related tasks as well as sitting together to eat. However, this opportunity may be declining with societal move away from eating together in the family home, use of mobile phones or other devices at mealtimes and an increase in eating independently at different times of day. This is made easier through general ease of access to readymade meals or delivery of takeaway meals. Such changes may then impact the role of mealtimes for family carers and those with dementia with opportunity for social connection being at risk.

3.5.2   Mealtimes and identity

The routines and rituals of mealtimes can affirm culture or identity such as when food is eaten, praying before meals, speaking during meals and roles related to meal time tasks (Larson et al., 2006). Genoe et al., (2010) develops the link between mealtimes and identity describing such occasions as an opportunity to 'honour identity.' Whilst this is from the perspective of maintaining identity of the person with dementia there is also a need to consider the identity of the family carer. Part of our identity can be reflected in

roles associated with mealtime tasks, food choice, routines, when and whom we eat with and the way we eat (Genoe et al., 2012). However, as dementia progresses role changes may be necessary impacting identity and sense of self for both family carer and the person with dementia. Furst (1997) argues that that there is a strong relationship between food and identity in that we confirm who we are and who we are not by the food we eat. A change in meals or food may be required to accommodate the needs of the person with dementia but this may compromise family carers preferences with the basic need for sense of identity and self not met.

Gender is another aspect of identity which is traditionally associated with certain roles or tasks depending on culture or environment. Food related tasks are seen by some as essential for the 'affirmation of gender identity' where women prepare and provide meals (Furst, 1997). However, with a wider cultural and societal acceptance of household and meal-related tasks being gender neutral this is does not sit well with the ideologies of 2021. That being said traditional gender roles including the provision of meals do remain particularly for older adults. Calastani et al., (2007) describes how husbands and wives cross such gender boundaries to deliver care and ensure household tasks and other activities continue. New tasks regardless of prior perception about gender roles are taken on by family carers to maintain independent living for the person with dementia but how these are delivered may differ (Calastani et al 2007). For example, Calastani et al., (2007) suggests that a woman might be focused on ensuring provision of home-cooked meals whilst a man focuses on just ensuring his wife was fed. This generalisation is arguably difficult to support in 2021.

Of more contemporary relevance is the gendered sense of self that is to say activities which help maintain the feeling of gender identity (Calastani et al 2007). Taking on tasks which are personally perceived as belonging to another gender might impact the sense of self and identify. However, it is suggested that mealtimes and related tasks can be an opportunity to nurture the sense of self or personhood even with changes in role occurring (Keller et al., 2015). Supporting the person with dementia to hold onto mealtime tasks and roles can help preserve their sense of self with and perhaps help the family carer to similarly hold on to some of their prior role (Genoe et al., 2012). However, to enable the person with dementia to do this the family carer will increasingly need to

provide supervision and support with dementia progression ebbing away at the former identity of both family carers and the person with dementia. Family carer experiences of mealtimes and related tasks will then differ according to their prior, personal association with identity and sense of self with food-related tasks.

3.6   Theme 3: The quest for knowledge and support around nutrition and eating

Family carers of people with dementia describe a desire for knowledge about eating-related issues and want the opportunity to discuss these (Fjellström et al., 2010). Such is the interest in this that Fjellström et al., (2010) found members of their focus groups persistently moved discussion away from the study topic to experiences of food and eating in the person with dementia. Nutritional issues and mealtimes are important to family carers of people with dementia (Li et al., 2020b). They want to understand more about food and the brain and the scope to impact dementia and memory loss through diet (Papachristou et al., 2017). However, family carers also report a lack of information or support, being unaware of feeding-related problems or changes in eating behaviour until they occur (Ball et al., 2015). Although able to then identify changes when they occur, family carers often do not know what to do or how best to respond resorting in a trial and error approach to nutritional care (Parkinson et al., 2017). It is easy to then understand how eating and appetite changes in dementia can result in family carer stress and feelings of burden, uncertainty in how best to keep their relative safe from a nutritional perspective or have the information to help them deliver nutrition related care. The need for timely support and resources for family carers is clear but what that advice should be and how best to provide it is not.

Family carers describe having little or no guidance, education, information or support from healthcare professionals relating to nutrition or feeding issues in dementia relying instead on peer support (Ball et al., 2015, Shatenstein et al., 2008). Awareness of the need for mealtime care was poor, with no training about nutrition in dementia nor access to a dietitian provided (Ball et al., 2015, Li et al., 2020b). Peer support therefore becomes an important source of support with some peer advice providing insight into the changes being related to dementia. For example, a family carer describes how food refusal is not a

reflection of cooking skills but rather the effect of dementia on the person's ability to eat or feed (Ball et al., 2015). Peer support can also be beneficial in offering emotional support, allowing opportunity for help to address challenges of caring as well as 'venting' of negative feelings (Lauritzen et al., 2015). A review of informal support for older family carers identified three themes from five studies showing peer support provides emotional benefit, helps face the challenges of caregiving and enables embracing the future (Lauritzen et al., 2015). These may help family carers to adapt to the changes which dementia brings around eating behaviour and appetite and support development of resilience.

3.6.1   Impact of education and support

Seeking advice and information about nutrition and feeding difficulties early on was seen as beneficial by family carers and perhaps counteracted feelings of anxiety, helplessness or failure described particularly when rapid weight loss occurred (Ball et al., 2015). Signposting family carers to help them navigate healthcare systems or find resources is also important. This helps avoid a trial and error approach and may improve internal feelings of control (Parkinson et al., 2017). Education programmes are one form of intervention used to help family carers learn about and/or manage eating and appetite in dementia. A program may be focused entirely on nutrition in dementia or nutrition may be part of a wider dementia education program. Nutrition components vary and might comprise of physical training, carer advice leaflets, home visits form a dietitian or nutritional supplementation including use of oral nutritional supplements or micronutrients (Mole et al., 2018). Such programs face criticism on two fronts. Firstly, interventions often lack a theory-base (Keller, 2016). Secondly, there is assumption that family carers' ability to cope is assumed to be associated with knowledge around the mechanics of why a person with dementia might have poor appetite or problems with weight (Ball et al., 2015). In contrast Ball et al., (2015) argues that carers ability to cope lies with psychosocial behaviours and the stress which families face. This links to the idea of family carer resilience and ability to adapt. It is suggested that education programs should include understanding of how to make mealtimes meaningful, strategies to help realise the potential of mealtimes, promotion of personhood and understanding of individual desires, nurturing of relationship and enhancing quality of life (Shatenstein et al., 2008).

Family carers felt support from dietitians with specialist training in dementia would be beneficial (Ball et al., 2015). Such dietetic support was provided as part of the Nutrition Intervention Study of community-dwelling, physcially well older adults with Alzheimers disease (Shatenstein et al., 2008). This included nutritional assessment, 3-weekly phone calls, dietetic consultations and individualised care plans with targeted advice to address modifiable dietary problems to improve the diet (Shatenstein et al., 2008). This education program was assessed by caregivers as good quality and easy to understand, motivating learning about nutrition and improving carer desire to adequately feed and care but it did not meet the objective of reducing carer burden (Silva et al., 2013). This may relate to the fact that weight loss and increased risk of malnutrition still occurred despite the expert support and motivation of carers to deliver individualised care plans (Shatenstein et al., 2008). Another approach to support family carers of people with Alzheimer's disease is the Comprehensive Educational Program Reinforced by an Individualised Component (CEPRIC) (Kuzu et al., 2005). This comprised of general information, an educational booklet and an individualised component alongside nursing assessment. Of note for the present review were the positive effects on nutrition with significant improvements using solution based strategies (87.5% (n28) vs 15.6% (n5) <0.001) (Kuzu et al., 2005). Carer burden and family coping also improved. Although there is suggestion of benefit the study group was small and the number of subjects in intervention and control groups not matched.

3.6.2 Healthcare professional perspective

Family carers felt that support from healthcare professionals around eating and appetite was lacking contrasting with the healthcare professional perspective of being in partnership with family carers (Keller, 2016, Mole et al., 2019). Potential reasons for this mismatch includes varied knowledge of healthcare professionals about nutrition in dementia and a need for training to increase confidence in providing advice (Mole et al., 2019). An interesting concern was highlighted by Mole et al., (2019) around the impact of the school curriculum such that younger (paid) carers did not have the skills or knowledge around food and cooking which might previously have been accepted as normally learnt whilst at school. This made it difficult for them to provide support or advice and may be relevant for younger family carers. A further barrier was caseload pressure with some

healthcare professionals questioning if supporting eating was a social care rather than healthcare responsibility (Mole et al., 2019). However, community nurses are described as being well placed to provide support in an accessible, economic and practical way providing food-related information, resources and services (Li et al., 2020b, Mole et al., 2019). Support from specialist healthcare professionals in the community can have significant benefit for family carers. A study conducted in France demonstrated that a mobile team of specialists supporting people with Alzheimer's disease living at home or in residential care (n424) was able to prevent 80% of potential hospital admissions and significantly reduce behavioural disorders (Krolak-Salmon et al., 2016). Of particular relevance is the finding of significant association of appetite and eating -behaviour difficulties with higher hospital admissions. The mobile team were particularly effective at preventing hospital admissions related to these issues. Thus, timely community-based intervention by experts can benefit family carers, the person with dementia and health and social care services.

Knowing what advice to give family carers can be challenging, as there is limited evidence for practice and no consensus around how best to support nutrition in those with dementia. A systematic review included twenty-two intervention studies to support older people with dementia in residential care to manage mealtime difficulties groups (Lui and Thomas, 2014). Quality of evidence was moderate with issues around confounding factors, sample size and power calculations and a lack of statistical analysis and control groups and outcome measures lacking. Training or education of formal care providers and changes in mealtime environment or routine were found to have limited benefit on mealtime difficulties whilst oral nutritional supplements had some benefit on nutritional intake, body weight and BMI (Lui et al., 2014). A Cochrane review similarly concluded that no environmental or behavioural modification could be identified to improve intake of food and drink due to the lack of number of studies (n9) and low or very low quality of these (Herke et al., 2018). A more recent review of non-pharmacological interventions for eating difficulties in dementia concluded there was poor reliability of evidence due to a lack of high-quality randomised trials and significant heterogeneity in interventions (Li et al., 2020a). Eighteen systematic reviews were identified with ninety-three outcomes relating to non-pharmacological interventions for eating difficulties in dementia; only nine were of moderate quality with the remainder low or very low quality (Li et al., 2020a).

There was some evidence to show that nutritional intake improved by supporting feeding but positive effect on nutritional state was not shown and concern around loss of independence raised (Li et al., 2020a). Carer training around feeding skills did not demonstrate nutritional benefit whilst education of carers may benefit weight but not enough to improve BMI (Li et al., 2020a). Use of oral nutritional supplements showed a weak effect on regular food intake however body weight increased and malnutrition risk reduced (Li et al., 2020a). There was some evidence to support changing the mealtime environment, providing education or training for carers and using oral nutritional supplements (Li et al., 2020a). Finally, there was little evidence relating to nutritional care in the home setting (Li et al., 2020a).

Due to the lack of evidence for practice, general common sense strategies are suggested including the need to identify reasons for poor nutritional intake with reminder to consider medication side effects or other manageable symptoms (Ragdale, 2014). Prompting eating, strategies to encourage healthy snacks, support food safety and a positive eating environment are suggested alongside the need to monitor nutritional state and eating (Ragdale, 2014). Delivery of meals might be beneficial but these are not always consumed without support from carers (Mole et al., 2019). Specialist feeding aids to support independent eating and drinking may be helpful and should be available from community nurses (McGinley, 2015). McGinely, (2015) uses experience from personal clinical practice to recommend small nutritious meals, extra time for meals, prompting drinking, assistance with feeding, finger foods if the person is wandering and cooked breakfasts if eating is best in the mornings. Whilst suggestions are made around strategies to improve nutritional intake and support independent eating these largely come from studies using trained carers in residential care settings. There is a clear need for evidence for practice to inform the advice and support provided to family carers about response to eating behaviour and changes in appetite in dementia.

Healthcare professionals identified that raising awareness of nutritional issues proactively such as at the point of diagnosis would be beneficial (Mole et al., 2019). A swift response to eating behaviour and appetite problems as described by Krolak-Salmon et al., (2016) is effective and can prevent hospitalisation. Healthcare professionals are aware of risks associated with nutrition and eating, ranking malnutrition and swallowing difficulties as

seventh (26.4%; p=0.044) and eighth (24.1%;p=0.9) respectively out of twelve common risks associated with dementia (Taylor et al., 2018). Community nurses can screen for malnutrition risk and identify symptoms impacting nutrition and will usually understand referral systems for dietetic assessment and advice (McGinley, 2015). There are a number of validated tools used to screen for malnutrition risk however a scoping review was unable to find any consensus around which should be used in dementia care (Mole et al., 2018). The mini nutritional assessment (MNA) is most commonly used to identify malnutrition risk in dementia and particularly favoured by European countries although a recent survey identified a preference in the UK for use of the Malnutrition Universal Screening Tool (MUST) (Taylor et al., 2018, Mole et al., 2018). There are also ethical considerations which come with screening for malnutrition risk. UK guidelines state that such screening should only be undertaken if there is intent to treat malnutrition risk (NICE, 2006 (update 2017)). A decision around whether it is appropriate to screen is then required adding a layer of complex, ethical challenge to a seemingly simple clinical activity. This may in itself be a barrier to healthcare professionals screening for malnutrition risk in those with dementia. Further, a gap in training around end-of-life feeding is identified for healthcare professionals involved in dementia care (De and Thomas, 2019).

3.7 Theme 4: Resourcefulness, decision-making and resilience in relation to eating and food

This review identified resourcefulness, decision-making and resilience as factors influencing family carer experiences of eating behaviour and food in dementia. In particular these may be associated with family carer stress around these functions (Aselage et al., 2011).

3.7.1 Resourcefulness

Resourceful approaches of family carers are described in the literature and include keeping food simple and traditional, consideration of personal preferences, offering regular drinks, limiting clutter on the table and limiting choice to aide decision-making at mealtimes (Ball et al., 2015). Ensuring the person with dementia is involved in decisions around meal-related tasks was also found to be important for family carers as these

provided cues to support eating, whilst limiting choice could help in the person's decision-making (Samsi and Manthorpe, 2013). Older family carers responded to changes in various ways including shopping together for food, preparing meals in advance, offering verbal reminders and motivators, eating together or watching the television for distraction during the meal (Silva et al., 2013). Keller et al., (2015) found that some family carers were able to identify changes in environment or food which could reduce stress around mealtimes. For example, choosing food that can be eaten using the hands or by feeding the person. Having patience and persistence was also a beneficial response to changes in eating behaviour whilst making an event of meals and supervision of eating were similarly important (Ball et al., 2015). Avoiding battles over food was a strategy recommended by family carers and reflects the need to choose which 'battles' are essential for safety and well-being or perhaps reflect a desire for peace (Ball et al., 2015). A positive, reassuring style of communication, guidance and reactions to the person with dementia's eating behaviour can improve food consumption and weight (Aselage et al., 2011). Although eating out was for some a relief from the usual routine there were challenges in managing eating behaviour with family carers sometimes feeling embarrassed or stressed (Keller et al., 2015). In contrast, others describe how despite eating behaviour difficulties they felt able to continue to take the person with dementia out to eat and socialise (Watson et al., 2003). Decisions to eat outside of the home may reflect family carer perception of eating behaviours as well as the ability to adapt to changes.

Safety in relation to meal-related tasks and food was of particular concern when the person with dementia lived alone (Watson et al., 2003). For example, leaving pans on the hob or eating out-of-date food. To mitigate the risk family carers explained or provide written instructions around meal preparation, monitoring how much was eaten and food safety (Silva et al., 2013). Agnosia also brought safety concerns impacting eating behaviour with loss of understanding and recognition of food and utensils as well as effecting ability to prepare food, cook or eating (Keller, 2006). Use of meals on wheels was one strategy suggested to help with kitchen and food related risks (Ball et al., 2015).

3.7.2   Decision-making

The need for family carers to undertake proxy decision-making is both difficult and distressing (Lord et al., 2015). Family carers describe limited information and a lack of support from healthcare professionals as a contributing factor to such decision-making being difficult (Samsi and Manthorpe, 2013, Lord et al., 2015). They also felt excluded from decisions made in hospital about their family member with dementia highlighting the need for healthcare professionals to establish good communication with family members (Lord et al., 2015).

Experience of decision-making was explored over one year, using repeated qualitative interviews of twelve dyads (person with dementia and family carer) (Samsi and Manthorpe, 2013). A process of moving from making decisions together as partners to carer led decision-making was identified. Such changes were similarly described in a longitudinal Swedish study of twenty spouses in a dementia carer role (Hellström et al., 2005). Changes in strategies used by spouses to live positively with their partner were identified with three phases of change: sustaining couple-hood, maintaining involvement and moving on (Hellström et al., 2005). Maintaining involvement and moving on presents the shift from a partnership approach to the person with dementia letting go of tasks and/or their partner taking on new roles (Hellström et al., 2005). When and how much to assist the person with dementia or take over tasks is part of this process of letting go and taking on new tasks (Samsi and Manthorpe, 2013). Keller et al., (2006) describes this in the context of mealtimes where family carers made judgments about when to step in to support feeding with some simplifying meals such that independent eating was supported. Allowing more time for completion of eating-related tasks or adjusting tasks 'quietly' rather than criticising or taking over too soon can help preserve the dignity of the person with dementia during this transitional period (Keller et al., 2015). Decision-making may be easier for long-term spouses than as an adult-child carer of a parent with implications for feelings of stress and burden (Samsi and Manthorpe, 2013). However, there is a point where the person with dementia is no longer involved with eating-related tasks and often associated with a decline in appetite (Fjellström et al., 2010). Whilst not explicitly stated this is unlikely to be causal rather it could reflect a general decline in function as dementia progresses. The move from shared decision-making to carer

decision-making will likely result in new roles in relation to food, nutrition, and mealtimes as identified by Li et al., (2020b) and Fjellström et al., (2010). For some this new role brings new tasks such as cooking, planning meals and preparing food and learning around meal-related tasks (Fjellström et al., 2010). The latter is described in one study as a particular challenge for men with their having limited prior experience of this (Fjellström et al., 2010). However, it could be assumed that similar difficulties would be found when women have limited culinary experience.

Strategies used by family carers to manage unintended weight loss included providing more nutrient dense foods, adding calorie dense ingredients to food and meals and using high energy and protein oral nutritional supplements (Ball et al., 2015). Yet family carers also raise concerns about the effect of increasing calories through higher fat diets on cholesterol levels and overall health (Fjellström et al., 2010). As a result there is often focus on 'healthy' foods with desire for more knowledge about these and concern raised about not providing 'healthy' meals (Fjellström et al., 2010). Despite a lack of evidence family carers perceived that healthy foods positively impacted dementia yet the pressure to provide these often made eating-related tasks more difficult and stressful (Fjellström et al., 2010). Changes in appetite also effected the routine of eating, with family carers having to make decisions around response to poor appetite or persistent hunger (Fjellström et al., 2010). As dementia progresses, communication ability can decline which can result in difficulties with engagement in food-related tasks, decision-making and choice about food and eating (Fjellström et al., 2010). Further, family carers describe feeling pressure not to disappoint with food choices made, with concern about not exacerbating problems with food preferences or taste changes (Fjellström et al., 2010).

In contrast to the drive for healthy food choice, some family carers are anxious to improve eating in response to appetite declines. Although not well described in the context of family carer experiences of eating in dementia, it is recognised that family carers particularly of older people who are not eating well, pursue measures to encourage eating regardless of the individual's wishes (Justice, 1995). This may be related to the common Western cultural association of eating and life, with eating and appetite heavily influenced by culture, religion and personal beliefs (Poole, 2002). Although there is limited research around the meaning of eating and appetite in advanced dementia for

family carers, a review of weight loss and appetite in advanced cancer describes how those caring were more often distressed by these symptoms than the individual themselves (Justice, 1995). Weight loss and not eating were seen by family members as a physical reminder of the persons impending death, with distress a physical manifestation of anxiety about the person's mortality (Justice, 1995). This may then help to explain the drive for some family carers to pursue measures to improve eating.

It is also important to recognise that some individuals choose to stop eating as they near death. Voluntary cessation of eating and drinking may occur towards the end of life in an attempt to hasten death due to extreme suffering or loss of control (Bolt et al., 2015). Ceasing to eat can be seen as affording the individual some control about death (Bolt et al., 2015). Within Western culture such control over death is seen, as having a 'good' death yet for family members and even clinicians there is sometimes difficulty in accepting that part of a 'good death' for some may be the cessation of eating and drinking. Some cultures are more accepting of this. For example, within Hindu culture stopping eating is a sign of preparing for death with dignity and being free from pain or risk of incontinence (Justice, 1995). It is suggested that this removes anxiety, distress and even conflict between family, carers and the person who is dying around not eating. Thus, understanding of meaning of eating and appetite in dementia for family carers is relevant for both family carers and the person with dementia. However, this review has identified a gap in knowledge about this.

The decline in eating which occurs towards the end of life can be a difficult and highly emotive for family carers. Support around response to malnutrition at the end of life is helpful (De and Thomas, 2019). A review of ethical considerations with regards to nutrition and dementia describes how family carers should be able to discuss feeding and drinking with palliative care services as part of advanced care planning (De and Thomas, 2019). This would help alleviate some of the responsibility and burden family carers may feel around this however, it is not clear how many families have access to palliative care support (De and Thomas, 2019). Reassurance that no discomfort or hunger in the terminal phase of dementia occurs if eating and drinking ceases is important, with comfort feeding an option if this does not cause distress for the person with dementia (De and Thomas, 2019). The evidence suggests that enteral tube feeding in dementia is not

without risk, with no extension of life or benefit identified and an increase in mortality of up to 70% described (De and Thomas, 2019). The NICE (2016) guidance therefore does not endorse the use of enteral feeding unless for a time limited period to manage an acute episode of illness.

Decision aides have been developed to support family carers in decisions about nutritional care, although evidence from randomised trials is lacking (De and Thomas, 2019, Lord et al., 2015). There is a risk of such aides introducing a topic which the carer was previously unaware of creating anxiety or feelings of conflict unless appropriate support is provided alongside this (Lord et al., 2015). Sharing decision-making with the wider family can help alleviate guilt or burden of a primary carer, with reassurance from family members often sought (Lord et al., 2015, Butcher et al., 2001). Family carers felt discussion with relevant healthcare professional was the most helpful element of a consultation and perhaps reflects the findings of Fjellström et al., (2010) who describe the importance of the need to talk about experiences of eating-related behaviours (De and Thomas, 2019).

3.7.3   Resilience

Family carer resilience can impact ability to sustain this role and capacity to manage eating behaviour and appetite changes in dementia. Resilience of family carers is described as having the ability to 'recover from, resist or adapt' to the demands of care-giving (Petriwskyj et al., 2016). Successful adaption appears to be an essential key for family carers as described in the Family Adjustment and Adaptation Response Model (FARR) (Patterson, 1988). FARR is a family stress model describing a process of Adjustment – Crisis – Adaption. Adaptions and adjustment following a 'crisis' such as a change in eating behaviour or appetite were found to positively effect ability to continue providing care. It is not surprising then that adaptation is also related to carer stress (Papastavrou, 2007). Shatenstein et al., (2008) identify how adaptation is necessary to negotiate the changes in meal-related tasks, whilst Wong et al., (2015) describes the benefit of adapting to the 'new normal'. The latter mirrors the adaptation to an evolving life described in the Life Nourishment Theory (Keller et al., 2015). Adaptation alongside positive strategies and continuing to learn in the context of eating behaviour and appetite are key elements for family carer resilience (Wong et al., 2015). A review of ten studies

about family carer experiences and perceptions of mealtime care similarly identified adaptation describing this as 'moving forward in the challenge' (Li et al., 2020b). Moving on or forward reflects adaptation to the changes resulting from dementia and is highly applicable for changes in eating behaviour and appetite. Of further relevance for the present review is the identification of ability to undertake activities to maximise quality of life by living in the present and enjoying 'life's little pleasures' (Hellström et al., 2005). This is particularly applicable to eating and mealtimes where enjoyment can be aided and sustained with adaptations. For some couples this may include activities associated with eating and appetite such as the enjoyment of mealtimes, specific food or drink or a routine or ritual associated with food such as cake with a cup of tea.

Petriwskyj et al., (2016) identified interventions to help family carers of people with dementia build resilience or characteristics supporting resilience such as psychological well-being, positive adjustment or coping skills. However, only three studies were included with only one finding an intervention (poetry writing) of possible benefit (Petriwskyj et al., 2016). A problem-solving approach as opposed to an emotionally-focused coping strategy was found to help reduced feelings of burden and may thus contribute to building resilience (Papastavrou, 2007). Life experience may also support ability to develop strategies and problem solve and in this way better equip individuals for a carer role (Greenwood and Smith, 2016). A review of eighteen studies across various cultures found that being an older carer could be beneficial however, there was a lack of consensus around the impact of providing care on the morbidity and frailty associated with ageing (Greenwood and Smith, 2016).

Response to becoming a family carer varies significantly with a scoping review identifying five themes centred around carer resilience: social factors, carer's physical health, carers quality of life, availability of key resources to support carer resilience and psychological resources (Parkinson et al., 2017). Parkinson et al., (2017) describes resilience in this context as having the assets and resources to provide a 'buffer' against adversity as well as supporting behaviour and actions to enable care to be provided. The lack of support and information described by family carers around eating behaviour and appetite may then negatively impact resilience, increasing stress and feelings of burden.

3.8   The effect of eating behaviour on family carers wellbeing

Feeding-challenges and altered eating behaviour can significantly impact mental and physical health including the nutritional state of family carers. This is described in Paul's (2020) model of the Vicious Cycle of Dementia and Nutrition (Figure 8).
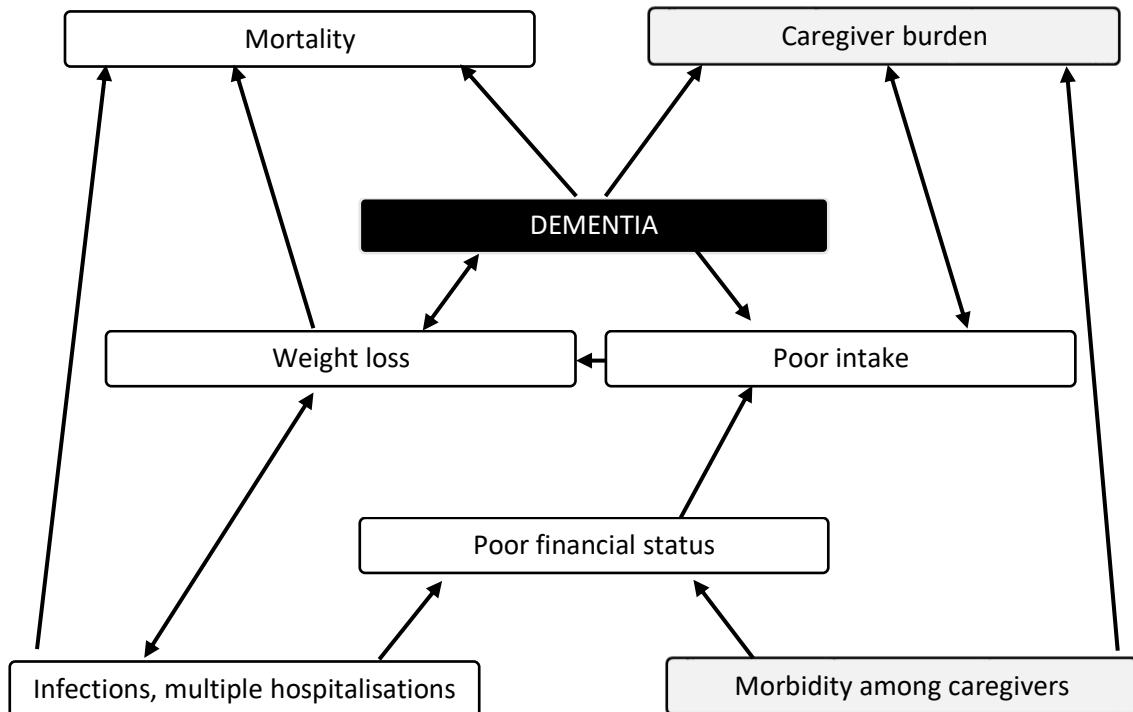
Figure 8 Vicious cycle of dementia and nutrition adapted from Paul (2020) [8]

Paul (2020) suggests that poor nutritional intake in the person with dementia can increase carer burden, whilst carer burden can adversely impact the nutrition of the person receiving care. Poor nutritional state of family carers has also been described by Rullier et al., (2007) with one third (32.1%) identified as being at risk of malnutrition and 5.4% malnourished. Causes of poor nutrition in this context included reduced financial state, carer burden, stress and exhaustion and mirrors the factors presented in the vicious cycle of dementia and nutrition (Rullier et al., 2013). Financial challenges may result from the family carers being unable to work due to caring responsibilities or as a consequence

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[8] Figure is copyrighted 2020 Journal of Family Medicine and Primary Care with use agreed as follows. "This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-Non-Commercial-Share Alike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms."

of their own morbidities (Brodaty and Donkin, 2009). This can make it difficult to afford adequate, nutritious food. It is therefore not surprising that association between nutritional status of the person providing care and the person with dementia has been found (Rullier et al., 2013). If a family carer is feeling stressed or burdened, they may also find it harder to find time to eat well. Further, it is recognised that such changes in eating behaviour or appetite in dementia can be difficult to manage, being a significant reason for family carers to contact a General Practitioner (GP), hospital services or request hospitalisation of the person with dementia (Krolak-Salmon et al, 2016).

Dementia family carers are also at greater risk of psychological and physical morbidity with higher mortality (Brodaty and Donkin, 2009). According to Paul's (2020) model morbidity increases carer burden and may exacerbate poverty. Family carers of those with dementia have a higher risk of cardiovascular problems, lower immunity, poorer immune response to vaccine, slower wound healing, higher levels chronic conditions and unsurprisingly a greater use of healthcare services (Brodaty and Donkin, 2009). Indeed, being a dementia carer is associated with worse physical health compared to age-matched carers of other conditions or those who are not carers (Sörensen et al., 2006). Rationale for this includes a lack of engagement in preventative health behaviour around drinking or smoking, limited exercise and poor sleep (Brodaty and Donkin, 2009). Such unhelpful behaviour may be exacerbated by being a carer due to increased levels of stress, limited time to exercise or access healthcare services and interrupted sleep (Brodaty and Donkin, 2009). Increased morbidity will make it more difficult to continue providing carer and manage changes in eating behaviour, appetite and feeding.

Changes in eating behaviour or feeding-related problems in dementia also impact family carer ability to meet their own basic needs including those related to nutrition. Nine themes of basic carer needs are identified by Pini et al., (2018) to help in understanding of the effect of providing dementia care: freedom, feel close to my relative, feel in control of my life, be my own person, protect my relative, share/express my thoughts and feelings, take care of myself, feel connected to the people around me and get things done. It is possible to consider this in the context of eating and appetite with having 'freedom' to eat and drink as they wish and be 'my own person however this has yet to be described in the literature. Keller et al., (2006) identifies how a carer's life 'shrinks' in terms of not

being able to eat out and socialise, or meals being limited in range of foods due to the need to simplify or modify food choice to manage changes in eating behaviour or food preferences. The desire to 'protect my relative' can be seen in relation to concerns about safety of the person with dementia cooking or eating out of date food. There may be little time to 'take care of myself' including the provision of good nutrition whilst the 'closeness to relatives' or 'feeling connected to people' mealtimes can bring maybe disrupted by caring responsibilities or difficult eating behaviour such that eating out or socialising is not possible. There is also a 'Hierarchy of needs for people with dementia' developed by Schölzel-Dorenbos et al., (2010) from the concepts of Maslow's original work describing the hierarchy of human needs in relation to motivation (Maslow, 1943). The reciprocity in needs between family carer and the person with dementia being cared for is demonstrate by mapping the framework of family carer needs on to the hierarchy of needs for people with dementia (Figure 9).
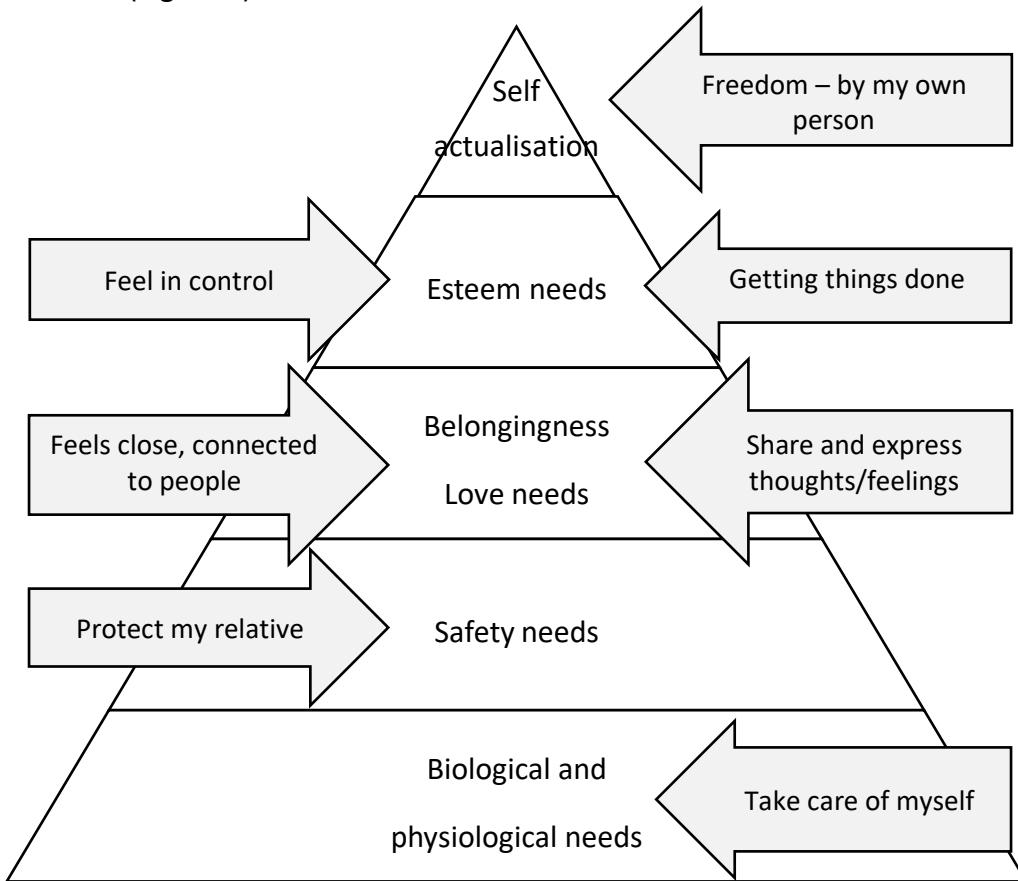
Figure 9 Dementia family carer needs (shaded boxes) adapted from Pini et al., (2018) and the hierarchy of needs in dementia adapted from Pini et al., (2018) and Schölzel-Dorenbos et al., (2020)

Thus, if family carer needs are met those receiving care are more likely to have their needs met. This can be applied to meeting nutrition and eating where if the need for

family carers to take care of themselves nutritionally is met, they would be better able to respond to eating behaviours and appetite changes in those with dementia and meet their nutritional needs. In this way it may be possible to impact the vicious cycle of dementia and nutrition by reducing carer burden and morbidity through meeting family carer needs.

3.9   Limitations of a hermeneutic framework

There are three limitations identified. Firstly, it could be argued that literature is missed using an iterative process rather than traditional systematic approach. However, this is not a random approach with a recognised framework and process for identification and critique of literature. Secondly, this hermeneutical literature review is a double hermeneutical analysis with interpretation of the already interpreted data by the research group. Thirdly, whilst there was no scope for translation there was no data identified of specific relevance which was not already available in English. To help mitigate these limitations the five themes from the review can be mapped onto the model for dementia family carer needs (Figure 10) adding validity to the review process and findings.

Freedom

Be my own

person

Quest for knowledge
& support (Theme 3)
Resourceful,
decision-making,
resilience (Theme 4)
Effect on carer
wellbeing (Theme 5)

Mealtimes more
than eating: identity
(Theme 2)
Effect on carer
wellbeing (Theme 5)

Feel in control

Get things done

Share or express thoughts and

feelings

Mealtimes more
than eating:
connections
(Theme 2)

Feel close, connected

Changes in eating-
behaviour &
appetite (Theme 1)
Resourceful,
decision-making,
resilience (Theme 4)

Protect

my relative

Take care of myself

Changes in eating
& appetite (Theme
1); Resourceful,
decision-making,
resilience (Theme
4); Effect on carer
well-being (Theme
5)

Figure 10 Literature review themes (shaded) mapped onto the model of dementia family carer

needs adapted from Pini et al., (2018)

3.10   Chapter summary

At the time of this review there were limited data regarding family carer lived experiences
of eating behaviour and appetite in dementia. Five themes were identified:

- Changes in eating behaviour and appetite

- Mealtimes are more than eating and nutrition

- The quest for knowledge and support around nutrition and eating

- Resourcefulness, decision-making and resilience in relation to eating behaviour

- The effect of in eating behaviour on family carers wellbeing

This review identifies a knowledge in relation to family carers lived experiences of eating behaviour and appetite providing justification for the present study. Chapter four details the theoretical framework used for the study of this phenomenon.

Chapter 4   Theoretical framework

The purpose of this chapter is to describe the theoretical framework used to develop the study design and provide justification for the approach taken. Hermeneutic phenomenological philosophy within an interpretivist research paradigm is used to explore the lived experiences of family carers in relation to eating and appetite in people with dementia living at home being a novel approach to exploring eating and appetite in dementia. Interpretative phenomenological analysis (IPA) is used for data analysis. There has been little empirical research little describing family carer lived experiences of eating behaviour and appetite in dementia therefore the present study is exploratory in nature. Specifically, this study will seek to explore meaning of family carers lived experiences of eating behaviour and appetite in dementia, response to changes in these functions and views on or experiences of related resources and support.

4.1   Theoretical approach

Phenomenological philosophy is focused on exploring lived experiences thus appropriate for the present study. Phenomenology is an umbrella term encompassing both philosophy and method (Finlay, 2009, Oiler, 1982). There are two primary branches of theory, phenomenology and hermeneutic phenomenology although commentary suggests that there are as many forms of phenomenology as there are phenomenologists (Paley, 1998, Dowling, 2007). The present study uses hermeneutic phenomenology enabling description and interpretation of qualitative data.

4.1.1   The concept of lived experience

The concept of lived experience within phenomenological philosophy is foundational, with phenomenological methods supporting exploration of this within the context of an individual's own world (Laverty, 2003). According to phenomenological philosophy conscious recall and interpretation of an event's memory is necessary for a lived experience to exist otherwise the memory remains in the pre-reflective state (Laverty, 2003). Moran (2013) explains this further using the terms noesis and noema. Noesis is the function of intellect or reasoning and involves perception, imagination, memory and

judgement whilst noema is the content of what is remembered or thought about (Moran 2013). Lived experience is therefore noesis of noema.

A further premise is that exploration of lived experience is within an individual's own context or life-world with argument that this is the only perspective from which true understanding of lived experience can be made (Laverty, 2003, Gelling, 2015). Such context supports in-depth description of a phenomenon adding richness to the data (Finlay, 2009). Prior experiences and context of life-world influence how noema is recalled and the noesis of this. A lived experience is therefore subjective but reflects personal reality and truth (Moran 2013). Phenomenology suggests that everyday life events are often mundane or routine and not usually consciously considered therefore remaining in the pre-reflective state (Laverty, 2003). Unusual events are more likely to be consciously recalled and become lived experiences (Laverty, 2003). For the study participants may not have previously considered their experiences of eating behaviour or appetite in dementia with many associated tasks or activities being mundane or routine. Therefore, although the study is exploring lived experiences of family carers there may be requirement for the participants to develop lived experiences during the interview process as they recall and interpret memories. This is alongside recalling events which are already lived experiences.

4.1.2   Understanding the participant's context

The context or life-world is central to phenomenology comprising of many elements adding richness to data. Hermeneutical phenomenology moves on from the idea of life world and 'what we are' in the world to seek 'a way of being' in the world (Ashworth, 2016). However, the eight fractions of the life-world proposed by Ashworth (2016) are useful for a novice qualitative researcher such as myself to help in understanding participant context and will therefore be considered during data collection and analysis helping add richness to the data. Eight fractions of the life-world are suggested of selfhood, sociality, embodiment, temporality, spatiality and its things, projects, discourse and 'moodedness' (Ashworth, 2016).

'Selfhood' is the personal meaning of thoughts, feelings and behaviours occurring in the background of our lives (Ashworth, 2016). Capturing the essence of the participant's

selfhood helps in understanding the participant perspective. Our relationships with others or 'sociality' describes how identity is apparent through interactions with others (Ashworth, 2016). It suggests that how people perceive us, endorse or judge impacts who we are and therefore how we experience life. Notation of people mentioned during interviews and reflection on their influence on the participant will be made during the study. 'Embodiment' influences identity and requires consideration of how the lived experience connects with an individual's view of their body (Ashworth, 2016). Consideration will be made during the study of the effect of a person's perception or feelings about their gender, disability, illness or other such area on experience of eating behaviour and appetite. For a family carer this may include gender roles and provision of care.

Time ('temporality'), geography ('spatiality and its things') and activities central to a person ('projects') are relevant to consider for the study adding richness to the data and improving depth of understanding of lived experiences. 'Temporality' is the forth element of life-world including when the lived experience began, its length of time and where it occurred in the timeline within the person's life (Ashworth, 2016). 'Spatiality and its things' describe the idea of geography within the life-world relating to physical location of places and the meanings associated with these (Ashworth, 2016). For example, ability to continue to access particular locations such as a favourite restaurant depending on experiences of eating behaviour and appetite of those with dementia. The effect of eating behaviour and appetite in dementia on ability carry out 'projects,' or activities central to a life-world will also be considered. This draws in researcher ability to empathise and gain insider perspective of the participant's lived experience.

The concept of 'discourse' or language is the penultimate fraction of the life-world (Ashworth, 2016). Discourse in phenomenology is not the same as discourse analysis rather it acknowledges it is part of understanding phenomena. This fraction requires the researcher to reflect on the words or phrases used to describe phenomena with language being an essential part of phenomenology (Reeder, 2009). How language is used to describe or reflect on lived experiences can help in understanding of the individual's perspective. This study will consider how participants describe eating behaviour or appetite with little prior description of this found during the literature review (Chapter

Three). This understanding is relevant for effective communication between healthcare professionals and family carers. The final fraction of the life-world is 'moodedness' where all lived experience has an emotional context. Ashworth (2016) describing mood as the atmosphere of an experience influencing interpretation of memories and their presentation.

Fractions of life-world offer structure to the development of rich data and interpretation of the lived experience. For hermeneutic phenomenological researchers these can support development of the emergent meanings of a lived experience (Finlay, 2009). As such they will be captured in reflective notation during data collection and considered during analysis adding richness to the data as required for IPA (AQR, 2020). As a novice researcher this is particularly helpful providing a guide as to what to consider to help develop rich data and gain an 'insider' view of family carer lived experiences of eating and appetite in dementia.

4.1.3   Phenomenology

Husserl is recognised as the founder of phenomenological philosophy developed from a desire to combine science with the everyday lived experience (Koopman, 2015, Reeder, 2009). Phenomenology is considered both philosophical and scientific. However, phenomenology accepts multiple truths in contrast to science which seeks an original truth presenting immediate challenge. To address this acceptance of the unique and commonalities of lived-experience is required, where every person has a unique perspective presenting their own truth and reality of a lived experience (Finlay, 2009). For this study this is the unique perspectives of participating family carers of their individual lived experiences of eating behaviour and appetite in dementia. Rather than multiple truths being of concern these are embraced by phenomenological researchers who seek to understand and describe in-depth the lived-experience using the unique perspectives of each individual's lived experience (Finlay, 2009). Husserl makes a philosophical assumption that in addition to the unique perspectives of individuals there are also commonalities. Commonalities are developed from the common essences of lived experiences (Koopman, 2015). It is this ability to generalise findings which provides the scientific element of phenomenology (Lopez and Willis, 2004). Phenomenology can therefore be described as a 'scientific way-of-knowing' about the world using the unique

perspectives of individuals and the generalisations developed from common essences (Koopman, 2015).

To identify essences of lived experience eidetic reduction is used (Koopman, 2015). Eidetic is an intense picture of the lived experience developed from noesis of conscious recollection and description of the noema of selected memories. Eidetic reduction is the process of hypothesising what would happen to the eidetic (the intense memory) of one element were removed. For example, how is an eidetic of a shared meal with a family member with dementia effected if the need to support eating is hypothetically removed? If nothing changes to the eidetic then this considered element is not found to be essential or an essence of this specific lived experience. However, if the eidetic changes, this element of providing support for eating is essential and considered to be an essence of the lived-experience. In this way the essence of a lived experience can be identified for the individual participant and then across participants, with essence used to identify the unique elements and commonalities of a lived experience. It is suggested that the explicit purpose of phenomenological philosophy is to describe the essence of lived experience within the context of a person's own world to produce a way-of-knowing about the world (Laverty, 2003, Reeder, 2009). The theoretical focus of phenomenology is therefore epistemological that is to say 'about knowledge,' with lived experience used as a method to find a way-of-knowing generating knowledge about the world (Koopman, 2015, Taylor, 1993). Such an approach enables learning about the conscious life (Moran 2013). However, the present study seeks to both 'know' and understand the meaning of eating and appetite in dementia for family carers.

4.1.4 Hermeneutic phenomenology

The research purpose of the present study is to understand the meaning of family carer lived experiences of eating and appetite in dementia therefore hermeneutic phenomenology is used enabling interpretation of lived experiences. Heidegger, a student of Husserl, was the first to include hermeneutics, that is to say interpretation of text, within phenomenology being concerned with ontology (Lopez and Willis, 2004). It seeks to understand by finding the 'what-is' and 'why-it-is' of lived experience requiring interpretation of data (Ashworth, 2016). Dasein, a German word translated as presence

or existence is used by Heidegger to present the theory that existence as humans or 'being' is inextricably woven into a person's world (Campbell, 2019, Laverty, 2003, Zuckerman, 2015). This moves on from the phenomenological concept of life-world to belief that to 'be' requires lived experience in-relation-to the world in which an individual lives (Zuckerman, 2015). This theory recognises that the individual's world is far more than the present, requiring recognition and consideration of the effect of the past, present and future and how these are connected and effect on the phenomenon of interest (Koopman, 2015).

For the present study hermeneutical phenomenology enables interpretation of lived experiences of eating and appetite in dementia for family carers to seek the meaning of these for family carers and an understand of a-way-of-being in-relation-to their own world. This is in contrast to Husserl's approach where description of events of the life of a family carer in relation to eating and appetite would only enable understanding of what-we-are. Hermeneutic phenomenological desires to reveal the complexities of lived experience, the obvious and obscure, the unexpected and surprising elements as well as contradictions or commonalities at its heart (Finlay, 2009). Indeed the very essence of being is described within this philosophy (Laverty, 2003). One method for analysis developed from this philosophy is interpretative phenomenological analysis (IPA) and will be used for the present study.

4.2   Interpretative phenomenological analysis

IPA is a recognised method to develop knowledge and understanding from lived experience set within a hermeneutic phenomenological philosophy (Smith, 2004). The purpose of IPA is for the researcher to recreate the lived experiences of participants providing an insider perspective of this. IPA explores lived experience by seeking to understand what it is like to be within a particular person's world. There are two theoretical axis underpinning IPA: the hierarchy of experience and the theory of interpretation (Smith et al., 2012).

4.2.1   Theoretical axis

The first theoretical axis of IPA assumes a hierarchy of experience. This describes a spectrum of life events from the mundane, ordinary or routine to major, significant unusual or out of the ordinary events (Smith et al., 2012). As already discussed the mundane or ordinary events are often left in the pre-reflective state however, it is such ordinary events which are commonly of interest to the researcher using IPA. Participants in studies using IPA are often required to consciously recall and interpret such ordinary events from their pre-reflective state. This can present ethical challenges with a participant being asked to recall pre-reflective events not previously consciously considered.

The second theoretical axis of IPA is the theory of interpretation or hermeneutics (Smith et al., 2012). This describes the natural tendency of humans to attempt to make sense of lived experiences using reflection, reasoning and interpretation. The theory of interpretation is the process through which analysis occurs described as the 'Hermeneutic Circle of Understanding' (Smith et al., 2012). Interpretation and understanding of the whole of a text or transcript is only possible by considering the fragments or parts and similarly the parts can only be understood by looking at the whole text. The part can be a single word, extract, episode, particular text or interview whilst the whole is the sentence containing the single word, the complete text, research project or life. Analysis needs to be done on a case-by-case basis before reviewing the commonalities, anomalies or unique elements across the complete data set. Double hermeneutics is used where interpretation of lived experience is firstly undertaken by the participant using noesis to decide how to tell their story and secondly by the researcher who interprets the participant's interpretation of their lived experience (Smith et al., 2012).This results in subjective but descriptive data (Smith et al., 2012). The practical aspects of IPA are discussed in Chapter Five.

Double hermeneutics enables an insider-outsider perspective (Smith et al., 2009). The participant is the insider and expert on their own lived experiences and as such can provide deep understanding of their experiences (Reid et al., 2005). Indeed, eligibility for participation in the present study is that participants must have expert lived-experience of being a family carer of an individual with dementia. The researcher as an outsider is

seeking to represent the insider (participant) lived experiences authentically. This requires the researcher to position themselves as if 'walking in the participant's shoes.' How well one can truly understand the specific lived experiences of another person is perhaps dependent on prior experiences and degree of empathy of the researcher. It is suggested that empathy enables the researcher to more readily take the vantage point of participants thus gaining a better insider perspective (Gair, 2012). It also supports the researcher in conveying the participant's story with a "felt understanding" enabling greater insight into their lived experience (Gair, 2012). As an outsider (researcher) with no direct experience of being a family carer of a person with dementia my ability to 'walk in the shoes' of such a person relies heavily on my ability for empathy and the construction of findings which authentically depict family carers lived experiences. Authenticity relates to plausibility in that the more authentic the reader feels the findings are the more plausible this makes them (Reid et al., 2005). Equally important to the success of IPA is transparency (Reid et al., 2005). Transparency is conferred by findings being supported by the data including considered use of direct participant quotes.

IPA is an analytical method which identifies commonalities, extremes and anomalies of the phenomenon of interest both within and across the data set using reflexivity and inductive reasoning to interpret the data (Greenhalgh and Taylor, 1997, Carter and Little, 2007). Such inductive analysis is not interested in simply identifying themes and patterns but rather uses these to elicit meanings within human experience (Ho et al., 2017). For each participant there is a focus on identifying the ideographic of the phenomenon (unique) as opposed to nomothetic or more generalised meaning (commonalities) (Finlay, 2009). Ideographic relates to the unique elements of a phenomenon requiring the researcher to focus on the detail of the data using in-depth analysis (Finlay, 2009, Smith et al., 2012). Yet as would be anticipated in hermeneutic phenomenology a search for commonalities across the participant group is also required (Reid et al., 2005). Such generalisations about lived experience use the Husserlian assumption and acceptance that there will be commonalities of lived experience (Lopez and Willis, 2004). Commonality of experiences can also relate to a community describing what they believe to be real, useful and have meaning within that specific community (Lincoln et al., 2013) Thus, the commonality should be considered authentic to those within a specific community. For example, a commonality within a community of family carers of people

with dementia could be that providing adapted cutlery (real) helps individuals to feed themselves (useful) as their dementia progresses. Meaning of this for the family carer could be interpreted as adaptive cutlery being useful in maintaining independence with eating for the person with dementia reducing the burden of care for the family carer.

4.2.2 Rationale for using interpretative phenomenological analysis

There are two reasons for selecting IPA as the method of analysis for this study - methodological and professional. IPA supports the achievement of the present study's aim and my position as an expert healthcare practitioner but novice researcher. IPA is an approach used to explore complex healthcare issues and the experience of these thus appropriate for the present study (Smith and Firth, 2011). Healthcare researchers often favour IPA due to its relatively structured and systematic form of analysis (Reid et al., 2005). Favouring of such structure may relate to the predominance of science in healthcare professional training and practice. This is described as a reason for healthcare professionals choosing IPA when under taking qualitative research (Finlay, 2009). IPA demonstrates how the scientific element of hermeneutic phenomenology helps to bridge the gap between science and philosophy. IPA's structure is also helpful for novice qualitative researchers but does require reflexivity drawing on aesthetic and intuitive ways of knowing to help describe and understand the lived experience (Finlay, 2009). Advanced healthcare practitioners such as myself will likely be more comfortable with intuition having previously developed skills in this way of knowing' as an advanced practitioner (Benner, 1984)

4.3 Research paradigm

Identifying the research paradigm for this study is the first step in understanding my own positioning and bias. The research paradigm used within a study provides information about the perspective from which it is developed and how data is collected, analysed and discussed. Acknowledging this adds a transparency and rigour to both the research process and findings. It can therefore be argued that decisions around research paradigm are the most fundamental, informing the whole approach to study design and production of new knowledge. Mackenzie and Knipe (2006) describe the research journey as

beginning with identification of a research paradigm from one of four approaches, transformative, pragmatic, interpretivist/constructionist or positivist/post-positivist.

The present study uses the interpretivist paradigm with this positioning influenced by the study aims and my own experiences. The interpretivist paradigm developed from the theory of phenomenology and sits within the theoretical and methodological choices of the present study (Mackenzie & Knipe, 2006). This research paradigm is concerned with participant perspectives of lived experiences and utlises inductive reasoning to develop meaning of this (Alharahsheh & Pius, 2020, Mackenzie & Knipe, 2006). It accepts researcher influence on the study and is therefore aligned with hermeneutic phenomenological (Mackenzie & Knipe, 2006). The associated interpretivist ontological position, that is to say how reality is seen, is one of subjectivity and change with no one truth (Bunniss & Kelly, 2010). This reflects multiple realities of the same phenomenon with no reality being considered more or less true (Denzin & Lincoln, 2000). The epistemological view is that knowledge is subjective, with many interpretations of reality and no 'correct' way of knowing (Bunniss & Kelly, 2010). Epistemology within an interpretivist paradigm is described as an attitude about, rather than a particular view on knowledge, seeing knowledge not as the absolute reality but the best understanding which can be found to date (Laverty, 2003). An interpretivist axiological position accepts each participants truth, valuing and respecting it and with no bias towards a particular truth (Sandelowski, 2000, Bunniss and Kelly, 2010).

Research using hermeneutics is by its very nature interpretative therefore it is logical to use an interpretivist research paradigm for the present study. Heidegger's phenomenology focused on ontology rather than epistemology, questioning what being in the world is like and the meaning of this to the individual (Laverty, 2003). This asks what the very essence of reality is and is at the crux of the present study's aim asking what it is like and what does it mean for that individual to be a family carer and experience appetite and eating changes in dementia. Reality is described as being local or specifically constructed (Denzin & Lincoln, 2000). So, the reality of a lived experience is constructed locally that is to say within the individual's own conscious thought and specifically as a result of being asked to recall the noema of an experience. It follows then that reality cannot be separated from knowledge as without knowledge reality cannot be

constructed (Angen, 2000). Research within an interpretivist paradigm is not seeking objective reality but rather the diversity of realities (Oiler, 1982). Indeed the view of a participant is critical to the interpretivist researcher who relies this to provide study data (Cresswell, 2007). Truth or reality within this paradigm is not grounded in an objective reality but rather multiple subjective realities which can contribute to a consensus of opinion within a community (Guba and Lincoln, 1994, Angen, 2000, Lincoln et al., 2013). Embracing multiple truths of experience requires the researcher to allow the spectrum of truths to co-exist, accepting the differences and the range of experiences and allowing emergent themes and a relative consensus to be discovered (Guba and Lincoln, 1994, Angen, 2000). The present study findings will therefore be presented through the interpretivist lens.

4.4   Researcher position

The hermeneutic phenomenology and interpretivist research paradigm used for the present study both acknowledge researcher influence with recognition this contributes to rigour, transparency and confidence to the study design and findings (Berger, 2015). Personal influence presents researcher bias where researcher perspective about the phenomenon being studied is influenced by their own experiences, influences and opinions (Berger, 2015). A researcher can consciously or subconsciously influence decision-making throughout the research process ultimately influencing findings. To help identify bias researchers are encouraged to be reflexive and consider the effect of prior experiences, views, knowledge and perceptions (Finlay, 2009). Reflecting on my own position in the decision-making for the present study design and identifying influence on analysis and interpretation of data is therefore important (Gubrium and Sankar, 1994).

My researcher interpretivist position used for the present study is influenced by my approach in clinical practice believing that patients bring their own truth of their situation and this may differ from that of a family member or healthcare professional. This reflects the ontological and epistemological positioning of an interpretivist paradigm (Bunniss & Kelly, 2010). Experience has taught that listening to and acknowledging an individual's thoughts and position helps to engage them in treatment decisions reflecting an axiological position of valuing the individual's perspective and accepting their reality

within the context of their life. A more holistic approach in clinical practice requires consideration of multiple factors offering contextual data much in the same way as consideration in phenomenological research of the participant's life world or context. Such personal preference will influence study design, style of interviewing and data analysis.

Empirical knowledge alone is inadequate for a holistic understanding of a patient with other ways of 'knowing' required such as aesthetic, personal, moral, socio-political, experiential, tacit and professional (Paley et al., 2007, Carper, 1978). In clinical practice intuition is often helpful in gaining aesthetic knowledge about the person or situation and this will no doubt impact my approach to data collection and interpretation of data. Aesthetic knowing allows for deeper and more contextual understanding (Ewenstein and Whyte, 2007). This requires consideration of the language used and non-verbal expressions whilst listening to one's internal sense or feelings about the situation (Ewenstein and Whyte, 2007). Intuition often relies on previous experience and is a sign of a more experienced practitioner and perhaps why this a familiar in my own clinical practice (Benner, 1984) .Such an approach supports empathy when negotiating treatment with empathy also helpful in understanding the insider participant view of lived experience (Gair, 2012). Thus, it can be seen that skills developed in clinical practice such as different ways of knowing, empathy, listening, reflecting and interpreting what an individual is saying will influence behaviour as a researcher.

4.5   Reflexivity

Reflexivity is an essential element of qualitative research and IPA. It supports a rigorous method providing a way of describing the decisions made and the rationale for these (Dowling, 2006). It is an important part of knowledge development providing a transparent approach through documentation of the thought process thereby adding trustworthiness to the data (Berger, 2015).

4.5.1   The reflexive researcher

Being a reflexive researcher is essential for adding credibility to the findings, also benefiting the researcher in relation to their own learning. Researcher reflexivity is seen

as thoughtful self-awareness about experience, knowledge, beliefs, empathy and feelings (Enosh and Ben-Ari, 2016). The purpose being to seek both what is obvious and implied (aesthetic knowing) (Enosh and Ben-Ari, 2016). Documenting a reflexive account helps to tell the story of the research process itself, providing evidence and rationale for changes and decisions made about study design, approach to recruitment, interviews and analysis, as well as relevant societal situations or political statements. As a reflexive researcher a researcher diary and field notes will be maintained throughout the study adding a level of authenticity and rigour, helping to demonstrate good quality research.

Reflexivity is built into the present research and utilises Sandelowski & Barroso (2002) definition of "inward reflexivity towards myself, outward reflexivity relating to the cultural, historical, linguistic, political and other external forces and lastly in-between reflexivity relating to the social interaction between the participants and I." Inward reflexivity begins with identification of personal influences, beliefs and experience enabling identification of researcher position and bias. Using reflexivity helped me construct researcher context, position and influence adding transparency and rigour to the method and findings (Gubrium and Sankar, 1994). In this way researcher bias is acknowledged. Outward reflexivity relates to consideration of the influences on the phenomenon of interest. Thus, for the present study I considered cultural, social, and political influences on being a family carer of a person with dementia and eating and appetite as presented in Chapters One and Two.

Reflexivity also provides opportunity for personal learning through consideration of what went well and not so well during the study (Edwards and Holland, 2013). Reflexivity can highlight the interview relationship indicating any tension, lack of engagement or level of rapport thereby adding rigour to the research process (Berger, 2015). It also provides opportunity to consider researcher impact on helping or obstructing data collection or the construction of knowledge (Berger, 2015). Concurrent reflexive learning during data collection will support development of researcher interviewing skills and awareness of personal influence on the study process. However, hermeneutical phenomenology acknowledges that both the researcher and participant have their own ideas, values, experience and thoughts influencing the interview and data collection process requiring both researcher and participant reflexivity (Edwards and Holland, 2013).

4.5.2   Participant reflexivity

Although not explicit the participant is effectively asked to be reflexive when participating in research exploring lived experience. They are asked to recall the noema of an event and use noesis and reflexivity to decide on how to present their truth about a lived experience. New knowledge therefore results from the interaction and reflexivity of both researcher and participant at interview (Enosh and Ben-Ari, 2016). Participant reflexivity is therefore congruent with the philosophical approach, paradigm and method of the present study.

The researcher needs to support and encourage participants to be reflexive during the research process with the level of participant reflexivity influencing the data. The more reflexive a participant is suggests greater engagement in the research process (Enosh and Ben-Ari, 2016). The present study frames questions, prompts and discussion to help the participant reflect and consider their experience. Participant reflexivity is fluid with movement in and out of the phenomenon of interest, switching between description of experience to reflection on this (Enosh and Ben-Ari, 2016). For the present study a participant may move from describing mealtimes to interpreting the meaning of this. Such reflexivity may result in a participant describing and exploring the meaning of a particular lived experience for the first time, moving memories from a pre-reflective state to lived experiences. This supports new insight and knowledge not previously identified by either participant or researcher (Enosh and Ben-Ari, 2016). Identification of support for the participant in this activity is therefore required and reflected in the method. For example, signposting to places of support following data collection.

4.6   Rationale for data sources

Qualitative, descriptive data about family carer lived experiences of eating and appetite is required to achieve the study objectives. Identifying the type and source of data informs decisions around method and is therefore a critical step in the research process (Cresswell, 2007). Since the data required for the present study is about family carer lived experiences of eating and appetite in dementia the primary data source is naturally found with individuals who have relevant lived experience. The data source or participant group can be further defined using eligibility criteria. These help to ensure participants can

engage in the research process, recall, discuss and reflect on lived experiences related to the phenomenon of interest.

Following discussion with the PPI representative it was agreed that a minimum of 6-months experience of being a family carer of a person with dementia was likely adequate to be of value for the study. The participant did not have to be providing care at the time of participation, as the interview required description of recalled events. The care recipient could therefore be in residential care or deceased at the time of the interview. Ability to speak English will also be required as this is the only language of the researcher. Although translators could be used there is a risk that the nuances or meanings are literally lost in the translation thus rendering the interpretation of the meaning of the data invalid.

Participants need to have the mental capacity to consent to participate and engage in the research process. Advice on assessing mental capacity within the research setting is provided by the Health Research Authority (2020) stating that a person must be assumed to have capacity unless otherwise established this is not the case. They must be provided with support to make a decision in their best interest (Health Research Authority, 2020). When recruiting from the general public without access to healthcare records decisions about capacity are required. For the present study this will occur during recruitment and the consent process whilst also being mindful of this during the interview itself as such ability to have capacity can change between these key events. A lack of capacity is described as being unable to make or communicate a decision due to a brain or mind impairment or disturbance (Department of Health, 2005). Discussion at eligibility screening should flag any initial concerns around mental capacity, which can then be documented. The interview will be stopped if concerns about mental capacity or best interest occur.

Efforts to minimise the effects of conditions other than dementia on eating and appetite were made. A primary exclusion was concurrent malignancy in the person with dementia. Malignancies commonly impact eating and appetite either directly as a result of the physical location of a tumour or cancer cachexia or indirectly through the iatrogenic effects of treatment. Therefore, a concurrent malignancy could confound findings.

Balanced with this is the prevalence of common comorbidities such as cardiovascular disease and type II diabetes. The risk of dementia in an older person is five-times more in those who have had an ischemic stroke (Tatemichi et al., 1994). The incidence of dementia is also higher in those with cardiovascular disease even when excluding stroke (Newman et al., 2005). Therefore, there is a high probability that an individual with dementia will have some form of concurrent cardiovascular disease. Type II diabetes is also associated with an increased risk of Alzheimer's disease, vascular dementia and mixed forms of dementia (Strachan et al., 2008). Although these comorbidities may result in changes in appetite or eating because of their strong association with dementia it would be difficult to exclude.

Aside from the data provided by participants at interview there are other data sources including field notes and researcher diary capturing reflections and thoughts. Field notes provide additional contextual data around biographical, historical, situational and relational information. This data provides the thick descriptors to interpret the primary data. The transparency and trustworthiness of the present study and findings are improved by having data sources such as researcher diary or field notes, which contribute to the audit trail for influence of researcher bias and decision-making during the research process. These data also provide evidence of a reflexive researcher approach.

4.7   Rationale for in-depth Interviews

The present study uses in-depth interviews which is appropriate for the achievement of the study aim, philosophical and methodological choices. Interviews are an exchange of information with purpose or meaning. The defining feature of in-depth interviews is the need for the researcher to probe for detail of the individual's lived experiences. This is essential for IPA, focused on the ideographic nature of lived experience. An in-depth interview gives flexibility in what is discussed as well as scope for deeper conversation (Edwards and Holland, 2013). A more authentic insight into participant lived experience can be gained from in-depth conversation particularly when a researcher is responsive and reflexive to participant cues (Crouch and McKenzie, 2006). Such an approach allows for greater participant expression and description of lived experiences with exploration of both the anticipated and unexpected. It is exploration in this way, which provides rich

data helping illuminate participant lived experiences, supporting the development of new understanding and knowledge.

Thick descriptors are required for development of rich data and relate to biography, history, situational, relational and interrelation components of a lived experiences (Ponterotto, 2006). The essential elements of thick descriptors described by Ponterotto, (2016) are accurate descriptions and interpretation of "social actions within the appropriate context in which the social action took place" which capture "the thoughts, emotions, and web of social interaction in their operating context." Thick meaning is developed through the merger of the participant's description and researcher's interpretations and highly relevant for IPA (Ponterotto, 2006). It supports those reading the researcher's presentation of lived experience to understand it in both a cognitive and emotional way. The latter is known as verisimilitude (Ponterotto, 2006). Enabling emotional connection allows readers to imagine and feel the lived experiences rather than simply having a cognitive understanding. Possible motivations and intentions for social actions can then be allocated through researcher interpretation of the participant's descriptions (Ponterotto, 2006). Thus, thick descriptors seek to describe and interpret each element of the lived experience within its context using the participant's own description of related thoughts, emotions and social interactions and researcher interpretation of this.

To elicit the relevant, quality data from in-depth interviews the participant must feel comfortable to share and discuss their lived experiences. Developing good rapport helps the participant feel more confident in sharing their story. Balancing the positions of researcher and participant such that there is a more equal status can also help the participant to feel more comfortable during the interview process. A more equal balance of power can be achieved by having both participant and researcher actively engage in the direction of the interview, co-constructing the development of understanding and knowledge (Holstein and Gubrium, 1995). Using this approach enables the participant to move from a passive role of responding to questions to actively participating in the interview process (Edwards and Holland, 2013).

For the present study an interview topic guide is used allowing for in-depth exploration of related topics the participant wants to present within a loose structure. This is not a rigid set of questions but rather a guide to the topics to be discussed, impacting the equality and interaction between researcher and participant. A less structured, more conversational style can improve interaction and balance power thus (Crouch and McKenzie, 2006). Interviews can have varying amounts of structure categorised as unstructured, semi-structured and structured (Edwards and Holland, 2013). In-depth interviews by necessity have little structure allowing for detailed exploration and discussion of a few topics relating to a phenomena rather than brief discussion about many topics (Britten, 1995). With less structure there is increased flexibility and freedom within the interview enabling the participant to share what is of importance to them rather than the researcher seeking answers to what is important to themselves (Edwards and Holland, 2013). Less structured interviews also allows for a more intuitive approach to interviewing with the flexibility for the researcher able to respond to verbal and non-verbal cues or pursue unexpected or highly interesting avenues (Crouch and McKenzie, 2006). The amount of structure within the interview will also influence the depth of interview discussion and nature of data produced.

4.8   Chapter summary

This fourth chapter presents the theoretical context from which the method for the study has been immersed. My own researcher position is explored identifying and acknowledging the influence of this on the study design and findings. Exploration of an interpretivist research paradigm and rationale for using a hermeneutical phenomenology approach and IPA is described. Consideration of the importance of reflexivity as a researcher as well as a participant is also made. Chapter Five details the method for the present study that is to say how the study is to be carried out.

Chapter 5   Method

This chapter details how the method was used in practice including sampling, participant recruitment, management of ethical issues, data collection and analysis using IPA (Bunniss and Kelly, 2010). A transparent method is important engendering greater trustworthiness in the data and knowledge generated (Tong et al., 2007, Carter and Little, 2007). Challenges to the recruitment process are discussed and reflections on this and the study design are made. The chapter begins by discussing patient and public involvement as this was influential for the method development and approach used.

5.1   Patient and public involvement

There has been considerable drive in the UK to promote the involvement of patients and the public in health and social care research. Of particular relevance to the present study and its funding is the importance placed on patient and public involvement (PPI) by the NIHR (Staniszewska et al., 2017). Collaborating with a PPI group can improve the relevance and quality of a study with consideration of its appropriateness and acceptability to the public (Staniszewska and Denegri, 2013). This supports an ethical approach, being unethical to undertake research not considered to be necessary or useful or with unacceptable methods. Further, transparency and therefore reliability of the research process and findings is increased by reporting on PPI activity (Staniszewska et al., 2017). Therefore, both engagement with and impact of PPI for this study will be described.

Identifying an appropriate PPI representative is a critical step to ensuring useful engagement. The term public as defined by INVOLVE (2012) includes patients, carers or people accessing health and social care services as well as service user organisations. For the present study the 'public' includes those with experience of caring for a family member with dementia. A PPI representative from the local Wessex CLAHRC Dementia and Ageing Research Group was identified as being willing to contribute and advise on the study design. This individual was not only a very experienced PPI representative but had previously cared for her husband when he developed dementia.

Research with PPI is described as research being undertaken 'with or by' the public as opposed to 'about or for' them and fits within the phenomenological, interpretivist approach used in the present study (INVOLVE, 2012). The Guidance for Reporting of Involvement of Patient and Public (GRIPP) checklist, specifically the GRIPP2-short form was used to help clarify how and why I was engaging with PPI. The checklist is described as the first consensus and evidence-based guidance to support researchers in reporting on how patients and the public were involved in a study and would therefore seem a highly appropriate approach to use (Staniszewska et al., 2017). The GRIPP2-short form comprises of five sections to report on: aims of PPI in the study, methods used to engage with PPI, outcomes of PPI engagement, influence of PPI on the study, critical comment and learning (Staniszewska et al., 2017). The authors of GRIPP recognise that the checklist has not been tested for all forms of research and that all the sections may not be relevant for some studies (Staniszewska et al., 2017). For this study the results and discussion are combined into one section to avoid repetition.

5.1.1   Purpose of PPI engagement in the study

The aim of involving PPI in the present study was to have the voice of dementia carers represented as a research partner particularly during the development of the study method. PPI can be undertaken across the research cycle however, the first steps of identifying and prioritising relevant research ideas and commissioning of the research were not necessary being an identified and funded project within the local CLAHRC and University (INVOLVE, 2012). PPI was however key to the design of the study.

5.1.2   Method - approach to PPI engagement

Engagement with the PPI representative was planned with an initial meeting to discuss the proposal and subsequent engagement via email. Additional opportunities for PPI engagement occurred both formally through local Wessex CLAHRC training and informally with engagement with the public at a local Dementia Festival, Dementia Carer's Groups and a Dementia Action Group.

5.1.3   Influence of PPI on the present study

The influence of PPI engagement on the research were overwhelming positive and significantly shaped the method design. Specific effects relate to public interest, ethics, ease of understanding of participant information, interview environment, remuneration and data collection.

5.1.3.1   Public interest

Although the study subject had already been identified prior to commencing this work it was helpful to identify likely interest of the public and importantly the study approach, research questions and recruitment. Opportunistic discussions about the proposed research were had when attending the local Dementia Action Group, comprising of healthcare professionals and individuals representing organisations providing dementia care. This group reflected a supportive approach to the study and suggestions for recruitment opportunities were identified. Engagement with family members at carers groups and the Dementia Festival gave reassurance that the study topic was of interest to this group with conversations helping inform both approach and content of the interview questions.

5.1.3.2   Ethics

Consideration of the impact on both the participant and the person being cared for was discussed with the PPI representative. Two key points were identified. Firstly, the risk that the research might increase concern about food and nutrition and cause worry about how to manage eating and drinking in the future. The researcher suggested that participant support could include signposting to appropriate information with advice to make contact with their GP or other health care professional as required. The PPI representative felt this would be appropriate and did not suggest any additional supportive measures. Secondly the time commitment required to participate and impact on the care of the person with dementia was discussed. The PPI advice agreed with consent on the same day as interview with less impact on both the participant and the person they cared for then two separate visits to consent and then interview.

5.1.3.3 Plain English

Having PPI support benefited understanding of plain English described as 'writing with your reader in mind using clear, concise language in the right tone' (Plain English Campaign, 2020). At a Wessex CLAHRC training day, I had the opportunity to explain my study in 'plain English' with critique from experienced PPI representatives. This provided valuable insight into how to use plain English and significantly influenced the way I introduced the study to gate keepers and the sample group and the study summary. The Plain English Campaign was also introduce with their guidelines utilised for writing participant and public facing information (Plain English Campaign, 2020).

5.1.3.4 Interview Environment

The environment for the interview was discussed with the PPI representative with specific consideration of where the interviews should take place with options including the participant's own home, a room in the local hospital or University. We agreed that the primary factor would be for the participant and researcher to feel comfortable and safe with confidentiality being maintained and therefore the protocol left the precise location open within these parameters. It was felt to be unethical for the person with dementia to be present during the interview as this was firstly disrespectful to discuss the provision of carer with the person being cared for present and secondly may inhibit exploration of carer experience. The PPI representative identified this requirement as being potentially challenging for the participant with alternate care not necessarily easy to identify.

5.1.3.5 Remuneration

Understanding how best to acknowledge participation in the study would have been challenging without the advice from the PPI representative. The suggestion of a supermarket voucher was extremely helpful and reflected the theme of the study around eating and appetite. Payment for participation in qualitative research should not be perceived as problematic and is increasingly common (Head, 2009). It should reflect the amount of participant time required and be clearly described in the participant information (Health Research Authority, 2014). Using money or gift vouchers as a way of expressing thanks for participating in a study is an approach used by other qualitative researchers (Head, 2009). The amount for each voucher was discussed and the

researcher's suggestion of offering to cover travel costs of up to £10 on production of a receipt was also supported by the PPI representative.

5.1.3.6   Data collection

Discussion with the PPI representative around data collection identified that interviews were an acceptable approach. The interview guide was developed following the initial PPI meeting and it was agreed that exploratory, open questions would be suitable. Discussion around using plain English and making the questions accessible to those with a range of cultural and educational backgrounds was had and helped to develop clear, easy to understand questions (Gubrium and Sankar, 1994). The final interview guide was sent to the PPI representative for comments but no significant changes were advised.

5.1.4   Reflections and learning from PPI engagement

Having PPI involvement was beneficial in two key ways. Firstly, PPI support provided reassurance to me as a novice researcher that the subject, method and written materials were likely acceptable to the general public and in particular family carers of people with dementia. This engenders greater confidence in taking the study forward. Secondly, PPI offered unique opportunity to gain insight into how a family carer may view the study and make changes to the study design and written information to improve acceptability and understanding. To successfully engage with patients or the general public the researcher needs to listen, be empathetic and understanding of the spectrum of views and opinions which may be offered (Staniszewska and Denegri, 2013). My approach to PPI was to listen and learn about public opinion of the study and use this to improve the acceptability and accessibility of the research with a focus on producing findings, which would be considered relevant and of benefit.

5.2   Ethical considerations

Ethical considerations for participants and myself were of primary importance for this study. The Health and Social Care Professions (HCPC) standards of performance and ethics helped inform this alongside the University of Southampton's Ethics Policy and Policy on the Ethical Conduct of Studies Involving Human Participants (HCPC, 2018, University of Southampton, 2019, University of Southampton, 2012). Further, ethical

approval was sought and informed consent taken from the participants. Support for participants following participation was considered alongside safeguarding, duty of care and researcher self-care.

5.2.1 Ethical approval

Formal ethical approval was required prior to commencing the study. Approval by the University of Southampton Faculty of Health Sciences Ethics Committee (ERGO 30523) was received with no amendments required (Appendix A). There was also requirement for NHS Health Research Authority Research Ethics Committee (NHS HRA REC) approval in order to recruit from the designated local NHS organisation (IRAS 239827 Berkshire Research Ethics Committee (18/SC/0213)). NHS HRA REC approval was received with two minor amendments. HRA approval was received on 16th May 2018 (Appendix A) and community recruitment began. An application to the local NHS organisation's Research and Development Department was made and application for an NHS research passport made. This was delayed due to unforeseen personal circumstances of ill health. Once the relevant documentation was received NHS recruitment could began. Minor amendments were subsequently submitted to the NHS HRA REC due to changes in the University of Southampton's requirements relating to GDPR. The Patient Information Sheet was now required to include a lengthy addition in relation to this with ethical approval received from the HRA on 13th May 2019 (Appendix A).

5.2.2 Participant support

There are ethical considerations of asking someone about their experiences for the purposes of research. Measures to help ensure no harm resulted from participation were required and explained within the ethics committee applications. Participating in a study may give rise to the participant having new understanding about their own experiences or highlight issues not previously considered (Crouch and McKenzie, 2006). There is potential for this within the present study. First the participant may not have previously thought about eating and appetite in the person they care for nor realised that this might be a problem. Secondly the participant may have never described their lived experiences of being a family carer or expressed how they felt about this role in relation to eating and appetite. There is a risk that the participant may require support or help to process what

has been discussed in their interview. The study design ensured that participants were advised to seek support or advice if needed during their involvement with the research with prompts on the participant information sheet, at the time of consent and at the end of the interview. Participants were signposted to see their GP reminded about the Dementia helpline and information available on the Alzheimer's Society website by the researcher following interview. Discussion with supervisors about any specific concerns had about a participant was also an option.

5.2.3   Consent

For ethical research voluntary consent to participate is required. This is an essential part of the ethical code of practice for clinical research (DOH, 2009 (b)). Having capacity to consent is described as being able to understand, interpret and retain information long enough to make an informed choice (DOH, 2009 (b), DOH, 2005). For this study the researcher made a subjective decision about an individual's ability to provide voluntary informed consent. This decision was based on interactions with the interested person during the recruitment process and the consent process.

A volunteer recruitment strategy of opting in was used to help reduce any perceived pressure to participate. Clear explanation was made that there were no adverse consequences not participating or withdrawing from the study at any point (DOH, 2009 (b)). Explanation of requirements of the study including the need for interview recording, data protection, storage and subsequent use of data was made (DOH, 2009 (b), GMC, 2002). Duty of care of the researcher to share information disclosed or observed about the participant's health or wellbeing or that of another person mentioned or observed during the study period was explained and formed part of the consent. Opportunity for questions was also provided. Written study information with contact details was provided for participants to keep (GMC, 2002, DOH, 2009 (b)). This small study did not have capacity to translate or obtain braille copies of information sheets and this was recognised as a study limitation. However, The PPI advice on the participant information sheet contributed to readability using a plain English approach (DOH, 2009).

If the individual was willing to proceed, consent was taken (Appendix B), documented on two consent forms and signed by the researcher and participant (DOH, 2009 (b)). For

those unable to write or read a mark countersigned by someone not involved in the research will be obtained (DOH, 2009 (b)). A copy of the signed consent form was given to the participant and the researcher copy filed in a locked draw within the University of Southampton.

5.2.4   Confidentiality

The law about participant confidentiality is described in the Data Protection Act and GDPR with a duty to only collect and retain data relevant to a specific purpose, maintain anonymity, keep data secure and restrict access (Data Protection Act, 1998) (HMSO, 2018). This legislation describes the management of sensitive personal data with two broad principles; who gains accesses and retains data and the rights of those whose data are collected and stored (Data Protection Act, 1998) (HMSO, 2018). To aide confidentiality a data management plan was put in place including how data is transported and stored, anonymising data and access to data (GMC, 2002). Participants were informed that every effort was used to remove identifiable data such as names and locations but anonymised direct quotes would be presented in a public forum with minimal chance of an individual being identifiable from these. Participants were informed that the anonymised data would be used for the researcher's thesis, research publications, articles, posters, formal and informal presentations and social media and may inform future work. Whilst confidentiality is essential, duty of care to report concern about health or wellbeing of individuals who the researcher meets or are described in the interview takes precedence. This was explicitly raised during the consent process and documented on the consent form.

5.2.5   Safeguarding and duty of care

As a registered health care professional with the Health and Care Professions Council (HCPC) there is a duty of care to maintain confidentiality but this can be over ridden to report concerns about safety or wellbeing of service users or vulnerable individuals (HCPC, 2016). Study participants were carers of vulnerable adults and participants may even be vulnerable adults themselves. Participants were informed that although the interview was confidential if during the interview information was disclosed which raised concern about a person's safety or wellbeing the researcher had a duty of care to act on

this and discuss with their supervisors any required action. This was explicitly included in the consent process.

5.2.6   Researcher self-care

As part of HCPC registration there is a duty to look after one's own health and wellbeing (HCPC, 2016). During the study, work was planned to ensure breaks during the working day and enough time to travel to see participants and reflect on interviews. Any concerns as well as reflections after the interview were discussed with supervisors. A researcher diary was also kept which was a cathartic mechanism to express thoughts, ideas and feelings during the research process. It also helped identify any concerns or worries, which could then be discussed (anonymised) with friends, peers or supervisors. Having a support network and a desire to maintain a healthy work-life balance was important to help maintain my wellbeing during this research. Additionally measures to ensure safety when undertaking interviews were put in place with the University of Southampton's guidance for lone working and home visits followed. Any concerns about personal safety resulted in the researcher leaving the location, phoning or calling for help if appropriate.

5.3   Limitations of method

It is important to recognise and identify the limitations of the method employed for the present study as this influences its rigour and reliability of the findings. A key criticism of qualitative research the lack of rigour particularly in relation to studies using interview methods for data collection however this has already been addressed in the section on quality measure (Crouch and McKenzie, 2006). Three further limitations for the present study are identified:

- Sampling and recruitment
- Homogeneity of sample group
- Influence of incentivisation for participation
- Data collection
- Data analysis
- Researcher influence

5.3.1 Sampling

Although gatekeepers within all identified routes for accessing the sample group were identified and engagement sought as recommend in the literature significant challenges were experienced in gaining access (Dahlke and Stahlke, 2020). This reflects the choices made at the start of the research process, unanticipated problems and lack of experience of recruiting out with a clinical role. It is recognised that recruitment success begins with the study design and planning (McMurdo et al., 2011). Whilst PPI opinion was sought about study design gatekeepers were not consulted. Identifying and consulting with gatekeepers during the study design is found to improve research access to the sample group and an approach I would choose in future (Shue 2011). Gatekeepers readily bought into the benefits of the present study and identified its relevance to practice. However, this did not translate into easy access of the sample group. Shue (2011) similarly found this, describing how gatekeepers were often interested in studies but provided limited scope for the researcher to access the sample group. Building good relationships with stakeholders can improve recruitment but for the present study there were limited opportunities to meet with contact reliant on email correspondence, telephone calls or a single meeting (McMurdo et al., 2011). Earlier engagement with potential gatekeepers in the study design may support development of better working relationships and buy-in to the study.

A further issue not considered was the potential for the present study to be competing (perceived or actual) with research priorities of organisations such as the Alzheimer's Society or Dementia UK. A busy caseload and other competing activities likely meant the study was understandably not prioritised. The gatekeepers' pressure of work, a perceived burden of the study on time, a risk of having a negative effect on participants and concern about how research related to practice can all be reasons for difficulties in researcher accessing sample groups (Shue 2011). When designing the study, I was mindful of these issues and tried to limit the burden of the study on gatekeepers. However, I did not provide any direct incentives nor overtly relate the study to specifically benefiting a gatekeeper's work. Thus, supporting the present study was not a priority for gatekeepers.

There were specific challenges engaging with the NHS Trust's Dementia Nurse Specialist and the expected carers groups and training were not running whilst I was recruiting. These were all routes I had anticipated as being able to use, highlighting how reliant researchers are on gatekeepers and anticipated activities to gain access to both study sites and sample groups (Dahlke and Stahlke, 2020). A similar experience to that of the NHS Trust was had with Admiral Nurses, the Alzheimer's Society and associated dementia groups and activities (2 branches) and Dementia Action Groups (two contacted). All appeared interested but there was minimal opportunity to engage with the sample group. Of exception was the invitation from one Admiral Nurse to attend a new Dementia Memory Café in June 2018. This provided opportunity to engage with family members, informally discuss the study and leave supporting material but there were no successful recruits. However, my own attendance was subsequently limited due to unforeseen health issues. Had I been able to continue in attendance for longer I wonder if this would have been a successful route of recruitment. One Dementia Action group also supported my attendance at their Dementia Festival with a stall and freedom to talk to anyone attending the event who was interested.

On a more positive note, there was real benefit experienced when there was direct engagement with a sample group whilst attending carer led groups. An amenable gatekeeper was still required but once attendance at meetings was agreed direct access to the sample group can be made and fewer barriers to recruitment experienced. This would influence my approach to sampling in any subsequent work with family carers.

5.3.2   Homogeneity of participant group

Whilst a criticism of the present study is a lack of diversity amongst the participant group there is clear rationale for this. A limited diversity within the sample group and homogenous participant group is advised for IPA (Smith and Firth, 2011). Thus, the present study's sample group was purposively selected to support homogeneity. Despite this it is useful to consider how closely the participant group reflects what is known about family carers of people with dementia. Brodaty and Donkin (2009) describe the 'typical' dementia carer as being middle-aged or older and more likely to be female although it is recognised that more men are taking on this role. Spouse carers are the most common family carer with adult children followed by adult children-in-laws (Brodaty and Donkin,

2009). The participant group mirrors this including spouses as well as adult children, with slightly more female participants and most being middle-aged or older.

5.3.2.1   Incentivisation for participation

The study used incentivisation for participation following discussion with a PPI representative. Incentivising is described as helping improve both gatekeeper engagement and success of recruitment (Head, 2009). This may improve participation more that the common but perhaps less successful approach of posters or social media (Shue 2011, Head, 2009). However, concern around the ethics of this and coercion or inducement in relation to payment is made (Grady, 2005). Whilst this may have influenced some to participate some declined a voucher suggesting that this was not necessarily an influential factor for all who took part.

5.3.2.2   Data collection

The present study only required one interview per participant and may have limited the scope of data collected and subsequent findings. However, this was an exploratory study. Each in-depth interview enabled exploration of the individual participant's lived experiences, which contributed to the final data set and overarching themes. Thus, the research aim could be achieved through one interview per participant. The participant burden of additional interviews or recording of data in a diary could not be justified as being essential to achieve the study aim. It could be argued that interview data reflects remembered data and may therefore not be considered 'pure' data (Oiler, 1982). However, a commonly accepted method to explore lived experiences is interview. For IPA it is implicit that the data is not only remembered but also interpreted by the participant as they tell their story. Therefore, the approach of one interview per participant can be justified.

5.3.2.3   Data analysis

A limitation also relates to the method used of analysis used. IPA requires a small, homogenous group therefore findings cannot be generalised (Finlay, 2009). This is accepted as a consequence of this approach. However, IPA does support the identification of commonalities across the participant group and that through contextual description, findings can be transferable to other groups.

5.3.3   Researcher influence

Recruitment for the present study was in two phases due to unforeseen personal circumstances resulting in my PhD and the present study being suspended for a significant period. This was disruptive to the recruitment process and made it challenging to re-engage with gatekeepers who had been contacted during the first recruitment period. As a result, I needed additional recruitment opportunities. The first recruitment phase began in May 2018 following NHS ethical approval but was quickly suspended in August 2018. It recommenced at the end of January 2019 continuing until mid-August 2019. I found the recruitment process difficult and frustratingly slow. This is not unusual with recruitment for health research being recognised as "challenging" (Marks et al., 2017). The reflection process has been helpful in my own learning and development as I consider the effect of the study design and my role as a researcher on the final participant group, data and findings.

Being able to attend the carer groups provided opportunity for me to spend time with interested individuals from the sample group to explain the study and provide supporting written information. This approach is thought to be particularly beneficial for older participants and relevant for the present study with the many family carers being older people (McMurdo et al., 2011). I also enjoyed attending the groups and this may have subconsciously influenced my own engagement and success in recruitment. Factors which can improve recruitment include gatekeeper confidence in the researcher, belief in the relevance of the topic being studied and perceived benefit to the participant group (McMurdo et al., 2011). My personal influence may have therefore positively influenced recruitment from the carer groups and lack of such opportunities with other gatekeepers and sample groups limited recruitment.

5.4   Recruitment and sampling

The sampling and recruitment strategies significantly affect the final participant group, the quality of data and findings for the present study. Sampling is about deciding which groups of people to recruit from and how many to approach whilst recruitment is the process of asking people to participate. Description of how the sample group were identified and accessed and recruitment process is described. Decisions about these

processes are an important step to ensuring good quality data is obtained. This includes management of difficulties in accessing the identified sample groups and unexpected interruptions to recruitment. A financially efficient and effective recruitment and sampling strategy is an important element to consider within research activities (Berger et al., 2009). The sampling and recruitment strategies for the present study are cost-effective utilising phone calls, email, fliers and posters. Travel was minimised and interview of participants who were unlikely to provide relevant data is minimised through eligibility screening online or via the telephone. Planning of sampling and recruitment helped in my identifying relevant tasks and decision-making during these study phases.

5.4.1 Sampling strategy

A broad, purposeful sampling strategy was used with convenience sampling to identify groups likely to have relevant knowledge about family carer experiences of eating and appetite in dementia. Purposive sampling is an accepted approach for recruitment within qualitative studies particularly when a homogenous group is sought. Measure to reduce research influence on recruitment included asking participants to directly contact the researcher if they were interested in rather than the researcher directly asking individuals to participate reducing the risk of researcher coercion and influence. Convenience sampling was appropriate to achieve the study aims within the relatively short time frame for a PhD study. Convenience sampling was used enabling selection of participants who were easily accessible to me as a researcher (Sedgwick, 2013). My own prior knowledge and investigation and discussion with my supervisors identified opportunities for sampling alongside discussion with colleagues and patient and public involvement representatives. To overcome the bias of purposive sampling random sampling is advocated (Shenton, 2004). The broad sampling group for the present study is summarised in Figure 11.
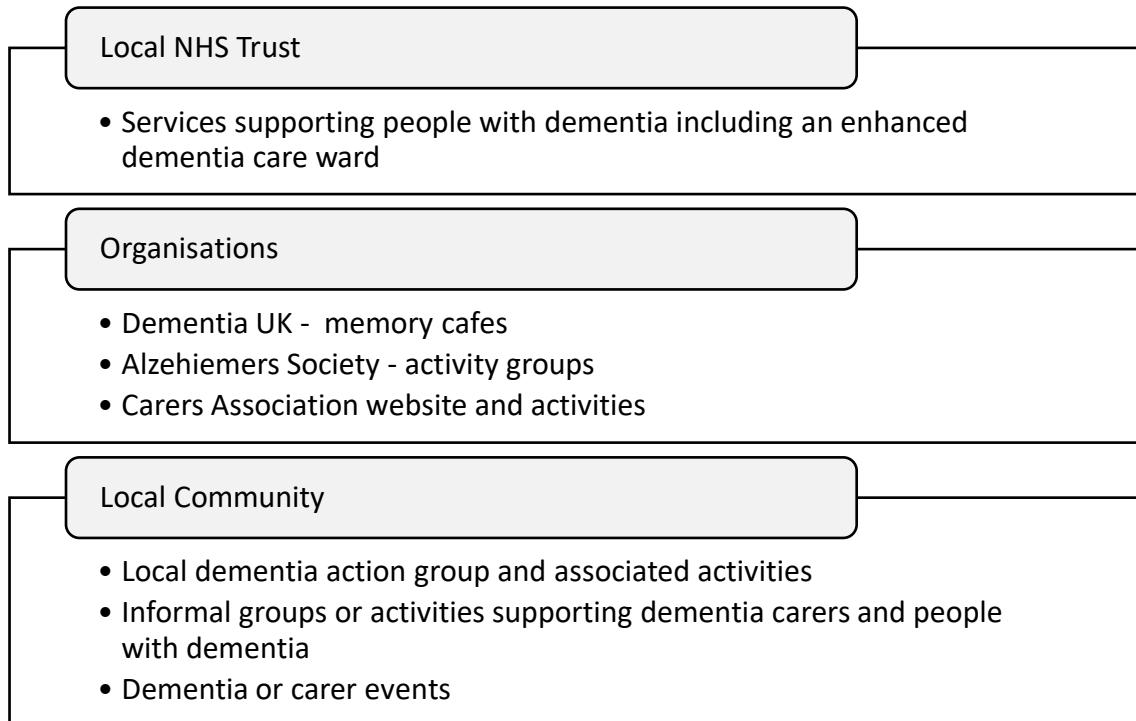
Figure 11 Opportunities for sampling

It was anticipated that the sample group of family carers could be accessed through the local NHS Trust when attending with the person with dementia, participating in local community activities and groups as well as formal activities or support provided by organisations. From meetings with key staff and gatekeepers this certainly seemed a practical possibility. Opportunities to share study information were taken when meeting with health and social care professionals, friends and university peers. Snowballing was also included in the ethical approval process as a method for recruitment to maximise opportunities and reach.

Access to the sample group was variable with some gatekeepers more supportive than others. Gatekeepers can consciously or otherwise obstruct researcher access to participant groups and may result from a need to protect individuals from burden of study participation or a personal uncertainty about the study (Preston et al., 2016). This is perhaps particularly understandable for those working with family carers of people with dementia. There is also a reality that most gatekeepers are extremely busy with a need to prioritise work, with engagement with research or promotion of a study to participants seen as lower priority than direct clinical care (Preston et al., 2016). Emails with

supporting recruitment information about the study, phone calls and visits were used as a way to try and keep gatekeepers engaged. Posters were provided, with an ask to place them on noticeboards in an office or clinic room, providing a visual reminder of the study.

Although staff at the NHS Trust were largely supportive of my accessing the sample group few potential participants were identified with no successful recruitment. Contact details, a plain English summary (Appendix C), fliers / posters (Appendix C) were distributed across clinical settings and online. Clinical meetings were attended to promote the study. Despite being on site at different times of day I was not successful in having appropriate opportunities to promote the study directly to family carers visiting those with dementia or attending clinic appointments. The recruitment process required participants to contact me if interested "opting in" rather than my directly approaching them. This was to reduce the risk of coercion but this approach made it extremely difficult to engage with the sample group. After around two months of unsuccessful recruitment, I made a pragmatic decision to focus on other areas.

Accessing family carers through non-NHS organisations and formal groups or activities such as a singing group and table tennis group was equally difficult. However, unlike NHS gatekeepers who were happy for my direct access to family carers these gatekeepers were generally more reticent to allow me direct access. This may have reflected a feeling of a need to protect those accessing services, protocols around engagement with external research activities or wariness about myself as a PhD student undertaking research. Gatekeepers were identified and meetings either in person or via the telephone arranged to present the study and seek permission and opportunity to access the sample group. Fliers, posters (Appendix C) and/or the plain English summary (Appendix C) were provided to interested gatekeepers to support promotion of the study. Permission to directly access the sample group was only provided by one Admiral Nurse where I was invited to attend a Dementia Café and one Dementia Action Group where I could attend a local Dementia Festival. A couple of organisations did however agree to promote the study on their website. This resulted in successful recruitment of two participants.

Early on in the recruitment process I attended an Alzheimer's Society conference presenting a poster about my research proposal. I had just received NHS ethical approval

and was able to begin recruiting. There was a lot of interest in and good conversations about my study and on request I provided several individuals with my contact details. Unexpectedly I successfully recruited one participant through this activity.

It was easiest to gain access to the sample group attending two local dementia carer groups. This followed a personal introduction from a colleague to one of the groups. The gatekeeper of the first dementia carer group had previously engaged with dementia research, was a family carer and interested in participating in the present study. This personal interest and prior experience was likely to have positively influenced the decision to allow my access to the group. Having already been invited to attend one group it was suggested I might like to also attend a second dementia carer group in the locality. Having an invitation to attend the second group made it easy to access the sample group.

The present study's participant group is very much influenced by gatekeepers and my gaining direct access to sample groups. My experience demonstrates how gatekeepers can bias a participant group through decisions about engagement and using their own criteria to decide who has information about the study (Preston et al., 2016).

5.4.1.1   Meeting family carers and people with dementia

Although I had met people with dementia and family carers during my clinical work I had limited opportunity to meet such individuals in a more informal setting. However, this changed when I was invited to attend the weekly dementia carer support groups. This was beneficial for two reasons firstly, for my own learning and secondly to improve recruitment opportunities. I attended group meetings between 17th June and 12th August 2019. This gave me time to "hang out" with family carers and people with dementia in an informal setting and enhance recruitment opportunities. At the first meeting with each of the groups I was offered an opportunity to tell the group about who I was and why I was in attendance. I decided to keep this brief and informal leaving fliers on the tables for anyone who was interested. I then spent the remainder of the time engaging with those in attendance listening to and talking with them. This helped develop rapport and trust between myself, the groups' gatekeepers and sample group itself. Building rapport with gatekeepers is described as an important element for successful recruitment (Preston et

al., 2016). As attendees got to know me many approached me to ask more questions about the research with seven choosing to participate.

5.4.1.2 Rationale for sample size

A further consideration of the sampling strategy is the sample size required to provide data to achieve the study objectives. Once the decision to use IPA was made a target sample size of ten participants was selected. This decision reflected a balance between generating enough data for an in-depth study versus being overwhelmed by too much data. Timelines and study resources also influenced the decision as data needed to be collected in a timely manner to enable completion of the doctoral study (Mason, 2010). Sample size was also informed by the method used (Mason, 2010). The sample size for qualitative studies is normally much smaller than quantitative studies as qualitative work seeks to know "whether" something occurs rather than "frequency" of occurrence. Qualitative studies often describe their end point as data saturation and continue to recruit until this is achieved (Mason, 2010). Using this approach sample sizes can be small with twelve participants likely required for data saturation to be achieved if there is a homogenous participant group (Guest et al., 2006). However, data saturation is not required for IPA as this method focuses on the ideographic with in-depth analysis of each participant. Only a small sample size is therefore required with ten participants being the maximum recommended for most studies using IPA (Smith et al., 2012). For doctoral studies a sample size of between four and ten participants is suggested (Noon, 2018). An example of a similar study using to explore the lived experiences of spouses of people with dementia had twelve participants (Clare, 2002). Thus, ten participants for the present PhD study can be justified.

5.4.1.3 Heterogeneity of sample group

A further factor for sampling is the need for homogeneity or heterogeneity within the participant group (Berger et al., 2009). IPA requires a homogenous participant group (Noon, 2018). A homogenous participant group supports the detailed examination of the convergence and divergence between participants when using IPA (Smith et al., 2012) page 3. This helps identify the commonalities and unique essence of family carer lived experiences of eating and appetite in dementia. Purposive sampling was used to help identify a homogenous participant group. All participants were family carers for at least 6-

months of a person with dementia living at home. They lived in southern England, were Caucasian and could converse in English to participate in discussion about their lived experiences.

5.4.2 Recruitment strategy

The recruitment strategy for the present study was successful with the target number of ten participants recruited to participate in the study. Seven participants were recruited from the Dementia Carer Groups and three from other events or online information. Factors identified as being important for successful recruitment include preparation and planning, engendering patient support and collaboration with clinicians (Newington and Metcalfe, 2014). The most successful recruitment was at the Dementia Carer Groups and likely due to the greatest opportunity to develop rapport and trust through my regular attendance. Preparation included development of posters, fliers and plain English summary of the study. These were developed in conjunction with the local Patient and Public Involvement (PPI) representative for dementia care to helping ensure ease of understanding and readability. Use of plain English for recruitment material is important to try and support as many of those who were eligible to understand the study and if desired make contact with the researcher (Berger et al., 2009).

Recruitment is suggested as being a three-step process identifying potential participants, making contact with participants and asking for their agreement to participate (Preston et al., 2016). The present study identified potential participants through engagement with identified sample groups either directly as in the Dementia Carer Groups indirectly through posters, fliers (Appendix C) or Plain English Summary (Appendix C). Interested individuals were asked to making contact with the researcher via email or telephone for further information and eligibility screening. This approach was felt to be more ethically appropriate for family carers reducing any direct pressure to participate in the study from either the researcher or gatekeepers of the sample groups. It also negated data protection and confidentiality issues for the gatekeepers of organisations or groups. The recruitment process is summarised in Figure 12.

Promote study		
Fliers, poster, plain English summary given to gatekeepers	Researcher access to sample group	Word of mouth, snowball effect

Interested individual
Interested family carer contacts the researcher directly

Eligibility screening
Researcher screens for eligibility

Participant Information
Researcher provides participant information sheet if eligible

Proceed to interview	
Researcher contacts participant after 1 week and invites to interview.	Interview date and location for interview agreed

Figure 12 Recruitment process

Discussion with the PPI representative was helpful in thinking through some of the practical issues for family carers to participate in the study. Reasons for non-participation can include being too busy to commit to a study and was something I was particularly mindful of when recruiting individuals who provide care (Head, 2009). I used a flexible approach to locality and time of interview to try and help overcome some of the known challenges of recruiting. This was relevant as most of the participants were older with barriers for older people to participate in research cited as mobility or transport issues, carer responsibilities and a preference for a home routine (McMurdo et al., 2011).

Screening for eligibility to participate in a study is an accepted practice within research. It is an effective approach to improving the chance of the participant group providing appropriate and good quality data (Berger et al., 2009). The recruitment strategy for the present study was developed such that the researcher would screen for eligibility once the potential participant make contact. The screening checklist can be found in Appendix D.

The final step of recruitment is seeking agreement of potential participants to take part in the study (Preston et al., 2016). If eligible the individual was provided with the participant information sheet providing detailed information about the study (Appendix B). If the participant had not made contact to confirm their interest within a week of being provided with this I emailed or phoned as per prior agreement to ask if they would like to participate. If the individual wanted to participate in the study a date, time and location for consent and the interview was agreed. A follow-up email or phone call was provided nearer the time to remind the participant and confirm if this was still convenient.

5.4.2.1 Incentivising participation

Incentivisation for participation was a £10 super market voucher for completion of the interview. Reasons for participating can be multiple but may include an interest in the study subject or desire to be altruistic (Newington and Metcalfe, 2014). However, incentivising participation through offering money or vouchers can improve the response rates to study adverts and aid recruitment (Head, 2009). Whilst accepted as in qualitative studies concern about the risk of coercion is often voiced particularly if the sums of money involved are large (Head, 2009). Individuals may feel unable to say no to participating if they cannot afford to turn down the financial incentive. To help minimise any of such issues advice from the PPI representative about financial incentives for participating in the present study was sought. This helped identify what would be considered reasonable by the sample group for compensation of time and sharing of experiences. Interestingly several of the participants declined this and may reflect altruism or wealth.

5.5 Development of interview topic guide

Using themes from the literature, reflection on my clinical experience and discussion with the PPI representative an interview topic guide was developed. The present study is exploratory in nature using in-depth interviews. This allows participants to lead and describe lived experiences they felt were important and wished to share with myself as a researcher. Studies using IPA commonly employ semi-structured interviews and often use an interview topic guide. This provides a loose framework for the interview supporting the in-depth discussion required for IPA (Smith et al., 2012) page 3. A guide as opposed to a strict set of questions supports an active interviewing approach supporting exploration of the topic and spontaneity of discussion (Gubrium and Holstein, 1997). The guide for the present study used open questions to support participant led interviews with consideration of the terminology and phrases used to maximise participants' ease of comprehension and engagement in the interview process (Greenhalgh and Taylor, 1997, Carter and Little, 2007). Adaptation of the questions during the interview were sometimes required to aide participant understanding or enable flexibility and in-depth discussion.

It is recognised that the eating and appetite in dementia is a topic not often considered by family carers of a person with dementia. Anecdotally the topic is infrequently discussed with family carers by healthcare professionals and many family carers are unaware of likely effect of dementia on eating and appetite. Associated events with eating and appetite as a family carer of a person with dementia are therefore likely to remain in the pre-reflective state. Thus, the questions and the interview approach needed to help the participant to begin thinking about this topic, giving space for the participant to recall events, providing prompts or encouragement as needed to continue in the conscious recall of noema and use of noesis to describe lived experiences.

The topic interview guide for the present study used four themes of mealtimes, changes in eating, carer concerns and support and resources with details of questions found in Appendix E. The first two topics support the exploration of changes in appetite and eating in the person with dementia and it is anticipated that these will comprise the main body of the interview. Exploration of this begins through discussion of mealtimes and observed changes in eating. During in-depth interviewing the 'what is happening' description of

mealtimes and eating changes which a participant provides can be followed up with probing discussion around the meaning of this for the participant - how it feels, the impact or consequences of this on their life. The third topic focuses on concerns about eating and appetite in dementia, which the participant might have. The final topic seeks to stimulate discussion about support both received and desired by family carers in relation to eating and appetite. All four topics help to provide relevant data to contribute to achievement of the five study objectives.

5.6 Data collection

IPA generally uses naturalistic data collection methods such as interviews or observations. Primary data collection for the present study was via recorded in-depth interviews complemented by researcher field notes and reflective diary. As recommended field notes during the interview itself were minimal as writing during an interview can negatively impact the participant-researcher relationship (Finlay, 2009). Thick descriptors were noted from observations, reflection, recorded interviews and field notes supporting rich data and interpretation such that the reader is impacted both cognitively and emotionally (with verisimilitude).

5.6.1 Interview environment

Interviews were undertaken in a setting agreed by participant and researcher, providing an environment considered safe and appropriate by the researcher. An interview setting where the participant feels comfortable helps put the participant at ease and encourages good rapport. Good rapport between researcher and participant improves participant engagement and interaction (Crouch and McKenzie, 2006). This is likely to improve the quality and relevance of data (Crouch and McKenzie, 2006).

A private space was identified for each interview in collaboration with the participant. It needed to afford confidentiality and be quiet enough to allow for recording of the interview and to aide concentration. Confidentiality is imperative from a data protection and ethical perspective, as well as supporting participants to freely speak. This was sometimes more difficult within a home environment where other people lived and discussion with the participant about how to manage was sometimes needed. A safe

environment is also critical and part of good research practice. To support this approach the Lone Worker Policy for the University of Southampton (Appendix F) were followed for interviews within a participant's own home. A colleague was notified of the interview location and time and importantly told when the interview had ended. A code sentence was agreed if I needed to phone for help when attending an at home interview. Being on site at the University of Southampton or NHS organisation posed less risk as the room was formally booked and there was support on hand if needed.

The primary localities for interviews for the present study were identified as rooms within the University of Southampton or participating NHS organisation or at the participant's home or place of work as per participant preference and researcher judgement. Aside from the ability to record the interview, no equipment was required with only two chairs needed for the comfort of participant and researcher. The person with dementia was not invited to the interview to allow for free discussion about the participant's experiences and avoid the person with dementia feeling excluded from the interview process.

5.6.1.1 The participant interview

Ten interview took place and all were in locations chosen by the participants. Most adult-child participants wanted an interview outside of their home with two interviews at the University of Southampton, one at the participant's place of work and the fourth in the participant's local hotel that had a business meeting area, free for activities related to dementia. The remaining six interviews were in the participants' own homes. For the home interviews two participants had carers for their partner during the interview period. Interruptions occurred in all home interviews regardless of whether carers were present. Carers needed to ask questions, the participant intermittently needed to check on their partner or their partner sought interaction, asked questions or entered the room. The only adult-child with a home interview had her mother unexpectedly arrive at the house but this was only a brief interruption. Recording was stopped on interruption and only resumed once the participant was comfortable in doing so and as the researcher I felt confidentiality could be assured.

5.7   Transcribing data

Prior to analysis the data from the recorded in-depth interviews were transcribed. I transcribed the interviews verbatim to familiarise myself with the data, and advance my listening skills. This required listening to the recording several times to initially note then edit the transcript such that it was a true representation of the interview. I removed factors such as names of people or places, details of health conditions or other such information where the specific detail was not considered to be essential to interpretation helping ensure anonymity. Pseudonyms were assigned for names or places. To help capture the meaning of the conversation non-verbal sounds such as laughter or sighs and pauses were notes within the transcript. The digital recording of the interview was deleted following transcription of the data to ensure confidentiality and anonymity.

5.8   Data analysis

To meet all of the study objectives IPA will be used. The process of classifying concepts is akin to thematic analysis. Two forms of thematic analysis are described: inductive and theoretical (Braun and Clarke, 2006). As the present review sits within hermeneutic phenomenology. Inductive thematic analysis was chosen to identify the strategies used by family carers to manage eating behaviour and appetite in dementia. This sits well with the hermeneutical phenomenological paradigm used throughout this study. Such analysis is driven by the data using inductive reasoning to develop the themes from the data (Hsieh and Shannon, 2005, Ho et al., 2017).

5.8.1   Interpretative phenomenological analysis

The hermeneutic circle of interpretation as described in IPA was used for data analysis (Smith et al, 2012). The purpose of data analysis is to address the research aim and objectives, developing knowledge from the data. Specifically IPA is used to identify what it is like to be in a specific situation helping me as a researcher to interpret the present data and describe the meaning of lived experience of family carers of appetite and eating in dementia (Smith et al., 2012). The process of the hermeneutic circle of interpretation as used for this study is presented in Figure 13.

Step one: Familiarisation with transcript
Immersion and active engagement with anonymised, verbatim data of a single transcription

Step two: Initial noting		
Interview transcript deconstructed to identify the particular		
Exploratory	Descriptive	Linguistic

Step three: Emergent themes
Grouping of conceptual codes:Emergent themes for the participant interpreting their lived-experience

Step four: Connections across emergent themes
Research mapping of how codes fit together: the researcher inteprets the participant's interpretation to connect the parts and recreat a whole

Step five: Moving to the next case
Repeat steps one to four for each participant (case)

Step six: Looking for patterns across cases		
Connections across cases	The unique and ideosyncratic	Shared major themes

Figure 13 Summary of hermeneutic circle of interpretation used in IPA adapted from Smith et al., (2012)

The hermeneutic circle of interpretation has six steps. During step one I read and re-read the first transcript such that it became familiar. Then in a line-by-line analysis I noted things of interest, observations or thoughts in a separate column to the transcript. Consideration of what is and is not shared by a participant during the interview helps provide understanding of the participant's perspective. Contradictions within the

transcript, emphasis of words or phrases (the parts), the language or type of words used as well as pauses or exclamations help to provide insight into the lived experience. Inferred meanings, metaphors, symbolic or non-verbal language were also considered – what did the participant mean by these? Such analytical approach required reflexivity and inductive reasoning. Reflective thoughts during this process helped me to identify my own bias or position. The analysis enabled me to begin to deconstruct the transcript into fragments seeking the idiographic that is to say in-depth insight through identifying the particular elements of the participant's lived experience.

On completion of the line-by-line analysis I began to cluster the particular elements into emergent themes. This was an iterative process moving throughout the transcript to identify both obvious clusters and those needing more careful interrogation. Each cluster or theme was named. Emergent themes were documented in the margin of the transcript and a brief phrase or couple of words describing the definition of this documented. Defining the theme helped in clustering for the individual participant and then across the participant group.

Step four of research mapping saw me use reflexivity and inductive reasoning to interpret the emergent themes (the parts) to reconstruct the participant's lived experience by making connections of the parts to create a whole (Smith et al., 2012) pages 91-92. The process required me to make sense of the participant making sense of their lived experience. IPA uses an inductive approach that is a bottom-up as opposed to top-down exploration of the meaning a participant gives to a lived experience deconstructing, interpreting and reforming the lived experience (Reid et al., 2005). I began to fit together the emergent themes such that I could authentically tell the story of that participant's lived experience. This completed the hermeneutic circle of interpretation for that participant (Smith et al., 2012) page 28. Steps one to four were then repeated for each participant.

Only on completing the analysis for each participant could connections across participants begin to be made. I sought to find both similarities and differences between participants being mindful not only to focus on the anticipated findings but looking for anomalies or unexpected findings to support the development of superordinate or major themes

(Smith et al., 2012). This involved weaving the findings together to develop a narrative that was authentic to the sample group of family carers. My narrative was supported by the selected verbatim extracts from the participant transcripts. This enabled my creation of the narrative of family carer experiences of eating and appetite in dementia from an interpretivist phenomenological perspective.

Researcher prior experience, history and ability to understand the lived experience from the specific participant's perspective is required (Smith et al., 2009). Reflexivity is therefore a continual process for the IPA researcher to identify and reflect on these factors and understand their influence. Throughout the research process a reflective diary was maintained and used to support data analysis in terms of development of thick data. This helped to highlight any potential bias and my own impact on the data and findings. The field notes and my reflective diary also helped in the development of Pen Portraits for each participant.

5.9   Data quality

The present study was transparent and used the recognised quality measures for qualitative data of transparency and trustworthiness to demonstrate good quality data. Transparency for the present study is demonstrated through provision of clear rationale for the research approach, identification of researcher bias, well described methodology, an audit trail of data collection, data analysis and development of findings. This reflects the elements described by Cresswell (2007) required for transparency in qualitative research. The present study also demonstrated good researcher and participant interaction, appropriate interview environments to support data collection and concerted effort to avoid bias using open questions supporting the identification of good quality, relevant data (Crouch and McKenzie, 2006, Tong et al., 2007).

Trustworthiness can be measured using four criterion: credibility, transferability, dependability and confirmability (Guba, 1981). These quality measures differ from those use for quantitative data as the purpose of the data collection and ultimate study aims differ (Shenton, 2004, Patton, 1999). Quantitative data is used to demonstrate a statistically proved truth with quality measures of rigour, reliability and validity however

this is not the purpose of qualitative research (Shenton, 2004). Qualitative research is not interested in finding a single truth or how often data occur rather if the data occurs and for some qualitative methods the meaning of this. Different quality measures are therefore used but this has resulted in debate around how best to describe the rigour and therefore quality of qualitative work (Shenton, 2004, Laverty, 2003). Comparison of quality measures for qualitative and quantitative are described by Guba (1981) in Table 1 and are helpful to demonstrate measures used to ensure good quality data for the present study.

Table 1 Comparison of trustworthiness in quantitative and qualitative research adapted from Guba, (1981)

Quantitative research measures of quality	Qualitative research measures of quality
External validity and generalisability	Transferability
Internal validity	Credibility
Reliability	Dependability
Objectivity	Confirmability

5.9.1 Transferability

Transferability of findings to other groups or cases of interest is a concept used to demonstrate trustworthiness of qualitative research (Shenton, 2004). Data context adds to authenticity and help others decide how transferable or relatable the findings of a study are. Contextual data includes the context of where the study took place, organisations involved, eligibility criteria, number of participants, data collection, number and length of data collection sessions and time over which data was collection all of which are provided within the findings section (Shenton, 2004). These provide thick descriptors, a feature of the present study and a requirement for helping the reader to have contextual understanding and decide the degree of transferability (Guba, 1981).

5.9.2 Credibility

The present study's credibility is demonstrated by a number of factors. The goal of credibility for this study was to demonstrate accurate identification and description of the lived experience of family carer experiences of eating and appetite in dementia (Lincoln

et al., 2013). Credibility is a key factor in establishing trustworthiness with regards to authenticity of study findings and can be conferred with adherence to protocols for data collection and analysis (Shenton, 2004, Guba, 1981). The present study had clear protocols with an audit trail of the research process complimented by the researcher's reflective diary. Credibility of data was checked where possible during the interview using probing questions to explore any apparent discrepancies or gain better understand of what the participant was meaning. Finally building trust and rapport is also a way to support credible findings (Shenton, 2004). When provided with access to members of the sample group I focused on developing good rapport using a friendly manner with interest in the group. My attendance at the Dementia Carers' Groups offered particular opportunity to do this and saw the most successful recruitment.

5.9.3   Dependability

Dependability and credibility are connected and therefore if one is apparent then the other is also likely (Shenton, 2004). The data for qualitative studies is dependable at the time and within the context it is collected being described as static within the ethnographic present (Shenton, 2004). For the present study the lived experience of a carer for a family member with dementia will change, with recall and interpretation (noesis) of the content (noema) of memory influenced by the participants current context or world. From a positivist stance qualitative data are therefore unreliable but this does not make them invalid rather it is accepted that qualitative data are a dependable representation of lived experiences, views or feelings at that point in time.

5.9.4   Confirmability

Being able to confirm findings in qualitative research is about being able to see the processes which were undertaken to collect and analyse data and the context within which this occurred (Shenton, 2004). This includes identification of researcher bias, the research lens and theoretical premise used. The present study clearly describes these and the rationale for decisions made with an audit trial of data collection and analysis.

5.9.5   Other quality measures

In addition to these various criterion it is suggested that within an interpretivist paradigm validity relates to morality as identified through the constructs of substantive and ethical validity (Angen, 2000). Measures to support substantive validity or the evaluation of the content of my interpretive work include a reflexive researcher approach, identification of researcher bias, influence of the research process on myself as the researcher and rationale for decisions made about interpretation of the data (Angen, 2000). The need for ethical validity during the research process is demonstrated by identification of clear reason and need for the present study and benefit to the target population, that is to say family providing care for individuals with dementia (Angen, 2000). Other signs of an ethically valid study is the ability of the researcher to keep an open mind and hear what is of importance to the participants as well as reflecting on what has truly been learnt as a result of the research (Angen, 2000). This is evident in the process of data collection for the present study.

Authenticity and thereby credibility of findings is enhanced by using contextual information and thick descriptors. For the present study these were identified from the transcripts of the recorded interviews, field notes and researcher's reflective diary. Using these to interpret the data required my being able to take a reflective approach, the latter being another factor associated with credibility (Laverty, 2003). To support my reflection, I engaged with peer review, debriefing and supervision to help identify my researcher bias, study flaws and broaden my researcher perspective.

5.10   Data Management Plan

To help ensure the present study was compliant with the legislation relating to General Data Protection Regulation (GDPR) I used a data management plan (HMSO, 2018). The plan provides rationale for the data collected, details of data security and confidentiality, management of data storage and disposal of data as per University of Southampton and Government regulations. Data collection must comply with data protection law including legislation relating to GDPR (HMSO, 2018). Data will be archived for a minimum of 10 years from the last date the data was accessed via the e-prints repository at the University of Southampton.

The log of enquiries to organisations or groups with access to the sample group provides an audit trail of enquiries and actions. Participant data were collected from the point of enquiry about the study with eligibility screening. Eligibility screening questions were asked and answers logged. If the individual was eligible for the study and wished to participate, their contact details were noted and consent taken with a copy of the consent form filed in a locked cabinet at the university of Southampton. If the person was not eligible their personal details were deleted or disposed of according to data protection guidelines.

Participants were given a pseudonym and only identifiable by accessing the study id code kept in a separate secure location away from other data to maintain confidentiality. These could be accessed by myself or supervisors or designated auditors. Participant outcome of the study was recorded as completed interview, withdrew with partial interview, withdrew with no interview. All participants completed the interview. All subsequent data collection relating to the participant interview, including recorded interview (audio) and field notes were transcribed and anonymised or kept on documents saved on to a password protected University of Southampton computer. Audio recordings and hand written notes with identifiable information were destroyed.

5.11   Chapter summary

This chapter details the method for the present study used to answer the research question and meet the study objectives. PPI consultation provided advice used to inform decision-making around the method. Ethical issues were considered and addressed. Accessing sample groups and recruitment was challenging and shaped the final participant group and findings. Attendance at two dementia carer support groups over a period of approximately three months provided a long period of engagement to develop understanding and insight into family carer experiences. Data from ten family carers was collected using in depth interviews, with transcribed, anonymised data analysed using double hermeneutics within a framework of IPA. Management of unexpected events and adjustments to accommodate these was made. Chapter six presents the context for each of the participants in the form of Pen Portraits to support development of thick data.

Chapter 6 Participant context

To understand participants lived experiences of eating and appetite we must first understand their experiences of adapting to life with a person with dementia more generally. The purpose of this chapter is therefore to introduce the participants and provide contextual data about each participant's context or life world using pen portraits. These are defined as "an informal description of a person or group of people" with a "focus on softer dimensions such as attitudes, appearance and lifestyle" (AQR, 2020).

 Ten participants were interviewed with five participants being partners of individuals with dementia and five participants adult-children of a mother with dementia. The group was homogenous as required for IPA with all being family carers of a person with dementia living at home for at least six months. All participants were Caucasian living in southern England. At interview all partner participants (three female and two male) were caring for a family member with Alzheimer's disease and shared a home. All partners were spouses and retired expect the youngest spouse, Emma. Emma was in her fifties and continued to work, relying on support from district nurses to administer her husband's medication and carers to provide meals. Only one partner, Matthew, used formal carers to provide personal care for a partner.

Of the five adult children only one was male and all had provided care for a mother with dementia. Three female adult-children had a mother with Alzheimer's disease, with the remaining mothers having mixed dementia and vascular dementia. Three mothers were still alive at the time of the interview. All had experience of caring for their mother whilst living with them. Bob had always lived with his mother and he provided care with the support of formal carers in the latter stages of her disease until her death. For the female adult-children the provision of care was more complex. All mothers of daughters had lived independently of their children prior to their dementia diagnosis. Sarah's mother then moved to live with Sarah before local

sheltered accommodation was found. Jo's mother had lived next door but was now in a nursing home. Julia's mother had moved to a nursing home but with changes made to Julia's home she was subsequently able live with her. Anna's mother initially moved to a nursing home from living independently before then living with Anna. However, as the dementia progressed nursing home care was required again. All of the female adult-child participants had partners and two also had children living at home. All adult-child participants had their working lives impacted as a result of supporting their mother with all needing to leave their prior job role at some point. Two changed careers following their mothers' admission to a nursing home; one had their work focused on dementia and the other was retraining. Two adult-child participants went on to do voluntary work around dementia following nursing home admission or death of the mother receiving care. Matthew, John, Maggie, Maria and Emma all lived in the same accommodation as their partner who had dementia. Bob and Julia also lived with their mothers when they developed dementia. Sarah's mother had lived with her until more local, sheltered accommodation was found. Both Jo and Anna's mothers required nursing home care. Table 2 summarises further details of the participants with assigned pseudonyms for each participant and person receiving care.

Table 2 Summary of participant demographics

Participant pseudonym	Employment status	Other caring responsibilities	Current care support	Relationship (Pseudonym)	Alive at interview	Type of dementia
Matthew	Retired	No	Personal care	Wife (Jenny)	Yes	Alzheimer's
John	Retired	No	No	Wife (Mary)	Yes	Alzheimer's
Maggie	Retired	No	No	Husband (George)	Yes	Alzheimer's
Maria	Retired	No	No	Husband (Trevor)	Yes	Alzheimer's

Participant pseudonym	Employment status	Other caring responsibilities	Current care support	Relationship (Pseudonym)	Alive at interview	Type of dementia
Emma	Working	No	District nurses & carers	Husband (Mike)	Yes	Alzheimer's
Jo	Retraining	Children	No	Mother (Linda)	Yes	Alzheimer's
Sarah	Gave up work to provide care	Children	No	Mother (Sofia)	Yes	Alzheimer's
Anna	Gave up work to provide care	No	No	Mother (Isabella)	Yes	Mixed dementia
Julia	Gave up work to provide care	No	No	Mother (Lillian)	No	Alzheimer's
Bob	Gave up work to provide care	No	End of life only	Mother (Elsie)	No	Vascular dementia

6.1   Maggie - "All the normal little things become a struggle"

Maggie is the wife of George. I interviewed her at home, a house in a quiet road, neatly kept with a welcoming feel. The home was compact, clean and ordered with lots of books displayed around the room including a neat pile by one of the chairs. I was warmly invited into the home. Chairs were positioned either side of the fireplace with a sofa opposite where I sat. After the initial formalities the conversation flowed before, during and after the interview had ended. Maggie began the interview by describing her relationship with George.

"…obviously as I'm his wife…" (Maggie)

She prefaces her statement about being George's wife with the word obviously suggesting she perceives a change in role from wife to carer or feels that this is how she will be perceived. She goes on to state tells that she shares her life with George cementing the idea that she is his wife.

"…we share out life together." (Maggie)

George is in his late eighties but extremely active and they are still able to go out for bike rides together. Prior to dementia Maggie and George's life centred on the village location where they currently live. She describes this in her general conversation with their ability to continue in community life has declining as dementia has taken hold of George. She only briefly mentions other people in her life aside from George namely her children, grandchildren and a long-term friend. She also mentions that both her parents are deceased. Reflection on her overall feelings of loss is made with her parents deceased, a loss of community life and now losing George to dementia. Maggie describes dementia as causing gradual changes and repeats this phrase for emphasis. George has gone from being independent to requiring increasing amounts of prompting and support to undertake everyday functions including those related to eating and drinking.

"…its gradually become more…to begin with he was very independent and I didn't need to do anything at all apart from just reminding him a few things but then gradually I suppose in the last couple of years err, he's needed more reminding of everyday tasks." (Maggie)

However, she reflects on how these gradual changes have resulted in significant progression of the dementia.

"So, it's gone, yes, another stage." (Maggie)

A consequence Maggie has had to become decision-maker for herself and George with the burden of decision-making dominating Maggie's thoughts.

> *"…and George finds reasoning difficult err decisions. Err at first it was major decisions but now its everyday decisions…Decisions about err what to do in the day, continually. I think all the time."* (Maggie)

This thinking and decision-making includes food and meal related tasks including what to purchase, when to eat and what to eat.

Maggie discloses her prior experience of dementia with her father and other relatives having the disease providing some insight and understanding of what is likely to happen to George. She describes the most difficult change in George as his diminishing ability to communicate with this repeated as if to confirm this thought in her own mind or for emphasis to me.

> *"…most of all it's the communication err unable to actually get the word out, if he remembers the word, and also err forgetting the actual word and err physically unable to get the words out, I think that's probably the most difficult aspect."* (Maggie)

George's difficulty in recalling or saying words causes conversations to take a long time thus making communication a significant challenge. This includes conversation about food-related tasks and discussion over mealtimes.

> *"Because, err, a normal conversation takes an awfully long..."* (Maggie)

The dominance of constant decision-making and the difficulties in communicating with George leads Maggie to the heart of the matter in that it's the normal little things which become difficult including those relating to eating and appetite.

> *"It's all the little things which you just take for granted between two people err suddenly they're breaking down and they're not there. And err so all the normal little things become a struggle."* (Maggie)

6.2   Maria – "I'm losing the man I know and love"

Maria is married to Trevor. I interviewed her at home which was situated in a quiet cul-de-sac. Her house and garden were clearly a source of pride and immaculately kept. The atmosphere was very calm and peaceful although Maria was very keen to get talking and told me how she much missed conversation. She has been married to Trevor for over forty-five years and only mentions other family members in a somewhat negative context. She felt that her son did not understand the reality of what it is like living with Trevor now he had dementia and was annoyed at his lack of acknowledgment around how difficult things are for her with his comparison of what he sees through his work context.

> *"I've even told my son…what it's like living with his dad and he said but Dad is nothing like what I see. But what he sees is in a home (nursing home). He might come across a man with no clothes on and get them back to the family."* (Maria)

Her sister also seems a source of irritation telling Maria what she should and should not be doing particularly in relation to health and food choice.

> *"…well, my sister is going through this health kick, driving me nuts with it."* (Maria)

Maria briefly mentions healthcare professionals including a GP, hospital consultant, consultant for dementia Dr Chan (Pseudonym), dietitian, the dementia carers group and 'the lady' at the group who supports families impacted by dementia. The lack of mention of friends or other family implies that she chooses to be self-contained within her relationship with Trevor.

She began the interview by providing a long narrative about how Trevor came to be diagnosed with dementia and the consequence of this.

> *"…because he's not the same. He looks the same but he's not."* (Maria)

She talks about her disbelief around what was happening and recalls how at one test she thought her husband was pretending not to know the answers to the questions.

> *"So, when we come out, I said…You taking the mick in there? And he said No."* (Maria)

However, she has now come to understand that Trevor's dementia is significant.

> *"So, it's all over, in the middle and right temporal lobe as well. Quite extensive."* (Maria)

She describes losing husband as a consequence of dementia.

> *"I'm losing the man I know and love* (Big sigh)*"* (Maria)

She expresses sadness and grief non-verbally through her sigh and anger at the situation.

> *"Why did he get it? He was a (job role) and now he struggles…it's not fair…It's cruel."* (Maria)

This countered by a fatalistic statement.

> *"So, it is what it is."* (Maria)

Maria expresses her desire to ensure Trevor is happy including providing food which he enjoys and how she will provide care for as long as she is able to.

> *"All that bothers me is if he's happy…and I said I'd look after him until I couldn't…"* (Maria)

This perhaps reflects the strength of their relationship or a sense of duty felt as a wife needing to provide care.

Maria believes that there is open communication between her and Trevor however she goes on to contradict this saying how she believes she can talk for him.

> *"…we've always been open in our marriage and feel that we should be able to say anything we like to each other…We've been married forty-five years*

and we know each other so well. I know if he's not feeling well without him

saying a word…cause I know what he wants to say…" (Maria)

It is very easy to assume that Maria talks for Trevor because of the effect of dementia on his communication ability however they may have always had this dynamic.

"I should not be talking for him all the time. But it's difficult not to because

I'm a talker and if someone said how are you today, I'd probably say Trevor's

quite well. But it is difficult because Trevor takes a long time to give an

answer and to think… It's difficult to zip it up and let him speak..." (Maria)

Maria expresses difficulty in not speaking for Trevor but 'difficult' for whom? Maria having to wait for Trevor to answer or Trevor as he tries to process his thoughts and formulate a response? She uses the sentiment of the phrase "I haven't got all day" during the interview reflecting her impatience with Trevor not speaking or responding quickly enough.

"…cause I haven't got all day." (Maria)

Maria's chosen approach will impact Trevor's ability to partner in decision-making around meal-related tasks including choice of food and when to eat. This is particularly relevant as Trevor undertook meal-related tasks prior to his dementia diagnosis. A metaphorical meaning of the phrase "I haven't got all day" could also relate to her feeling that she is losing Trevor and really does not have much time left with the man she loves.

6.3   Emma "I've coped but there is a break point for everyone"

Emma is married to Mike. She was the youngest partner to be interviewed being in her late fifties and the only partner who was still working. The interview took place in her home situated in a street with terraced housing in an urban environment. The lounge and kitchen were ordered and clean with minimal clutter or objects around. Initial conversation was a little stilted but as rapport built it was difficult to end the

interview. It transpired that Emma had just returned from a counselling session, which was not ideal but the time of the interview was her choice.

"Yes, funnily enough I've been to my counselling this morning" (Emma)

Emma tried to fit her counselling and the research interview into the same morning as she had arranged for care for Mike and only needed to take one morning off from work. She was therefore very keen to continue with the interview.

"If it's too much talking (Interrupted by Emma)*"* (Researcher)

"No, No." (Emma)

The need to compress activities into her life reflects the immense pressure she was feeling to keep going in her multiple roles. Emma describes herself as being strong and coping but things were beginning to take their toll.

"I'm quite a strong women and I've coped but there is a break point for everyone." (Emma)

As a result, she was utilising various forms of support including her adult daughter, formal carers and district nurses, a weekly group for dementia carers and support from a dementia nurse specialist and a counsellor. There was also an element of respite for Emma with Mike going to a memory café twice each week and she was exploring the possibility day-care.

Emma recalled how she gradually became aware of Mike's dementia with a significant increase in symptoms over the past couple of years.

"...in high insight we probably saw signs of it about five years ago and it escalated about three years ago." (Emma)

This diagnosis impacted Emma financially, emotionally and socially. With a reduction in household income following Mike's ill health retirement, she needed to continue working and thus had to rely on carers to provide meals for Mike.

> *"Now he's got carers coming in three times a day specifically to give him food."* (Emma)

This was particularly important as Mike has type 1 diabetes with significant complications.

> *"Mike has been diabetic for fifty years so it's no new thing…type 1 diabetes's and renal failure and diabetic retinopathy and diabetic neuropathy"* (Emma)

District nurses administer his insulin as he is unable to manage this safely.

> *"They administer his insulin. Because he is no longer capable of managing his diabetes."* (Emma)

Emma describes significant tension within her and Mike's relationship expressing how he seems to be more compliant for other people. Mike either would not let her or did not want her to do certain things within the context of providing care.

> *"He is quite compliant for other people… Other things he won't let me do or wouldn't want me to do."* (Emma)

This may be Mike trying to exert some control or perhaps by limiting Emma's physical caring role is trying to maintain their partner roles. She tells me of the angst and difficulty in their relationship particularly in relation to food and his perceptions of her own behaviour.

> *"…angst between him and I…he thought I was bullying him."* (Emma)

She does not describe how their relationship was before Mike's dementia diagnosis although the way she presents her narrative implies the difficulties have arisen as a result of the behaviour changes resulting from dementia. These changes have also made it difficult to have the usual social interactions with friends.

> *"He…our social life has changed."* (Emma)

The pause after "he" suggests a change in what she was going to say. Does she blame Mike for the change in her social life? Was she thinking that Mike has changed and this was too difficult to acknowledge verbally? Mike's change in behaviour is

impacting his decisions about food choice resulting in arguments with Emma and effecting their relationship.

6.4   John - "Why can't I sit down and enjoy my meal?"

John is married to Mary. I interviewed John at his home, which he shares with his wife Mary. The interview felt as chaotic as the environment and it was a challenge to keep John focused on the topic of eating and appetite. On arriving John wants to show me Mary's paintings. He proudly tells me of her various achievements and Mary is happy to join in this activity. Despite Mary's impaired verbal communication, she seeks to communicate with me and her personality shines through. John then tells Mary that he and I are going to talk in the kitchen and he settles her in front of the TV.

The interview begins by him telling me about the initial changes he noticed in Mary's driving and how he thought she needed to stop driving.

> *"…Look I really think you ought to stop driving. Just going 'round the big junction roundabout, all over the place. Just driving across the lanes and not thinking about or understanding what the problem was."* (John)

This change began the journey to a diagnosis of Alzheimer's disease.

> *"She was diagnosed with Alzheimer's stroke, early onset dementia."* (John)

John seems to be seeking an explanation for this diagnosis and appears to struggle with the idea that his highly intelligent and talented wife could have dementia. He repeatedly tells me about how bright she is with intelligence important to John even mentioning both his and Mary's IQ scores.

> *"I understand that she is possibly a bit sharper I think her IQ is xxx* (higher than Johns) *and mine is xxx last I've been measured."* (John)

I wonder if John is in denial of the reality of Mary's dementia diagnosis as he speculates if her symptoms are due to Lyme disease and not Alzheimer's disease.

> *"…got ischaemic patches in the brain err she had had been bitten and got a bull's eye patch – Lyme disease… Whether it's Lyme disease?"* (John)

His description of Mary gives some insight into why he might be struggling with the changes in her.

> *"She needs attention and I think she's probably had a lot all her life cause she was quite smasher err and bright with it – yeah she's a good-looking woman and she can be utterly charming."* (John)

The need for attention is quite clear as Mary comes into the kitchen several times and we stop the interview and recording. John seems exasperated at this and says how impossible it is for him to do anything around the house or manage things like the household finances with stacks of papers needing attention in the hallway, kitchen and lounge. He seems exhausted and is considering live in carers as he is struggling to cope without any respite.

> *"Of course, I can't leave Mary alone and I haven't got respite."* (John)

This need for some respite and normality is telling in his comment about just wanting to be able to sit and enjoy a meal without the need to manage Mary.

> *"…and I think "Oh God, why can't I sit down and enjoy my meal?""* (John)

The pleasure of mealtimes together has been replaced with John feeling distressed and even angry. He has had to take over all the meal-related tasks and responsibility for provision of Mary's food and drink, prompting her to eat and drink, modifying food choice and coping with the decline in her ability to use cutlery and associated mess at mealtimes. He shows me the food on the floor following breakfast which he has yet to clear up. For me this was one of the more distressing interview experiences seeing a bright couple that enjoyed life together now struggling to cope with the impact of dementia. As I drive home, I hope John is soon able to find live in carers to allow him to begin to enjoy the time he has left with his wife.

6.5 Matthew - "No problems only solutions"

Matthew is married to Jenny. I interviewed Matthew in his home while a regular carer looked after Jenny. We were interrupted a couple of times by the carer needing to access things from the kitchen where the interview was taking place and the interview was stopped on these occasions. Conversation was easy although keeping to the topic of eating and appetite was somewhat challenging at times as Matthew seemed to want to tell me his own story of his ill health and providing care for Jenny.

Jenny had quite advanced Alzheimer's disease at the time of the interview. Her diagnosis was around the time Matthew was being treated for cancer and he describes how he began to notice changes in her whilst he was receiving treatment.

> *"…and in that period Jenny could drive and had no problem driving and was taking me to the hospital. And she started to say, "I don't know the way.""* (Matthew)

He describes how he knew something was not right.

> *"So, I didn't really know what it was but I started to think well she's starting to forget things."* (Matthew)

His approach to problem solve and on receiving Jenny's diagnosis they decided to move house.

> *"'Cause no problems only solutions – she's got that (dementia), we need to move."* (Matthew)

Although Matthew knew he was there to talk about eating and appetite in dementia he was more interested in talking about other challenges he faced and in particular managing her wandering from the house.

> *"And she got to the stage where sometimes she'd say I'm just going for a while and she'd come back. But then she stopped coming back."* (Matthew)

There was a particular incident, which was clearly traumatic for Matthew when she went missing for many hours into the night and support from the emergency services was needed to find her.

> *"But then this time she went off and didn't come back so I got the emergency service out."* (Matthew)

As a result, Matthew in his "solutions not problems" mentality made a decision about how to keep her safe.

> *"So that was the point where we decided then we would have to lock her in if I wanted to go outside cause she would still want to go out."* (Matthew)

It seems shocking to lock an adult in a house but his perspective was that this was safer than the alternative of her getting lost. With Jenny now wheelchair bound this was no longer an issue and this in conjunction of having regular carers and support from his son and family made it easier for Matthew to care for her at home. Matthew's motivation to continue caring for her came from the years Jenny had looked after the family particularly when he was away a lot for work.

> *"I always say, I mean, she looked after me for a lot of years and she looked after the family and ran the family and it was the least, I could do to make sure she was fine."* (Matthew)

He repeats this again perhaps for emphasis or perhaps to convince himself.

> *"So, I wasn't home a lot in some of the part of our lives so she ran everything - she managed the money, she managed the house and err it was the least I could do to make sure she was alright."* (Matthew)

Matthew now has sole responsibility for providing meals and Jenny needs support to eat and drink. Mealtimes take much longer with carers sometimes sitting with Jenny while she finishes eating to allow Matthew to get on with other tasks. They have gone from having a good social life, having friends over for meals or going out to eat to very limited socialisation Matthew describes the effect of dementia on his life.

"Life with Jenny was slowly going down." (Matthew)

His own life as he had known it is ebbing away with Jenny's decline in health alongside the hopes he had for the future.

6.6   Sarah - "It's like having a third child"

Sarah's mother, Sofia has Alzheimer's disease. I interviewed Sarah at her home where she lives with her husband and two young daughters. The house was peaceful, ordered and welcoming and an easy setting to undertake the interview. We sat in the large kitchen looking out into the garden and began the interview. Sarah's experience of caring for her mum, Sofia, was varied. At her diagnosis Sofia was living independently on her own before moving in with Sarah then onto sheltered accommodation close by.

> *"…some experience of living on her own when she was completely isolated as well as her living on her own near us where I manage."* (Sarah)

Whilst living alone a carer was privately funded to visit Sofia on alternate days.

> *"She had a carer, going in every other day, um ,so I 'spose that was for the first two years of her diagnosis."* (Sarah)

However, the carers did not appear to check on how well her mother was eating, make a note of her weight or look at her fridge or cupboards to see if she had food. Sofia began to lose weight and as her dementia progressed Sarah and her family decided to have Sofia live with them.

> *"So, um, we've got experience I 'spose of her having lived with us for nine months."* (Sarah)

Sofia's weight improved as she joined in family meals and responded to prompting to eat. She now lives in sheltered flat close to Sarah.

> *"And she now lives in some sheltered accommodation about 6-minute walk from here."* (Sarah)

Sarah describes the general lack of support for carers even when registering at a new GP surgery.

> *"…they have a question on the registration sheet 'are you are carer?' tick…nothing happens, absolutely nothing happens. I'm not even sure what that box is there for."* (Sarah)

She goes on to identify how no one is asking how she is coping as a carer.

> *"Yeah, well there's no one like you that says how's it feel? How are you? And that's what's upsetting I suppose."* (Sarah)

In contrast Sarah checks in on her mum at least once each day including taking meals to her, checking her fridge for out-of-date food and ensuring she has food to eat. On asking what it's like having to be her mother's carer she becomes very tearful saying it is like having a child.

> *"It is, it's like having a third child."* (Sarah)

She doesn't feel there is any alternative but to just keep going and provide the care her mum needs.

> *"You've just got to crack on and do it…Once you're in the middle of it you're just chugging away and surviving."* (Sarah)

I am struck by how isolating the lived-experience of being a family carer for a person with dementia can be with little support or advice.

6.7   Julia - "My sibling and I couldn't agree"

Julia's mother, Lillian had Alzheimer's disease but is now deceased. I interviewed Julia in her place of work, in her office. Although quiet, there were several interruptions. At one point she needed to leave returning sometime later to continue. This led to the interview being a little disjointed. Her mum has lived independently a couple of hours drive away when she was diagnosed with Alzheimer's disease.

"…she lived on her own…and I would go and see her um every four weeks, go down for the day." (Julia)

Although Julia would regularly visit, her sibling provided day-to-day support.

"My (sibling) was round the corner, literally round the corner and they were dealing with the day-to day things…and it was the day-to-day things they were looking at. I was less involved because I was so far away…" (Julia)

With a complex family dynamic, the decision to refer to Julia's sibling in a gender-neutral fashion was agreed at interview. Lillian's condition deteriorated to the point where she wasn't coping.

"...because she (Lillian) couldn't cope because she was being ill…and not being able to cope with how that was..." (Julia)

She was not eating well and Julia was concerned about her food hygiene wondering if her physical illness were related to this. Julia also felt that her sibling was not providing adequate support for Lillian with regards to shopping and cooking with limited, in-date food in the house when she visited. Even when Julia supplied food for her mum would forget to eat it.

With a decline in Lillian's health Julia's sibling wanted her to live in a nursing home. Julia visited the nursing home and was unhappy with what she saw refusing to allow her mum to go there even though her sibling made it clear they could no longer cope.

"I just went home to my sibling and said absolutely no mum is not going there. Well, we can't cope." (Julia)

Julia stated she would look after her mum if her sibling could not.

"I said fine 'cause I'd always said if you can't cope at any time just tell me and we will look at it from there." (Julia)

As a result, Julia and her partner stayed to care for Lillian for a month as the siblings unable to agree on the best course of action

> *"…So that ended up in us staying down there for a month, luckily I had some leave um but we couldn't leave her on her own she was much too um vulnerable…My (sibling) and I couldn't agree."* (Julia)

Further complicating the situation was Lillian's to stay in her own home. Julia felt with support this was possible.

> *"First of all, I wanted her to stay at home and trying to get people coming in, someone living there to support her where she wanted to be. 'Cause she wanted to stay at home."* (Julia)

However, this was complex to arrange as Lillian needed practical support including help with meal planning and preparation. Julia and her partner eventually brought Lillian back to live in a nursing home near them.

> *"It ended up in us bringing her to stay down here… and she was in a home..."* (Julia)

Julia was then shocked to receive a phone call from paramedics to say they had found her mum with the nursing home unaware Lillian was missing.

> *"…I had a phone call saying the home had just had a phone call from paramedics, who had picked my mum up…They didn't know she was missing…deep laceration, broken wrist um so I met her at the hospital and um yeah so we, so she stayed overnight and she came and lived with us, following that."* (Julia)

Julia originally felt her own home was not appropriate for her mum but with significant adjustments it became possible. Julia's highly successful career was also sacrificed.

> *"'Cause we said even though we didn't think our house was suitable…so I had to give up my work."* (Julia)

Lillian's eating improved when she moved in with Julia. Adaptations around food choice and meal textures were made and various supportive interventions to help with eating and drinking tried as the dementia progressed and eventually eating and drinking declined again.

6.8 Anna (adult child): "It's not her it's just the disease"

Anna cares for her mum, Isabella, who has mixed form dementia of Alzheimer's disease, vascular and frontotemporal dementia. She reflects that her mum probably began developing signs of dementia after her dad died.

> *"…so, she was beginning to get the signs of dementia after my dad died."* (Anna)

Isabella lived on her own and life was busy for Anna and her family such that the progression of dementia symptoms were not noticed.

> *"And she lived in a flat on her own. And I was working fulltime and as you do, don't really notice that things are progressing."* (Anna)

Isabella's family eventually recognised she could no longer live on her own.

> *"…we kinda recognised that she did have a problem living on her own as well."* (Anna)

Isabella was admitted to a care home close by Anna's home but Anna felt her mum didn't really need this level of care, as she was still active and mobile.

> *"…she went into a care home first of all just up round the corner from here. And, um I, she was there for seven months and I didn't feel that she needed to be there at that moment in time."* (Anna)

Anna expressed to her brother how she felt the care home was the second-best option for her mum and would like her living with her. However, she couldn't afford to give up her job to provide care.

"And I said, well really it's a second-best option for mum to go in a care home. And he said, well what's the first? And I said for me to look after her. Well, why don't you? Well, I need my expenses!" (Anna)

Her brother was supportive and with his help finances were arranged and Isabella moved in with Anna and her partner Matt.

"I gave up work and you know just looked after mum." (Anna)

To ensure Anna had some respite Isabella also went to day care.

"She went to day care twice a week um and I had respite." (Anna)

Over time Isabella's dementia got worse and as Anna puts it her filters switched off.

"… so, all her filters started to switch off." (Anna)

This made it increasingly difficult to take Isabella out even for everyday activities such as shopping.

"…trying to do your shopping there and she'd gone up the other end and you'd have to chase after her." (Anna)

Anna chooses to see this change in behaviour as being the disease rather than her mother's fault.

"Oh well it's not her it's just the disease." (Anna)

She talks of the challenges of providing care and her reliance on the Memory Group for support and understanding.

"If it wasn't for Memory Group there every week…it would be difficult to cope." (Anna)

Matt is also key to helping Anna manage Isabella's care and clearly an integral part of Isabella's care at home.

"Me and him work together." (Anna)

One of the significant challenges is Isabella persistent asking for food regardless of how much is provided. When she was more mobile Isabella would search for food and leave half eaten food around the house forgetting she had started to eat it. There was also increasing mess associated with eating and Anna shows me the consequence of this with significant food and drink stains on the pale carpet. This is similar to John's experiences of mess being associated with eating and drinking.

Like Sarah, Anna describes parallels with caring for a parent with dementia with caring for a child. She develops this idea further with a role reversal of her partner as 'Dad' helping her care for Isabella as the 'child.'

> *"…it's like having children when Dad comes home "it's your turn.""* (Anna)

Isabella became totally dependent on Anna and her partner for meals and drinks, being unable to participate in decision-making about food choice or when to eat. This idea of role reversal is perhaps possible because Anna no longer views Isabella as her mother, as dementia has taken her away.

> *"…I didn't see her as my mum any more. My mums not there…I'm looking after a person that looks like my mum but obviously it's not like the real mum that I knew."* (Anna)

This is similar to how Maria describe Trevor – looking the same but not the same. Anna tells me that this makes it easier to cope yet it doesn't take away the challenges and frustrations.

> *"It made it a bit easier in a way."* (Anna)

Despite this Anna is able to reflect on some of the happier times and as she puts it funny moments.

> *"We've had lots of funny moments."* (Anna)

Perhaps it is these moments along with her supportive partner and view of her mum's behaviour, which help Anna to continue supporting her mum visiting her regularly even now she is in a nursing home.

6.9   Jo (adult child): "Kept an eye on what was going on"

Jo's mother Linda had Alzheimer's disease. Jo requested the interview took place at the University. Unfortunately, the interview was interrupted by a fire alarm disrupting the flow of the conversation. The interaction with Jo was more difficult than in other interviews and she seemed somewhat reluctant to talk about her experiences. She became emotional as we talked in more depth about her experiences and on reflection her reticence to talk may have reflected her trying to contain emotion. Linda was deceased at the time of Jo's interview perhaps making a reflective interview emotionally difficult. As a result, the interview was terminated earlier than planned to minimise her distress. The conversation was brought back to more general things, reminding her of sources of support available before she left the room.

Jo lived with a partner and children and is the younger of two siblings. One of her relatives had a healthcare background and although did not live locally offered advice and support around the care of her mum. Jo describes a close relationship with Linda partly as a result of her being widowed very young and she has always lived close by. Jo describes how Linda supported her and her siblings when they had their own children and how the roles changed as her mum became more elderly.

> *"So obviously as life changes she was becoming more elderly so the care err relationship changes. So, from her caring for us and helping us out a lot then to us having to care for her."* (Jo)

Jo describes how Linda never remarried with no partner to care for her when she developed dementia.

> *"I didn't have a dad to take on a caring role…"* (Jo)

The role of supporting her mum therefore fell to the siblings. Although her sister lived some distance away her brother was in the same local area as Jo. Despite this Jo provided care reasoning it was more of a daughter than a son's role.

"I think that tends to be something that daughters tend to take on. More of a caring role err I was the one living in (locally) so that's why I was the one who became primary carer." (Jo)

Her mum lived close by when first diagnosed but moved next door to Jo a couple of years later. In Jo's mind this meant they were able to support her mum living at home as she was on hand.

"…so, we moved my mum into the house next door, which was all very convenient…I mean in the early stages it wasn't so difficult but because she moved next door. It actually meant we were able to keep her at home a lot longer than if she hadn't moved next door because just things about keeping her safe…" (Jo)

Jo would provide Linda with meals or ensure carers were there to heat up food for her. As the dementia progressed she increasingly needed prompting or reminding to eat and drink. However, the social element of eating remained while Linda lived in her home with Jo describing family take-aways at the weekend or friend's visiting for coffee and cake.

The challenge of providing care for a parent as an adult-child is alluded to by Jo when she mentions other demands on her time.

"…obviously, also I have other things in life…children, job and things like that so it made it easier (to have her live nearby)…" (Jo)

Linda needed nursing home care for about three years before dying. The nursing home was local and Jo still saw herself as providing care for her mum during this time and ensuring the nursing home staff provided her with good care.

"…we chose a nursing home that was very close so that I could go in on a very regular basis although I didn't do her primary care needs err I sort of was still her main carer certainly from a family point of view. Kept an eye on what was going on." (Jo)

This last comment is telling in Jo's concern for her mum and the responsibility she felt for her. This was Jo's approach to looking after her Linda always keeping an eye on her to keep her safe regardless of where she lived.

6.10   Bob (adult child): "Quite a journey"

Bob cared for his mother, Elsie, who had vascular dementia describing his experience as journey.

> *"..but it was quite a journey as I say it was 14-years."* (Bob)

Bob had always lived with his parents with his father initially providing care for Elsie whilst Bob worked. However, Bob's caring role increased as Elsie's dementia progressed and his father became more elderly.

> *"I took over responsibility from Dad..."* (Bob)

Bob talked a lot about his different jobs with this very much informing his identity. Eventually when his father died the caring for Elsie was left to Bob he resigned his job.

> *"I started off as a partial carer and then it gradually grew and grew..."* (Bob)

Although Bob told me he was happy to provide care there were glimpses of how difficult this could be. He describes how it felt like he was the bad cop trying to get Elsie to take medication.

> *"... I used to go home during the lunchtime to administer the medication for mum err because dad found it difficult...when I used to do that I was the worst thing since it's like good cop bad cop."* (Bob)

A further consequence of his carer role was the loss of friends.

> *"...as I say I lost virtually...most of my friends at that time that."* (Bob)

Instead of meeting his friend he took Elsie out for lunch every week and sought opportunities for Elsie to socialise as she was able to. He describes how helpful he found café or restaurant owners when he asked for food to be blended or drinks to

be put into a beaker for Elsie. He relied heavily on ready-made meals or food which could be easily heated up at home and found blending food at home. Instead, he bought ready-made puree meals and supported Elsie to remain independent with eating for as long as possible.

Bob came from what he described as a 'caring' family involved in helping the community with caring for his mother fitting within this culture.

> *"Err, I was quite happy, err, I was brought up…we were quite an active community family and so we were always involved in that."* (Bob)

He repeatedly told me that as long as his mother was happy he was happy and this viewpoint over shadowed any losses I perceived for Bob.

6.11   Chapter summary

These pen portraits support description of the participant life contexts adding to the richness of the data whilst supporting the reimagination of lived experiences of eating and appetite in dementia. The essences of each participant life context are used to construct contextual understanding of participants in the following poem.

The life world of dementia family carers

All the normal little things become a struggle.

Kept an eye on what was going on as,

I'm losing the man I know and love.

Why can't I sit down and enjoy my meal?

It's like having a third child!

Well, it's not her, it's just the disease.

My sibling and I couldn't agree,

But no problems, only solutions.

I've coped but there is a break point for everyone.

All that matters is he's happy.

(Created from participant's own words)

The next chapter will focus on the findings relating to family carer lived experiences of eating and appetite in dementia within the participant contexts described.

Chapter 7 Daily ethical challenges of appetite and eating in dementia

This chapter presents and discusses the findings of the present study, answering the research question of 'what are family carer lived-experiences of appetite and eating in people with dementia living at home' and study objectives one and two:

- To explore family carer lived experiences of appetite and eating in individuals with dementia living at home
- To identify meaning of these lived experiences for family carers

These findings present new knowledge, with daily ethical challenges being the essence of family carer lived experiences of eating and appetite in dementia. This is informed by three superordinate themes of complex ethical decision-making around eating behaviour and appetite, recognition of the impairment effects of dementia on eating behaviour and appetite and the cost to family carers of eating behaviour and appetite in dementia. These are presented alongside subordinate themes in Table 3.

Table 3 Themes from interpretative phenomenological analysis

Overarching theme	Superordinate themes	Subordinate themes
Daily ethical challenges of eating behaviour and appetite in dementia	Theme 1: Complex ethical decision-making around eating behaviour and appetite in dementia	- Decline in shared decision-making - The meaning of food and eating - Keeping safe - The power of health promotion messaging
	Theme 2: Recognition of the impairment effects of dementia on eating behaviour and appetite	- Not making connections - Understanding of changes to eating behaviour and appetite
	Theme 3: The cost to family carers of eating behaviour and appetite in dementia	- Financial cost - Cost to relationships - Personal cost

Daily dilemmas of family caring in dementia, as well as ethical factors and consequences of decisions made by family carers have previously been separately described (Mole et al., 2019, Miller et al., 2016). However, these have not been considered in the context of family carers responses to appetite and eating behaviours in dementia. Thus, these are new findings, building on prior understanding about family carer experiences of these functions. The ethical challenges come from the need for complex, ethical decision-making, with judgements required around how best to respond to changes in eating behaviour and appetite. This involves balancing providing support to enable autonomy in decision-making around food and related tasks, with family carers' own needs. Such daily ethical challenges are shown in this study to impact family carers wellbeing, with these being a source of anxiety and distress. In this way, eating behaviours and appetite changes in dementia are implicated as a potential cause of carer burden.

7.1 Theme 1: Complex ethical decision-making around eating behaviour and appetite in dementia

Family carers lived experiences of eating behaviour and appetite changes in dementia involve complex ethical decision-making, with participants describing uncertainty around how to respond or what to do. Personal meaning of food and eating, a need for safety, the influence of public health messaging about healthy eating, and a decline in shared decision-making all contribute to the complexity and ethical components of decision-making. These factors can compound uncertainty around how to respond. McGIinley, (2015) suggests that nutrition in dementia is complex not because of complex nutritional requirements but rather as a result of the consequences of the effects of dementia on cognitive and physical function. However, this is described in the context of healthcare professional experiences of delivering nutritional care. The present study identifies similar experiences for family carers. This offers new insight into family carer lived experiences.

The literature also describes eating as an opportunity to socialise, connect with others and experience pleasure rather than just about meeting nutritional needs (Johansson and Johansson, 2009). Participants similarly expressed this view, that eating was more than about consuming food.

> *"…it's a lot more than just eating food."* (Maggie)

However, for participants the "more than just eating food" included knowing how to respond to changes in eating behaviour and appetite, with variable experiences of enjoyment and socialisation at mealtimes described.

7.1.1   Decline in shared decision-making

Decline in shared decision-making is well recognised in the family carer dementia dyad, being discussed in the context of a change in roles in relation to food (Miller et al., 2014, Mole et al., 2020). The present study similarly identified a change in roles however, this is viewed as a loss of shared decision-making. This was a contributing factor for the complex, ethical decision-making described. Knowing how to respond to changes in appetite or eating behaviour can become more difficult as the scope for shared decision-making declines, and a move to sole responsibility for associated activities increases. This is shown to negatively impact family carer feelings of pressure and burden (Hellström et al., 2005).

Although Maggie has always been the main provider of food, her role changed as she took on sole responsibility for most daily tasks. She expresses this as a need to constantly think and make decisions, including prior tasks related to food and eating.

> *"…decisions about err what to do in the day, continually, I think all the time."*
> (Maggie)

This represents a change for Maggie and as a result she is no longer able to provide home cooked food in the same way in which she would choose, with increasing reliance on convenience foods. In this way her role in relation to food changed. She describes difficult decisions being made, having to balance the need to deliver on new tasks in her caring role with her desire to provide home cooked food.

All participants consciously or otherwise described a loss of shared decision-making in relation to food, eating or appetite. A simple example is illustrated by Jo who sought to share decision-making with her mother about meal choice by asking her what she would like to eat.

"Well, we did get a variety of Wiltshire Farms Foods…I used to say if I was doing it do you want you know you've got shepherd's pie." (Jo)

However, shared decision-making was lost when carers were employed to prepare her meals.

"I suppose the problem is latterly she didn't get a choice" (Jo)

Jo has to balance supporting her mother to engage in shared decision-making with her own personal needs and the support of formal carers. This presents an ethical challenge around whose needs to meet. Maria also attempts to use shared decision-making but is frustrated at Trevor's slow cognition and executive function.

"…because Trevor takes a long time to give an answer and to think." (Maria)

As a result, she opts to make decisions for him.

"I say to him I haven't got all day for you to decide what you want to say cause I know what he wants to say." (Maria)

Shared decision-making is lost, along with opportunity for Trevor to have some control over his food choices. Maria assumes sole responsibility for provision of food in the belief she already knows what he wants because of the longevity of their relationship. Whilst not well described in dementia such 'knowing' is similarly described by family carers of people with eating difficulties following stroke or traumatic brain injury (Johansson and Johansson, 2009). Maria's complex, ethical decision-making is bound in believing she knows what her husband wants to eat and her inability to adapt to Trevor's slow response to questions or engagement with conversations. This raises a question about whether her belief that she knows what Trevor wants to eat is a way for her to rationalise her response to the changes in his ability to engage in shared decision-making. The pressure of providing care are such that Maria does not feel she has time to wait for Trevor to respond to her questions about food. These examples illustrate how the loss of shared decision-making can contribute to complex, ethical decision-making around food and eating.

7.1.2   Personal meaning of food and eating

The meaning of food and eating for participants in the present study was commonly associated with a way of showing love, quality of life, and preservation of health. These are not new associations per se however, there is limited empirical research about the meaning of food and eating for family carers of people with dementia. The present study identified that personal meaning of food and eating was a factor which could contribute to complex, ethical decision-making. All participants' responses to these functions were influenced to a greater or lesser extent by the meaning of food and eating to them personally. Maria most clearly expresses, equating pleasurable food with quality of life.

> *"But what life if no chips or chocolate?"* (Maria)

This is particularly important for her in the context of her partner who had reached old age and had a limited life expectancy.

> *"It's hard to not give somebody what they want to eat and going to enjoy when there in the seventies and your prognosis isn't one hundred and five." (* Maria)

There is little empirical research around family carer experiences of pleasurable food and quality of life in dementia. However, a small study of four female family carers of malnourished older people does reflect a similar perspective, with nutrition a feature of quality of life for such family carers (Marshall et al., 2017). Maria expresses her belief that providing food which is enjoyed by her partner is a way of making him happy and associated with love.

> *"Because life expectancy is not very long so why can't you make the person you love happy?"* (Maria)

However, she is also aware of an association between food and health, having had previous advice from a dietitian about diet when Trevor had heart problems. Public health messaging around healthy eating is reinforced by her sister. Maria has a complex, ethical decision to make. Does she follow her personal belief, that giving food allows her to show love and enhance Trevor's quality of life or does she provide food which she understands to be better for his health but less pleasurable for him?

*"Now what do I do? Do I give the man I love a hot sausage roll which he is going to enjoy and dip it in the ketchup or do I give him some beans on toast? Healthy but not crazy about eating it." (*Maria)

Her rhetorical question of "what do I do?" reflects the sentiment of most participants. It is embedded in a context of little support, information or advice being received or accessed by participants about how to respond to eating behaviours and appetite changes in their family member with dementia.

Emma's lived experiences also reflect complex ethical decision-making around food choice and her personal beliefs about the best food for her husband. The focus for Emma is on healthy food choices to help control Mike's type I diabetes. However, Mike has decided that since being diagnosed with dementia he wants to eat for enjoyment and have high sugar foods. This results in arguments and challenging behaviour, including stealing money from Emma to buy high sugar foods, stealing such food items and when given a pre-paid card for a local café using it to purchase high sugar treats. Emma refuses to compromise her belief around what she feels are the best food choices for Mike to remain healthy. This has a negative consequence and opposes Mikes own wishes.

"…a lot of the angst between him and I, me saying no you can't have sweets and I'm not going to buy them. He thought I was bullying him." (Emma)

Things become increasingly difficult culminating in an assessment of Mikes mental capacity, where he was assessed as having capacity to choose the foods he wants to eat. Whilst there is now less outward tension and argument, Emma struggles with Mikes choices.

" So, there is a lot less angst since last week but that's because he is doing what he wants to do even though it's to his detriment." (Emma)

She is left with a new complex ethical situation. Should she continue to pursue her personal beliefs, only purchasing what she considers to be appropriate foods, or should she compromise her beliefs to support Mike in eating as he wishes? Emma acknowledges Mike's right to choose what he eats but is unable to accept his choices.

"…if he's got capacity, which he has, then you have to respect his right to choose. (Pause) But equally it's really selfish with no thought for anyone else. So, basically I have to sit and watch him self-destruct and that's tough. But it's the right thing to do for him. (Pause) It's not the right thing…I would never do that, ever be that selfish, and I'm not and he is." (Emma)

Her personal beliefs are compromised and in this way her personal needs are not met. She articulates her own understanding of Mike's reasoning for his choices, wanting quality of life and pleasure over longevity of life.

"I like cakes and sweets and I know what they do to me and I'd rather eat what I want now and have a shorter life than behave and have a longer life'. And we all agree that he has capacity to make that decision. So he is very into sweets, cakes and biscuits." (Emma)

This mirrors Maria's view of the importance of quality of life and eating food which is pleasurable. However, Emma prioritises the need for healthy food choices over pleasure and views Mike's decisions as being akin to committing suicide.

"It's less wearing so there is a positive and there that little bit that says and he is self-destructing, and effectively committing suicide and it's within his control to do that. So very frustrating." (Emma)

Such a strong phrase reflects the depth of her emotional response and perhaps innermost fear of Mike dying. The meaning of food choice for Emma is implicitly intertwined with health and ultimately living or dying. Her personal needs are not being met with Mike taking back control of his food choices. In contrast to Maria, she makes no recognition that food is also for pleasure and potential for changing needs and priorities of a person with dementia. Emma's association of eating with life and death is perhaps at the heart of complex ethical decision-making for family carers, with such association seen in other participants narratives.

A third example of the contribution of personal beliefs on complex, ethical decision-making comes from Julia's experiences. She along with several other participants, believed that provision of home cooked food is important for health and wellbeing. Julia describes the significant effort she puts in to preparing this for her mother.

"I'd gone to the effort peeling, cooking, roasting…" (Julia)

Although the literature does not explicitly describe this in the context of dementia, it does observe how family carers often spend more time cooking than prior to their caregiver role, using this as a way of showing consideration, care or love to the person receiving care (Johansson and Johansson, 2009, Hopkins, 2004). This may have been the case for Julia. Despite her efforts, Julia's mother rejects the home cooked food triggering a significant emotional response in Julia.

> *"…she'd say to me Well what's for dessert?... she loved err um trifles and you know real sweet stuff like that, and that tend to be shop bought. Um so um I got over myself eventually um by going in the kitchen and screaming, you know."* (Julia)

This could be interpreted as frustration and anger or response to having her act of love rejected. This then presents an ethical challenge. Does Julia continue providing food which allows her to express love and care and she believes is best for her mother but is not enjoyed and even rejected? Or does she compromise her personal beliefs about food and purchase the ready-made desserts which her mother likes? Rejection of food can therefore impact family carers own personal meanings of providing food, being interpreted as a rejection love (Hilario and Augusto, 2021). In this way it can add to the complex ,ethical decision-making processes family carers experience.

These three examples illustrate the influence of personal meaning of food on complex ethical decision-making. It shows how providing care for a family member with dementia can compromise such personal meaning. Maria is torn between supporting her husband's health or meeting her own need to show love and add to his quality of life through food. Emma is compromised because of her husband's food choices compared with her own beliefs, whilst Julia is conflicted about whether to meet her own need to show care for her mother through home cooked food or providing her with ready-made desserts which are enjoyed. Compromising personal meaning of food and eating can be considered in the context of the 'Hierarchy of Dementia Carer Needs' as not 'taking care of myself' (Figure 14) (Pini et al., 2018).
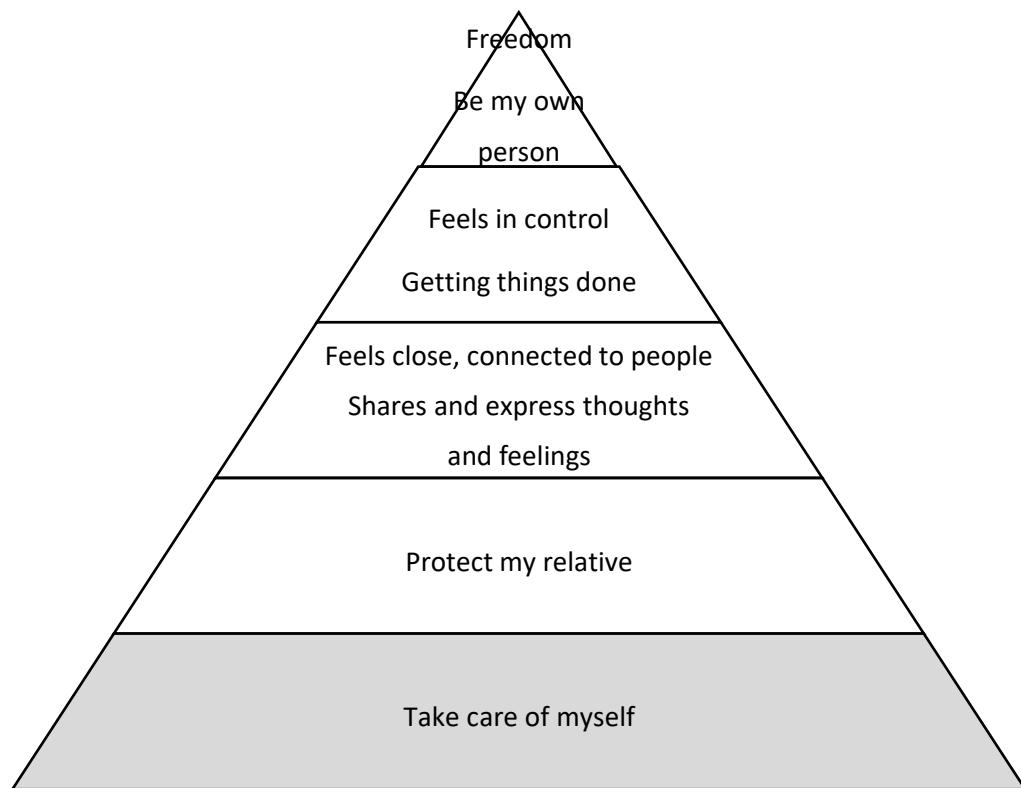
Figure 14 Family carer needs in dementia adapted from Pini et al., (2018)

Pini et al., (2018) identify how providing care for a person with dementia can negatively affect health. Even with a recognition of concern about what would happen if they were unable to provide care, few family carers were able to prioritise their own needs to improve or maximise their own health (Pini et al., 2018). The present study found that being unable to meet personal need in the context of meaning of eating and food resulted in internal conflict, uncertainty, distress, and even anger and frustration. This is detrimental to mental health and wellbeing and compromises family carers' ability to 'take care of myself.' Thus, complex, ethical decision-making and in particular the personal meaning of food and eating can be described in the 'Hierarchy of Family Carer Needs' model (Pini et al., 2018). This presents new understanding of family carers lived experiences of eating and appetite in dementia.

7.1.3   The need for safety

The need to keep safe is a factor contributing to family carer's experiences of complex ethical decision-making around eating behaviour and appetite in dementia. Safety and managing risk in dementia is usually described in formal health care settings or in the

context of healthcare professionals (Ragdale, 2014). It is not commonly described in the context of the home. Pini et al., (2018) suggest that family carers have an 'underlying instinct' to protect vulnerable family members and keep them safe. The present study similarly identifies this need to protect in the context of eating and appetite. Additionally, a need to protect themselves is also identified. This then contributes to new knowledge.

Keeping the person with dementia safe in the context of eating behaviour, appetite or meal-related tasks was described by most participants. Complex, ethical decision-making was evident around food safety, safety in the kitchen, malnutrition and choking risk. These findings mirror safety concerns of healthcare professionals, where home appliance accidents, malnutrition and swallowing difficulties key risks for people with dementia living at home (Taylor et al., 2017). Balancing keeping safe and independence is an ethical challenge which participants described. Encouraging enablement of the person with dementia in food-related tasks is important and a key task which formal homecare workers are well placed to support (Mole et al., 2019). However, without homecare support, family carers have to make decisions about their own ability to support independence around food-related tasks and know when to take over to ensure safety. The present study found that such assessment of safety utilised personal judgements in relation to how much risk was acceptable to them as individuals. Some described adapting and living with an element of risk in order to preserve the independence of the person with dementia.

> *"It was a bit scary if she did get up in the night to make a cup of tea. Thankfully we never had any incidents over that. We sort of got used to it."* (Anna)

Ability to adapt is part of a resilient approach to caregiving (Petriwskyj et al., 2016). The present study shows how family carers make ongoing assessment of risk, adapting to changes. In this way they are demonstrating resilience. This is illustrated by Anna when she felt that the risk of her mother making tea independently was no longer acceptable.

> *"In the end you actually have to say no it's a bit dangerous so we stopped it."* (Anna)

Conscious or otherwise, risk assessment of food-related activities is undertaken by family carers, balancing risks and making judgements about safety and scope for independence of the person with dementia.

The study also found that a critical event would trigger a review of risk, with the insidious decline in functional or cognitive ability seemingly not a factor. An example is illustrated by Emma's experience.

> *"I came in when it was in the oven and it didn't look very nice. And then he'd done himself some sauté potatoes but he burns things and he just sat there and he asked for a steak knife with the duck. He didn't eat all of it and I watched him throw it away and it was raw…he wouldn't admit that. He said it was lovely but that last bit he threw away"* (Emma)

This critical event resulted in her preventing Mike from cooking, with carers brought in to provide meals when she was at work. The risk of food poisoning, injury to Mike and fire was too great for Emma to live with.

> *"…I have said to him it's too dangerous for you to cook, you've got carers let them do it for you."* (Emma)

Interestingly, food safety is not always described by healthcare professionals as a risk (Taylor et al., 2018). Anna also experiences a critical event where she realises her mother can no longer safely provide her own meals.

> *"…there was a smell in her flat and we couldn't work out what it was…in the end I was in the kitchen… I thought where is that smell coming from? So, I stuck my hand under the cupboard…and I ended up working my way around to the oven and she'd obviously cooked dinner and God knows how long it had been in there and I picked it up and it was like dust. And then I found another one in the microwave…"* (Anna)

The description of Anna's findings in the kitchen suggests her mother's ability to provide meals had been declining for some time. Yet even though Anna had visited very regularly she had not identified the insidious decline in her ability around meal-related tasks and the risk to her health until this critical event. Sarah had a similar experience of a critical event finding out-of-date food in her mother's kitchen. This led her to mitigate the risk of food poisoning by asking paid carers to regularly check her mother's fridge.

> *"…food going past its use by date or uncooked food or cooked food that's not eaten in the fridge, not being covered, left, forgotten. So that was becoming an*

issue. So, we had to sort of instruct the carers you know, could you do a sort of Friday check in her fridge and ditch stuff that's going off." (Sarah)

Matthew describes a critical event which put both his own and his wife's safety at potential risk. He describes how his wife's unpredictable behaviour put them both at risk when in the kitchen.

"What I mean by her angry stage, I knew she'd be a bit more dangerous 'cause there were lots of knives around and you'd never know if she was going to pick a knife up." (Matthew)

This critical even and judgement about it being an unacceptable risk resulted in his decision to have her leave the kitchen.

"So, I then started to edge her away from the kitchen and just do it all then." (Matthew)

These three examples from Anna, Sarah and Matthew illustrate the strong need of family carers to keep relatives safe in the context of food safety and meal related tasks. Participants provided additional support such as is seen by Sarah ,or sought to remove the individual from the risk as described by Anna and Matthew. Keller et al., (2015) describe how family carers of people with dementia seek to minimise risk at mealtimes. Lee and Bartlett (2021) explore risk in dementia in relation to the use of everyday objects for everyday tasks, such as clearing away plates or washing-up. They go on to identify how care home staff make judgements based on their own perceived risk of objects either removing the object or supervising activities accordingly (Lee and Bartlett, 2021). This study has demonstrated similar judgements about risk in relation to meal related tasks and food being made by family carers of people with dementia in a home environment.

7.1.3.1   Risk of choking

Concern about choking was only described by two participants, with both Jo and Bob providing modified texture food as a result.

"Yes she had to have um soft food later because of what err, the risk of choking so she had to have pureed…" (Jo)

Jo had family members who were healthcare professionals who may have advised on the type of food to provide to reduce the risk of choking. Bob had access to a speech and language therapist through his mother's doctor.

"… because she used to cough a lot and we used to be worried she'd choke and things like that. And that's when we got speech and language therapist involved" (Bob)

Although healthcare professionals identified choking as a risk for Anna's mother when she was in hospital Anna, in contrast to Bob and Jo, was not concerned.

"They found she could have problems choking that they worried about it more than I did." (Anna)

This suggest a lack of understanding of the consequence of this. Maggie noticed her husband coughing more yet does not seem to make the connection between this and swallowing problems resulting from dementia.

"…things tend to irritate his throat and make him cough…" (Maggie)

This was even though she recognised he managed better with softer textures.

"So, anything that's a bit hard, crusty, chewy, either he doesn't eat it or I have to soften it in some way." (Maggie)

Perhaps as a result of the discussion at interview she goes on to reflect that she should monitor his cough but still does not seem to connect his coughing with swallowing problems.

"Err, I must perhaps keep an eye on things." (Maggie)

Choking, coughing when swallowing, taking a long time to swallow or difficulty in swallowing are problems described in those with dementia, particularly as the disease progresses (Kai et al., 2015). Such dysphagia can put the individual at risk of aspiration with potential for developing pneumonia (British Geriatric Society, 2020). Most participants seemed unaware of potential risks and implications for health. The NICE

guidelines (2018) recommend that those with dementia have access to a speech and language therapist for assessment and advice but only one participant had this support. If family carers are unaware of the significance of symptoms they are unlikely to seek such support. The present study shows that although family carers have a need to keep their relative safe around food and eating, this was only in the context of perceived risks, with other risks such as choking often unrecognised.

Assessment of swallowing gives opportunity for interventions to help manage dysphagia. However, these can present ethical challenges in a person with a life limiting condition such as dementia particularly at the end of life. Such interventions often mean significant change to food and drink textures and the type of food consumed. In a worse-case scenario all oral nutrition is stopped and enteral tube feeding recommended. The use of enteral tube feeding is not currently advocated in dementia unless to manage an acute, short-term problem presenting an ethical dilemma in the management of dysphagia in dementia (NICE, 2018). Recent guidance on the management of dysphagia at the end of life includes consideration of the individual's wishes as well as pleasure, cultural and social engagement associated with eating and drinking (British Geriatric Society, 2020). However, the individual with dementia's wishes are often not known or documented and capacity to discuss will likely be limited. This presents particular difficulty for those providing formal and informal dementia care.

7.1.3.2   Malnutrition risk

Concerns around poor appetite or weight loss were not as commonly expressed as had been anticipated by the study participants. These symptoms potentially indicate malnutrition risk. Two participants explicitly articulated their concerns about poor eating, both being daughters of mothers with dementia. For example, Julia describes her worry about her mother's decline in eating.

> *"Then she was hardly eating, I mean, hardly eating anything and I was getting really worried because she was losing weight and became ill…"* (Julia)

In contrast, healthcare professionals report recognising malnutrition as a safety issue in dementia however, they describe not being confident in their own knowledge about how to advise family carers to manage this (Taylor et al., 2018, Mole et al., 2019). Family

carers of those with a stroke or traumatic brain injury describe concern about malnutrition risk (Johansson and Johansson, 2009). However, unlike participants in the present study this group of family carers had access to support and information from healthcare professionals. This may have improved their awareness of malnutrition risk, with help to recognise and understand changes which increase risk (Johansson and Johansson, 2009).

More common in the present study was a rationalisation of an observed decline in eating or weight. Bob rationalises his mother's eating, describing improvement in appetite with her dementia diagnosis.

"...she never ate as well as she did when she had dementia." (Bob)

Yet in contrast to this is a detailed narrative of advice from the doctor around how to maximise calories and use oral nutritional supplements to improve nutritional intake.

"...and the important things was to keep her calorie count up which we were told as well...We used to have something called build up..." (Bob)

In the same way Julia rationalises the decline in her mother's eating despite expressing concern about this change.

"...she had a small appetite which appeared to be getting smaller...and she used to eat half of it...She'd never been a big eater..." (Julia)

She repeats this as if for emphasis, perhaps to convince herself that there was no cause for concern.

"So never a big eater anyway..." (Julia)

Such rationalisation as shown by Bob and Julia may occur in an attempt to provide reassurance that the nutritional care being provided is adequate and the person with dementia is 'safe.' This may extend to family carers feeling a need to keep 'safe,' distancing themselves from the consequences of dementia on eating and nutritional state. Such denial, intentional or otherwise, may mean that interventions to improve or support nutritional intake are not able to be considered, with further decline in nutritional state likely.

Why then might family carers find it difficult to accept the changes observed in weight, eating behaviour or appetite? These symptoms are a physical representation of dementia and decline in health. Physical changes such as significant weight loss in those receiving palliative care were found to be distressing for family carers (Hopkins, 2004). This may also be the case for family carers of those with dementia. Eating in a Western culture is usually associated with health and life, therefore weight loss, poor appetite or refusal to eat in the context of illness infers poor or declining health and even impending death. Julia makes an association between life and eating.

> *"…she would be someone who was eat to live."* (Julia)

With such a connection between life and eating, rationalising changes in eating may be a protective mechanism for the family carer. Not eating well or food refusal is a constant, physical reminder of the dementia, with the safety of the person with dementia threatened. By rationalising the changes Julia and Bob are perhaps able to protect themselves from the reality of what is happening. This presents ethical challenges. Acknowledgment of the implications of a decline in weight or changes in eating may offer opportunity for support to respond and benefit the person with dementia. However, this may come at a personal cost for the family carer, risking an increase in personal distress. A coping strategy of rationalising changes is understandable and may enable family carers to more readily continue providing care by keeping themselves 'safe' from the reality of what is happening. Further, it may also help to believe that the care they are providing is good enough. How family carers would respond if they had improved knowledge and understanding about risks of choking, swallowing problems or malnutrition is not well known. Supporting family carers to protect their relative and themselves in relation to eating behaviour, meal-related tasks and appetite is therefore important in enabling continuation of this role.

The present study has shown a desire to keep the family member with dementia as well as themselves safe in relation to eating, appetite and meal-related tasks. Confidence in such a finding can be conferred as this can be related directly to the fundamental needs of family carer as expressed by Pini et al., (2018) (Figure 15).

Figure 15 Family carer needs in dementia adapted from Pini et al., (2018)

7.1.4 The power of health promotion messaging

A factor adding to complex, ethical decision-making for family carers is the power of health promotion messaging. This is significant in the UK, with focus on the need for low fat, low sugar and low salt diets with more fruit and vegetables encouraged (Avgerinou et al., 2019). It is therefore not surprising that participants commonly sought to provide healthy meals or food choices for the person they provide care for. Participant narratives often emphasised foods being 'healthy' although interpretation of this varied. This presents a family carer 'nutrition ethos' of healthy food choice (Marshall et al., 2017). Sarah expresses her focus on healthy eating describing how she questioned herself about how healthy the food she provided for her mother was.

> *"Thinking about what have I bought? What am I making? How do I keep everything balance? And healthy?"* (Sarah)

Maggie similarly wants her husband to have a healthy diet and limits the amount of foods she perceives as being unhealthy.

> *"…I do want to limit the amount of crisps and sugary things which George eats."*
> (Maggie)

Fjellström et al., (2010) found family carers of those with dementia were interested in providing healthy foods and this was linked with the belief that healthy foods could positively effect dementia. A metaphor for the power of public health messaging is Maria's description of her sister being 'in her head' telling her what to eat.

> *"I think I've got my sister inside my head talking to me. She's e-mailed today saying that I should be eating this and doing that!"* (Maria)

Maria mentions this narrative several times and is frustrated that her sister does not recognise the pressure this is adding as she cares for Trevor.

> *"…and I said to her don't you know how busy my life is?"* (Maria)

Family and social pressure to eat healthy foods is an under recognised issue for family carers of people with dementia adding to complex, ethical decision-making. Keller et al., (2006) describe how the attitudes of society and the medical community around food as medicine increases pressure to provide food which family member 'should' be eating. Food is described as being 'inextricably linked' with wellness, healthy diet and lifestyle and may explain the focus of participants on healthy foods with their desire for family member to be healthy (Hopkins, 2004). However, the consequence can be an increase in family carer stress and argument. Emma illustrates this when she talks about her attempt to reduce the amount of salt her husband was using.

> *"I was despairing of the salt for a little while um because I know it's not good for him… yeah because I put low salt in and he didn't like it… he went ape"* (Emma)

This mirrors the findings of Fjellström et al., (2010), where the drive for healthy eating resulted in eating-related tasks becoming more stressful, with concern about not being able to provide healthy meals. Rejection by the person with dementia of healthy eating is at odds with the way some family carers chose to eat. This may make it more difficult to ensure both their own nutritional beliefs and needs and those of the person with dementia are met.

> *"…he likes butter, he likes fatty foods…He'll eat the fat whereas I'll leave it."*
> (Emma)

No participant described receiving advice about how to respond to their nutrition ethos of healthy food choice or rejection of this by the person they care for. A desire for support and advice by family carers was highlighted by Fjellström et al., (2010) with more knowledge about how to provide healthy foods for the person with dementia wanted. Although not explicitly expressed by the present study's participants, support around response to their own need to provide healthy food would likely be beneficial. Although few participants received advice from healthcare professionals those that did described this as allowing the person to eat what they enjoyed. This is in direct contrast to the strong nutrition ethos of most participants for healthy food choices. This advice reflects the findings by Hopkins (2004). Although Hopkins (2004) work related to palliative care rather than dementia care, messaging about diet was confusing for family carers with public health messaging promoting healthy eating at odds with healthcare professionals advising individuals to eat as they wish. The present study mirrors this finding.

Agreement about diet and nutritional care between the individual, family carers and if involved healthcare professionals is recommended when using a palliative care lens, seeking to minimise distress of any nutritional interventions in the individual receiving care (Hopkins, 2004). The particular challenge for family carers of people with dementia is lack of scope for discussion about eating and food choice, with changes in eating and appetite often occurring alongside decline in cognitive and executive function and ability to discuss and communicate wishes as shown in the present study data. Further, there would seem resistance within the dementia community to viewing this as a palliative disease.

> *"Very much steer away from that, palliative, terminal and all those words. You know the Alzheimer's ethos is all about living well."* (Julia)

Yet this reflects confusion around what palliation is perhaps due to the evolution of this area of medicine and a lack of consistent meaning. The meaning of palliative care has transformed since it was first used less than fifty years ago (Pastrana et al 2008). The principle goals of palliative care are the "relief and prevention of suffering" and

"improvement of quality of life as a main goal" (Pastrana et al 2008). These fit well with the ethos of dementia care. If palliative care is embraced it could help family carers to feel less driven to provide healthy food and instead focus on maximising quality of life through food and eating, reducing suffering through less beneficial or unwanted nutritional interventions. This may help reduce the complexity of ethical decision-making and challenges whilst alleviating some of the associated distress and anxiety experienced by family carers. It could also enable family carers to receive reassurance and support for the ethical decision-making being made on a daily basis about eating behaviour and appetite, helping to improve their own wellbeing and keep their family member and themselves safe.

7.2   Theme 2: Recognition of the impairment effect of dementia on eating -behaviour and appetite

The present study identified that family carers do not commonly recognise the impairment effect of dementia on eating behaviour and appetite. Although changes in these functions were observed and described by participants when they occurred, connection with dementia being causal was variable. This influenced the response of family carers to observed changes. Not knowing about possible changes to eating behaviour and appetite before they were observed has been previously described by Ball et al., (2015). However, there is little describing recognition of the impairment effect of dementia on these functions. This adds new knowledge to the understanding of family carer lived experiences of eating behaviour and appetite.

7.2.1   Not making connections

Participants often did not make connection between a change in eating behaviour or appetite with dementia. Such changes in these functions not really known about before they were observed.

> *"Appetite wasn't really on my radar…"* (Emma)

Emma recognises how she does not always make connections between changes in eating and dementia.

> *"…but you know sometimes you don't join up the dots"* (Emma)

It likely reflects the lack of information, advice and support around these functions described both in the present study and the literature (Kuzu, 2015, Ball et al., 2015). As Sarah puts it you don't know what you don't know.

> *"And unless you've had experience of it you know as a carer as well as a sufferer you're going through it at the same time. So, you don't know what you don't know."* (Sarah)

A lack of connection between the impairment effects of dementia on ability to eat is identified in the narrative of several participants. Maggie recalls how her husband now needs the crusts cut off bread.

> *"…but with the crusts cut off now a-days. He didn't used to have the crusts cut off."* (Maggie)

When asked directly about the reason for difficulty in managing such textures she responds with it being a "chewing thing."

> *"No, no it's a chewing thing. Definitely a chewing thing. So, anything that's a bit hard, crusty, chewy, either he doesn't eat it or I have to soften it in some way."* (Maggie)

She recognising a change in his eating behaviour but on probing she denies a particular cause for this. She also describes an increase in coughing but again does not make connection with the effects of dementia instead alluding to nuts being the problem.

> *"…he has been coughing more recently and things tend to irritate his throat and make him cough, you know like nuts and things. But he has been worried with a cough this irritating cough for several months on and off and some things irritate his throat."* (Maggie)

Maggie may of course be intentionally declining to make connections or choosing not to articulate these perhaps because it is too of the meaning of these changes for her. She has experiences of relatives with dementia and may be aware that such changes in eating-behaviour represent a decline in health. Acknowledgement of this connection may be too difficult.

The significance of changes in mastication and symptoms of swallowing difficulties also do not appear to be understood by participants in terms of aspiration risk, with variable awareness of interventions which could reduce these risks. Anna demonstrates this as she recalls how only the healthcare professionals were worried about changes in mastication and swallowing ability in her mother.

> *"We didn't worry about it but they did. She started to roll her tongue around her mouth when you feed her, food is going round her mouth and having trouble getting rid of it."* (Anna)

John similarly fails to make connections between his wife's difficulty in managing some food textures and dementia, attributing it to problems with her teeth despite no issues being identified at a recent dental review.

> *"She's started complaining about the granola being hard and lumps and I think it maybe to do with her teeth."* (John)

He also shows no understanding or insight around how dietary changes could make mastication and swallowing easier for his wife. Of interest is his prior description of not needing advice about eating or appetite as he felt able to provide a 'healthy diet' for his wife. This lack of insight and knowledge illustrates why it is important for family carers to be provided with information such that they can more effectively understand the symptoms observed and the options for response.

Sometimes connections with the impairment effects of dementia are complex to make such as in Emma's situation where her husband has type I diabetes, early renal failure and dementia. She states that she thinks it is 'bizarre' that despite not drinking well he was passing lots of urine.

> *"Yeah which is bizarre because at the beginning of September we were struggling to get him to drink anything because he didn't want to drink..."* (Emma)

This is in the context of his blood sugars running extremely high, a symptom of which is passing more urine. His poor drinking may have been due to dementia or reflected the severity of his illness which required hospital admission. On recovery from this episode of illness he resumed drinking without issue and was passing usual amounts of urine

suggesting illness rather than dementia was the reason for his change in drinking behaviour. In a similarly complex situation John interprets his wife's weight gain as a sign he is over feeding, despite noticing she has swollen legs.

"Yeah make sure there's a very good balanced diet – I don't think from that point of view she's deteriorating, I've given her too much cause she's put on weight. Also, her legs are very swollen as you've probably noticed." (John)

He is restricting her portion sizes but her oedema would mask true flesh weight. Such oedema also suggests underlying co-morbidity. It is also highly possible she has lost flesh weight due to restricted portion sizes and is at risk of malnutrition despite increased weight. Julia also does not seem to make the connection between the latter stages of dementia and declining nutritional state.

"And she…ate ok and they tried to give her things that she'd enjoy and she, she ate ok but was losing weight." (Julia)

This was despite her perception that her mother was eating satisfactorily. In much the same way Jo is perplexed by her mother's significant weight loss at the end of her life despite Jo's belief she had a good appetite.

"When she died she was very, very you know, a quarter of the woman that she was err, but her appetite she still maintained a good appetite. Which you know in some ways when I was looking at this right, I sort of still struggle with it about why she lost so much weight because in the end she wasn't active…know she did always like her food right all the way through until the very, very end when she stopped eating." (Jo)

Providing support and information for family carers about the changes in eating behaviour, appetite and weight, particularly as the disease progresses, would likely address some of the concern and distress experienced. The relationship between malnutrition and cognitive decline in dementia is recognised and suggests that as dementia progresses weight loss and reduced nutritional intake can be anticipated (Lopez and Molony, 2018).

Some participants described their family member as being awkward or difficult in terms of eating behaviour and appetite, with seemingly limited insight as to how this might be a result of dementia rather than a deliberate act to be difficult. Matthew interprets his wife's changes in eating behaviour as a reflection of her personality rather than the dementia itself.

> *"Well part of her challenging behaviour was her eating – she'd mess around, put food around, just generally be awkward in all phases. And I used to say that that's probably her own personality because she was very stubborn, she had a firm personality and you couldn't budge her if she'd made her mind up. And I used to think well that's it coming out of her, you know, you could say as much as you like, you know, a naughty child, "Don't do that" and they carry on doing it just to spite you. And there was a bit of that."* (Matthew)

He further interprets this as her way of "spiting him." Whilst this may be the case there is also possibility that this reflects how he feels about her eating behaviour or even dementia itself and the impact it has had on his life. Further, her eating behaviour has changed and is likely due to a combination of factors. Whilst it is good to consider other reasons for changes in eating behaviour as suggested by Kitwood (1997), it is also important not to blame the person for changes which they are unable to control. Discerning this can be difficult for the family carer particularly with limited prior knowledge and poor access to information and support.

Some participants expressed confusion or bemusement around changes in eating behaviours and food-related tasks. Maria cannot understand why her husband is suddenly asking about buying foods they have never eaten before when they are out shopping.

> *"Trevor will go round and say "Do you want this? Do you want that?" Things we've never had in our lives."* (Maria)

She is also confused as to why food previously enjoyed is now being refused.

> *"You've always liked fish and chips so why don't you like fish and chips?"(* Maria)

This reflects a lack of knowledge and understanding about the effects of dementia. Provision of information and support around how to respond to such changes could help reduce the daily, ethical challenges around these functions which family carers experience.

7.2.2 Understanding of changes

Family carer understanding of reasons for changes in eating and appetite in the person with dementia has not been widely explored. The present study findings contribute to greater understanding of family carer lived experiences of these. There was variability in participant understanding of such changes. Maria shows some insight into why changes in these functions might be occurring.

> *"I don't know if that is to do with his dementia or is it to do with his other conditions?* (Maria)

Understanding of the impact of memory issues on eating behaviour were described by Jo and Julia.

> *"I mean I think probably she would have not necessarily remembered if she had had breakfast later on so I think if someone had gone in and presented her with to eat she'd have probably eaten it…"* (Jo)

> *"And I think with mum a lot of it was not remembering to eat you know."* (Julia)

Such insight is helpful for family carers, with opportunity for them to provide appropriate support or prompts to help mitigate for memory changes.

Loss of diurnal rhythm, ability to tell the time or recognition of other cues such as hunger was only described by one participant.

> *"Um they might not have…a clock that they can actually read properly anymore that's increasingly you know what I understand about the condition. You know I might say mum look at the clock you can see what the time is, and she cant. So, I think you know they're looking their cues to time so that impacts that they need a meal to eat let alone appetite. You and I know oh its round about lunchtime so our*

brain is therefore telling us if our stomach hasn't told us first that we're feeling hungry." (Sarah)

Sarah makes further analysis of the reason for her mother's weight loss, connecting ability of the brain to communicate with the stomach. This insight reflects the gut-brain axis previously described in Chapter Two as central to appetite regulation. The combination of not being sure what time of day it is or what to do, perhaps due to a decline in memory, cognition or executive function is a further explanation made around why someone might not eat well.

"I guess if you're feeling like you're not sure what time of day it is and finding it quite stressful about what am I going to eat now? What have I got in the fridge?" (Sarah)

Sarah also cites the stress of living alone as a further reason for weight loss.

"But what I do know is that she lost a huge amount of weight. And I think that was partially just well I think it was mainly the stress she felt of living on her own. And that affected her appetite and she just wasn't hungry." (Sarah)

Whilst stress could certainly impact appetite so can loneliness being a factor associated with malnutrition risk and may have been a contributing factor for Sarah's mother (Ramic et al., 2011). Ability to make such connections with the effects of dementia on eating behaviour and response to appetite may alter the response of family carers to changes in these functions and the support they provide. This enabled understanding that it is likely the effects of dementia and not the individual being difficult resulting in changes in these functions.

Change in ability to prepare food or cook were understood by some participants as resulting from the effects of dementia. Maria's husband was the primary cook before dementia yet now struggles to make a sandwich. She understands this is due to his loss of understanding about this process of sandwich making.

"But he couldn't understand what the other slice was for… He was confused over what's coming next… understand the process of how to make a sandwich or boil an egg or anything." (Maria)

Similarly, Matthew recognises a loss of understanding as the reason for his wife needing support with eating.

> *"...she will feed herself with a spoon she doesn't seem to know what it was. But now she can turn it upside down and let it fall."* (Matthew)

This further demonstrates how some family carers can make connections between the effects of dementia and changes in eating behaviour and appetite but understanding of this was variable. Understanding and recognition of the impairment effects of dementia on eating behaviour and appetite will influence family carer response to changes.

7.3 Theme 3: The cost of eating and appetite for family carers

The present study identified three costs to family carers of eating and appetite in dementia being financial, relationships and personal. This is the first time such costs have been clearly described in relation to family carers lived experiences of eating behaviour and appetite in dementia, contributing new understanding and knowledge. The literature commonly describes costs to family carers of people with dementia in terms of physical, emotional, financial and social burden, with detrimental effect on physical and mental health (Connell et al., 2001). Discussion of the need to reduce the cost for family carers around nutrition is only made in the context of burden and nutritional interventions (Jansen et al., 2015). It is important to consider costs of eating behaviour and appetite as appetite is described as one of the top three most intense symptoms of dementia determined by family carers as assessed by frequency and severity of symptoms (Fauth, 2014). This sits alongside motor behaviours and apathy with both having potential to impact eating behaviour and appetite.

7.3.1 Financial cost

The financial cost of family caring is well described in the literature and includes costs of unpaid care, equipment and services (Stommel et al., 1994, O'Shea 2003, Brodaty and Donkin, 2009, Prince et al., 2015). The financial cost of provision of nutrition is also discussed by Mole et al., (2019) but from a healthcare professional perspective with reference to meal delivery service and support for people with dementia during mealtimes. However, the financial cost in terms of eating behaviour and appetite for

family carers has not been presented. These are described by participants as pertaining to the cost of adaptions to support both independence and safety with eating.

A need for adapted cutlery and cups to support independent eating and drinking.

> *"…got her the ones with the big handles err and got plate guards so that she was able to still feed herself."* (Jo)

These had to be purchased by the participant without scope to try them first to see if they were beneficial.

> *"I sent off for cups with spouts, tried special cutlery…"* (Anna)

When asked about the cost of these and whether the NHS should be purchasing them most participants seemed pragmatic about covering the cost. This may reflect the socio-economic demographic of the participant group and scope for how carers allowance could be used. The main irritation reflected by participants relates to inability to purchase small numbers of items.

> *"At the time probably fair to say yes I do think it was a grey area because we used the attendance allowance for things…so we could get things for her and I sometimes think it's the simple things like, like they'd be in a pack ,the spoons and the type of cutlery would be in a pack of ten or twenty so we had to buy that. We couldn't just buy one or two. But, but the difference it made for her as far as we were concerned we were happy."* (Bob)

For participants being able to support the person with dementia seemed to be more important than the financial cost. Jo reflects that if she had persisted she may well have been able to have these items from the NHS but was happy to provide them.

> *" I'm sure if err we pushed hard and long enough but we just provided them"* (Jo)

The financial cost of the items needed was high compared with normal items particularly because of needing to purchase a large pack.

> *"…she had the special dysphagia spoons, which cost the earth like sixteen pounds…there was a special dysphagia cup and I think that was about six or seven pounds."* (Bob)

Bob was the only participant to purchase pureed ready meals as he struggled to cope with making these at home being happy to use attendance allowance for this.

> *"It was a trade-off and as far as I was concerned the attendance allowance…I had I used to think that was going to be used for those sort of things. I could have a meal for two pound thirty-five which was a ready meal. Hers would cost four pounds sixty-five so that was quite a change."* (Bob)

This study describes a financial cost for family carers in providing adapted equipment to support independent feeding or changes in dietary need. Financial security and ability to manage dietary changes in the home will influence the impact of this cost on family carers. This relates to the 'vicious cycle of dementia and nutrition' where financial status is associated with poor nutritional intake (Paul, 2020). Using the findings of this study poor financial status could limit scope to purchase adapted equipment and ready-made meals of required textures, negatively impacting nutritional intake of the person with dementia (Figure 16).
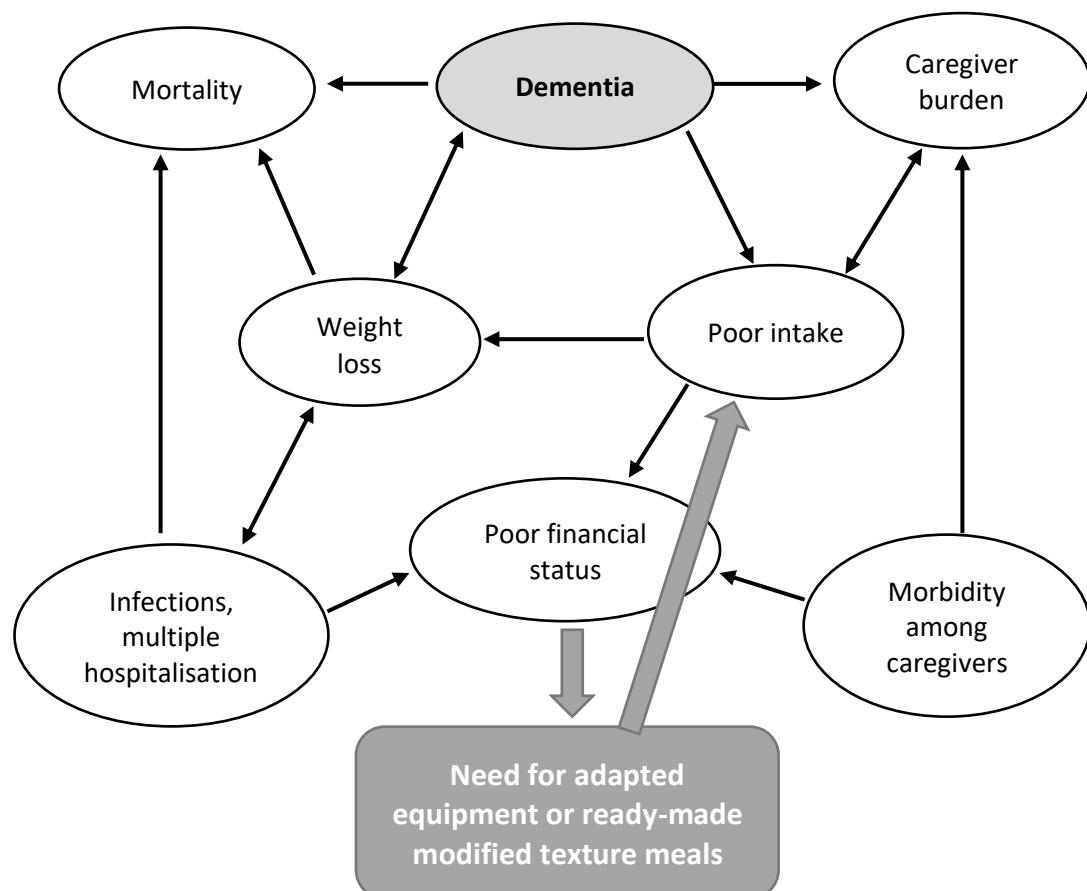

Figure 16 Vicious cycle of dementia and nutrition adapted from Paul (2020)

This adaptation of the vicious cycle of dementia and nutrition by Paul (2020) presents new insight into family carers lived experiences of eating behaviour and appetite in dementia. Financial status is therefore implicated in the daily ethical challenges family carers experience about eating behaviour and appetite.

7.3.2 Cost to relationships

The cost to relationships of eating behaviour and appetite is recognised in clinical practice with many participants describing eating, cooking or food choice as a source of tension or argument between family carer and person with dementia.

> *"…we'd have a shouting match in the kitchen…Trevor your making a terrible mess in the kitchen, which was out of character. Why are you putting all that oil? That's not healthy? Or whatever it was and you're putting the oven on wrong and leaving the oven door open…"* (Maria)

However, was perceived by some in spousal relationships as part of normal life.
> *"It's normal married life."* (Maria)

Of note is that the finding that the cost to relationships of eating behaviour and appetite was different for adult-children compared with partners. This presents new knowledge. For adult-child family carers there was a sense of the relationship moving from parent and adult-child to child and adult-child. Sarah describes the impact of altered eating behaviour and ability to manage food related tasks on her relationship with her mother.

> *"Um it's not great. (Tearful)…It is, it's like having a third child especially as my children are just coming out of that, just and are able to ultimately feed themselves and not cook meals clearly but becoming more and more independent."* (Sarah)

Mother-daughter relationships in the context of dementia are described as being task orientated or emotion-based which if applied to eating behaviour and appetite would primarily be described as task orientated (Ward-Griffin et al., 2007). However, this study has shown an emotional consequence of such task orientated relationship for adult-children in this context presenting new understanding. The cost for adult-children of eating behaviour and appetite relates to loss of a parent adult-child relationship and is a

paradigm which could be used to better understand family relationships in the context of dementia care.

7.3.3   Personal cost

Personal costs of eating behaviour and appetite were identified in the present study as a change in role, damage to home and loss of freedom. This has not been well described in empirical studies adding to greater understanding of family carers lived experiences of eating and appetite. Change in roles in relation to food related tasks has been described in the literature as a move to becoming 'cook' (Mole et al., 2020). Such change can effect sense of identity with personal cost (Calastani et al., 2007). All participants had a change in role whether that was becoming 'cook' or taking on new roles in addition to already being 'cook.' Maggie describes 'traditional' gender roles with the need to now take on new tasks but is finding this difficult. She also mentions how as a result she is increasingly reliant on ready-made foods as she no longer has the time for the same amount of home cooking.

> *"…feeding the family that sort of stuff that was my role…George did all the men's things… which have now been passed over to me which I've struggled with and you know, yes, coming to grips."* (Maggie)

In contrast Marie admits to being a terrible cook but with the decline in Trevor's function she is learning to cook with Trevor's advice. She sees this more as a role reversal than taking on both of their roles.

> *"…he's me and vice versa…He had to show me how the oven worked because it's a grill in one switch and an oven in another..."* (Maria)

This illustrates the importance of not assuming gender roles in relation to food related tasks and the differences in perception or experience of this. It might be more helpful for focus on understanding how dementia has effected provision of food and any support needed for new roles.

Whilst not commonly described in the participant group nor in the literature eating behaviour was associated with personal cost to Anna due to damage to her home.

"Um, If I did shout at her, y'now, you can't help it sometimes she did used to pick up on it and say, oh don't shout at me. And then I'd go off in the kitchen and have a bit of a cry because oh, what did I do that for? It was just a natural reaction to seeing someone throwing a cup of tea on the carpet." (Anna)

Anna describes her reaction with similar frustration at changes in eating behaviour also described by family carers of people who have had a stroke or traumatic brain injury (Johansson and Johansson, 2009).

The personal cost of loss of freedom of choice to socialise as a result of eating behaviour in those with dementia is identified in the present study. Some participants felt no longer able to go out to eat or attend social events with meals.

"We used to go out at least once a month, always go and have our dinner in a pub… during that difficult period, we didn't really go out. It wasn't worth it because it would be too difficult, she'd be too awkward…We've got some good friends that we used to sort of have dinner parties…all that stopped." (Matthew)

Loss of socialisation a recognised problem for family carers but not well described in the context of eating behaviour (Kuzu et al., 2005, Brodaty and Donkin, 2009). Eating behaviour was also found in the present study to bring a personal cost of loss of time due to the amount of time needed to support feeding. Matthew describes supervision of eating an increasingly long task.

"…about half an hour sometimes instead of five minutes…I sit with her…she chews and chews and chews. Takes her time." (Matthew)

Having carer support for this task frees Matthew's time removing this personal cost.

"I mean if I don't do it the carer will if they're here, and sit and have a drink and help feed her and let me get on with other things." (Matthew)

Maggie similarly reflects on how her husband now eats much more slowly with meals more time consuming.

"George eats far more slowly now…We sit down and news is on and its (the news) usually finished so getting on for an hour, three quarters of an hour I would think." (Maggie)

She has adapted her own eating to accommodate George's change in eating behaviour but this also comes at a personal cost of not being able to eat as she would normally.

"I'm very conscious now of time and I try not to gobble my food so I'm trying to slow down, but I'm still finished long before George." (Maggie)

Emma also experiences protracted meals when she is able to eat with her husband but describes this in the context of leaving him to continue eating on his own.

"…we'll finish way before him. Like he can sit up there for 40 minutes eating." (Emma)

These three examples present different response to the personal cost of loss of time due to changes in eating behaviour and the way in which family carers experience the daily ethical challenges of eating behaviour and appetite in dementia.

7.4   Relating findings to theory

The subordinate themes of this study relate directly to the hierarchy of family carer needs in dementia (Figure 17) (Pini et al., 2018).
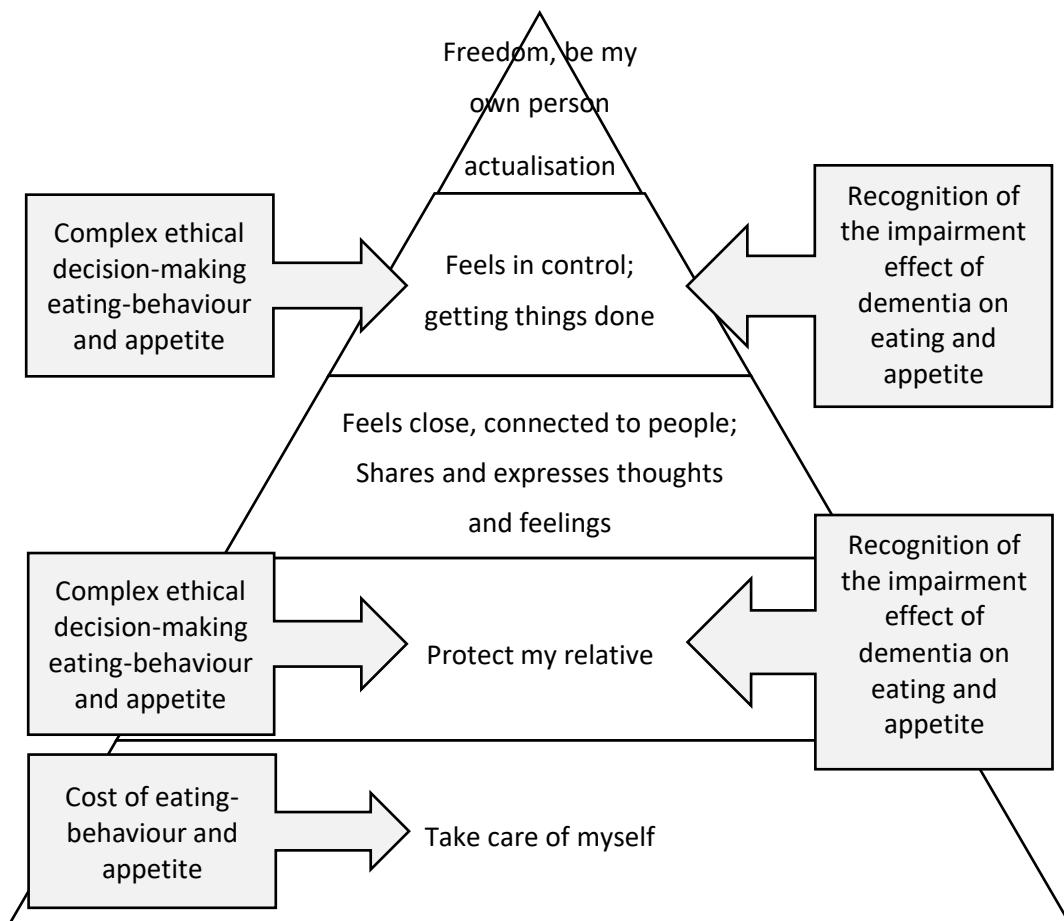
Figure 17 Family carer needs in dementia adapted from Pini et al., (2018)

Taking care of oneself can be impacted by the cost of eating behaviour and appetite. The drive to protect the relative requiring care is challenged by complex ethical decision-making around eating behaviour and appetite and recognition of the impairment effect of dementia on these functions with similar impact of these findings on feeling in control and getting things done. Help to recognise the effect of dementia on eating and appetite and respond to changes would help to better meet family carer needs. Further, improving knowledge about why decision-making about eating and appetite can be complex may similarly be beneficial.

Daily ethical challenges of eating and appetite in dementia is the essence of family carer experiences of these functions. It is possible to apply this to the model of consequences of unmet need which is continues results in the person with dementia requiring residential care (Figure 18) (Schölzel-Dorenbos et al., 2010).
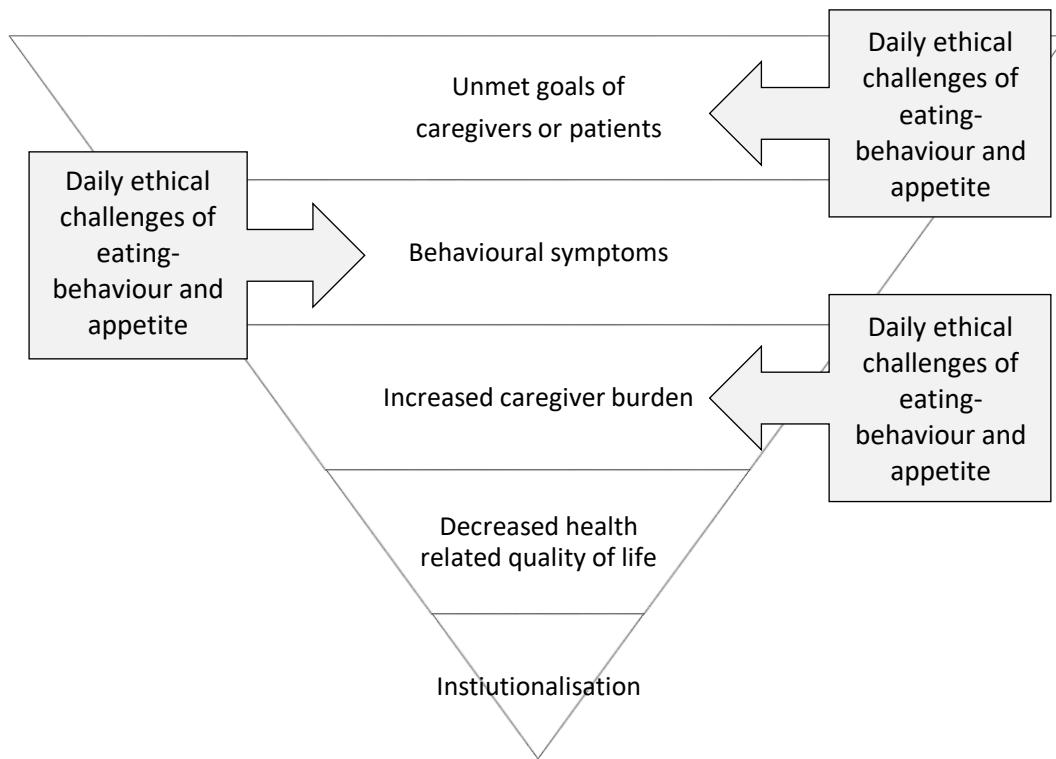
Figure 18 Model of the consequences of unmet need in dementia and effect of daily ethical challenges of eating behaviour and appetite adapted from Schölzel-Dorenbos et al., (2010)

Daily ethical challenges of eating behaviour and appetite in dementia can impair the ability to meet the needs of both caregiver and family member requiring care. Participants described the need for constant thinking, ethical decision-making and consideration of cost of these functions, making judgements and balancing the needs of the person with dementia with their own personal needs. This results in daily ethical challenges around these functions. Similarly, behavioural symptoms, specifically eating behaviour of the person with dementia can contribute to daily ethical challenges for those providing care and increase caregiver feelings of burden. Using this model ability to respond and adapt to the daily ethical challenges of eating behaviour and appetite in dementia will likely influence ability of the family carer to continue in this role (Schölzel-Dorenbos et al., 2010). The study demonstrated variable understanding of the impairment effects of dementia on eating and appetite, and a lack of participant knowledge around signs, symptoms and consequences of imparied eating. Limited support and advice was also noted, with lack of insight from some participants about the benefits of adapting diet as changes in eating and appetite occurred. Whilst many participants demonstrated remarkable resourcefullness and resiliance, better support and

advice could help reduce the daily ethical challenges around eating and appetite which they face. In this way, it is possible that both family carer needs and those of the person with dementia could be better met and care at home more likely to continue.

7.5   Chapter summary

This chapter presents new knowledge about family carer lived experiences of eating behaviour and appetite in dementia. The essence of family carer lived experiences is one of daily ethical challenges, with complex ethical decision-making around response to change in these functions. Ability to recognise or understand the effect of dementia on eating behaviour and appetite is variable, with family carers at risk of financial, relational and personal costs in relation to eating behaviour and appetite in dementia. These can influence response to changes in these functions and ultimately how well family carers and the person with dementia's needs are met. Chapter eight presents the strategies participants used in response to changes in eating behaviour and appetite and their description of these functions.

Chapter 8   Family carer strategies and descriptions

This chapter presents the findings of family carer strategies in response to changes in eating behaviour and appetite in people with dementia and their description of these functions. This meets study objectives two and three:

- To explore strategies employed by family carers in response to appetite and eating in people with dementia

- To discover how family carers describe appetite and eating in people with dementia

The strategies identified in the study comprise of six themes:

- More cutting down calories than keeping them up
- Eating together
- Pictures and prompts
- Eating adaptions
- Drinking adaptions
- Supervising or taking over

Such family carers strategies to changes in eating behaviour and appetite in dementia are not well described in empirical research. These therefore contribute new insight into this phenomenon.

8.1   More cutting down calories than keeping them up

Unexpected emphasis on healthy eating and weight gain as opposed to poor appetite and weight loss were identified from the present study's data. Whilst poor food intake is cited as a common problem for those with dementia, it was not often described within a context of provision of a 'healthy' diet (Keller et al., 2015). Changes in appetite were also described by participants with experiences of hyperphagia, desire for perceived unhealthy foods and reduced appetite. Bob was the only participant to focus on calories which perhaps provided a tangible way to check if 'enough' calories were given and therefore 'good care' provided.

> *"…and the important things was to keep her calorie count up…"* (Bob)

None of the participants talked about the need for food fortification or approach to maximise nutritional intake, with limited use of ONS described. Two participants were 'vigilant' around the amount of food consumed, checking or watching to ensure food was eaten

> *"I'll be fair I was checking up on them (paid carers), sometimes they needed checking up on."* (Jo)

> *"I will hang around a little bit so I'm so there and can see that she has eaten a little bit."* (Sarah)

Strategies of coercion and negotiation around eating were used by Marie when her husband declined to eat, with little description of this approach from other participants.

> *"If he says he doesn't want to eat I would say well, just have some crackers then… Or I'll say ,let's have an omelette. I've got some mushrooms I'll do you an omelette. Or some eggs. That's if he doesn't want to eat."* (Maria)

Although an increase in appetite, particularly for sweet foods, was described by several participants there was only one who with experience of hyperphagia. Anna's mother searched for food, took bites out of what she found and consistently asked for food regardless of how often or how much was provided.

> *"…excuse me can I have something to eat 'por favor'…so I sat there with my phone one day timing how many times she'd say it. And it was literally every 30 seconds."* (Anna)

Anna left a tray with snacks of food she knew her mother liked so that she had constant access to food but this had little impact on her repeated requests.

> *"…I bought a little mini tray and always had something on that with a biscuit or cake or banana and that was there all day."* (Anna)

Of note is that Anna did not talk about a need for her mother to lose weight, despite her constant desire to eat.

Responses to desire for perceived unhealthy foods were seen as more successful, perhaps because of the degree of control participants had over the person with dementia's access to food. Limiting portions or monitoring the amount eaten was one approach described.

> *"… I limit (crisps) to a small handful… it's a case for hang on for the sugar on the shreddies (Laughs), half a teaspoon please…"* (Maggie)

Such restriction of food is also seen in the literature (Ikeda et al., 2002). Some participants used their personal views about food as a measure for the amount of unhealthy food allowed.

> *"I'm aware I don't want to eat too much salt so I do want to limit the amount of crisps and sugary things which George eats."* (Maggie)

John simply reduced portion sizes for his wife in response to him perceiving she had gained weight.

> *"…and I've cut down on her food a bit..."* (John)

No participant described the reverse of increasing portions in an attempt to help weight gain. A more creative approach to managing appetite for less healthy foods is used by Emma where she increases flavouring in the food as a way to minimise excess use of salt.

> *"…and I thought maybe he needs more flavouring…So, I've done some meatballs…which I've put garlic in and some paprika in there as well and a bit of mixed herbs just to give it more flavour so that maybe he doesn't need to add the salt."* (Emma)

Adding salt and other seasoning to food is described in the literature, particularly for those with Alzheimer's disease, reflecting altered appetite as a result of taste changes, loss of taste or smell (Kai et al., 2015, Ikeda et al., 2002).

8.2   Eating together

Eating together is a recognised approach to improving eating in older people, with the present study has showing this to be beneficial in dementia (Silva et al., 2013). This approach has previously been suggested as an effective strategy for improving the amount of food eaten in those with dementia (Keller et al., 2015). However, Mole et al.,

(2019) suggest more evidence is needed to demonstrate the benefit of social interaction in supporting people with dementia to eat. The present study provides such evidence, contributing to improved understanding of the benefits of eating together on nutritional intake in dementia. Sarah's mother's consumption of food improved when meals were eaten together, where prompting and encouragement from the family could be provided.

> *"Her appetite came back massively so she might sometimes say oh I'm not really hungry and she's said that countless times with us but I can guarantee you she will sit and eat, when she's sitting as a family."* (Sarah)

Eating together also provided opportunity for mirroring of behaviour which could support independent eating.

> *"I always remember that speech and language therapists…used to say that that was quite important for her because she could then replicate the way I was eating."*
> (Bob)

Socialisation was also identified as benefiting eating.

> *"And it always helped when we were sitting with her cause that was another thing is that social thing, she'd eat better whilst sitting with other people…"* (Julia)

8.3   Pictures and prompts

Prompts and pictures were used by some participants to aide contribution to meal related tasks. There is little prior research describing family carer use of these in the home setting and in this way contributes to new knowledge. Such lists and pictures to aid memory were found to be limited in their usefulness by a decline in recognition and understanding of words or pictures. Maggie describes how George now finds it difficult to undertake routine tasks even with the lists she provides to prompt him.

> *"I've written out lists so George knows, err, so there is a list of what to put on the table at lunchtime and breakfast time and dinnertime."* (Maggie)

I only observed the pictures on the kitchen cupboards as I was leaving the interview with John. I had sat at the kitchen table with my back to the cupboards and noticed them as I turned to leave. On asking John about them he said they had been helpful but Mary could

no longer recognise them. However, this alongside use of written prompts would offer useful interim approaches to support people with dementia in undertaking food related tasks.

Prompting to eat and drink was used by most participants with varying impact. Anna for example reminded her mother to drink each time she walked past her but this did not always result in her mother actually drinking.

> *"You'd walk past and say mum drink your tea and she'd say I am I am and you'd come back a few minutes later and say drink your tea."* (Anna)

Routine and familiarity were strategies which participants found helpful when eating was impacted by memory issues. Maggie used this approach which perhaps added a sense of control around her responses to the tasks required of her as a carer and sole decision-maker.

> *"…we still try to have meals the same times each day and keep to a regular routine… the meals are very similar to what we've always had."* (Maggie)

Sarah identifies further benefit of having a routine around mealtimes, with her mother using breakfast as a prompt to take her tablets.

> *"…and she's been good with her breakfast because she knows that's when she has to take her pills as she has to take them with food. She has totally lodged that in her memory."* (Sarah)

8.4   Eating adaptions

The present study identifies a range of family carer responses to changes in eating behaviour in dementia. There is little empirical research about this, with the present study contributing to evidence for practice. Having meals delivered to family members with dementia living alone was found to be helpful until dementia symptoms progressed making reheating and eating meals difficult. Sarah describes this, with deliveries of frozen meals working well for her mother until her condition deteriorated further.

"…she was getting um Farm foods, the readymade frozen foods um and that worked ok for probably I don't know 4 or 5 months." (Sarah)

Sarah was living away from her mother at the time and perhaps did not recognise how dementia might impact ability to remember to reheat meals or eat. The first "she" in the quote could then refer to Sarah or her mother as Sarah herself perhaps felt relief at the idea her mother was getting a "good meal."

"..she knew she was getting a good meal." (Sarah)

Adaptations to support independent eating are described by participants and include cutting up food to make it easier to pick up, or using adapted cutlery and plates. Cutting up food made it easier to pick up with the hands or a spoon.

"…toast in the morning and I cut that up into little inch squares and she can pick those up and eat them…We cut it up small so if she has a spoonful it's a mix of things." (Matthew)

In contrast, the benefits of adapted cutlery and plates were variable. Whilst Jo found these were effective in supporting independent eating for her mother, others felt these brought little benefit.

"…got her the ones with the big handles err and got plate guards so that she was able to still feed herself." (Jo)

"… tried special cutlery which didn't work as she wanted to hold her knife and fork properly which didn't work." (Anna)

Previous findings describe how caregivers want to promote autonomy around food choices but recognise there is sometimes a need to step in (Keller et al 2006). This was the case for some participants when spoon-feeding was required.

"…use a fork to feed her." (Matthew)

Anna describes how her partner supported spoon-feeding her mother, being an important factor in her being able to continue providing care at home.

"…so maybe one of us might start giving her breakfast while the other one eats there and we'd swap over it just depends. That's how we coped with it." (Anna)

Some participants described the need for modified texture foods including liquidised meals. In Anna's case this was without healthcare professional advice, reflecting a need for creative adaptation to changes in eating behaviour.

*"…then we started to have to liquidise everything…yes we even had to liquidise porridge as there started to come a time where she didn't like texture in her mouth and any grains." (*Anna)

However, when Bob was advised by healthcare professionals to provide pureed meals for his mother he struggled.

"I didn't even know what puree foods were to start with. She'd had thickeners that she had to put in all her drink and food which we did, which the GP had put for us and ….err I didn't get on with the blender when I went to use it for the first time and that's when the speech and language therapist came round and brought us a booklet from a company that were a well-known company that did puree foods…they didn't look appetising…they look more appetising now but…she ate well." (Bob)

As a result, he bought ready-made puree meals and when they went out to eat asked the chef to mash up the food for his mum.

"… people were very good to us they'd mash the vegetables up if we asked…" (Bob)

Pureed and mashed foods differ in texture and are not normally interchangeable when managing dysphagia. Bob's differing descriptions of the textures his mother ate may reflect changes in treatment advice or a lack of understanding about what was needed. Anna did not find it difficult to cook and puree foods but did express how this was time consuming. As a result, she would batch cook pureed food helping save time or sometimes used tinned soup.

"I did use tinned soup as back up." (Anna)

Finally, one participant described cutting up food to help minimise the mess associated with eating.

> *"…it's much better to cut it up otherwise it gets spread around or not eaten."* (John)

Very few participants mentioned mess around eating and no one else described strategies to manage this.

8.5   Drinking adaptations

Participant responses to changes in drinking behaviour had varying degrees of success. Use of straws and beakers were trialled. John found them of no benefit whilst Julia felt they were helpful in improving fluid intake.

> *"…that's what those things on the table are for (points to large drink containers with straws filled with water) that's mine and that's hers"* (John)

> *"And it was like we tried straws and we could see the liquid going up"* (Julia)

Bob describes how using straws also supported 'safer' drinking.

> *"When we used to go out and about we used to have straws at one time so she wouldn't drink too quickly. Then we got special drinking cups with spouts on them…"* (Bob)

The success of using beakers seemed to be dependent on participants feelings about these. Julia felt beakers were not helpful for her mother and found them reminiscent of those used for young children, being interpreted as degrading or embarrassing to use.

> *"…beakers, I didn't like them because they just remind me so much of toddler drinking that absolutely…(Pauses)…The look on her face when I gave them but she didn't say but I felt it. Whether I was projecting my feelings on to my mum I couldn't be absolutely sure…"* (Julia)

In contrast Anna found these helped her mother.

> *"Um and with the beaker it was better as she could drink better with a beaker than she could with a cup."* (Anna)

Using carers to prepare drinks was another approach used. However, carers were not around in the home all the time to prompt drinking.

> *"…they would prepare drinks for her. I mean she couldn't do it on her own you know."* (Jo)

The strategies which seemed to be most effect with regards to hydration were regular prompting and trying different types of drink. Anna describes how her mum went from being good at drinking tea to forgetting to drink.

> *"In the early stage of her being here she was really good. She'd drink tea and she'd be really good. But then tea started to get really difficult and she'd leave I and forget it's there and stop drinking."* (Anna)

She began prompting her regularly to drink and experimented with different types of fluids. Changing the type of drink offered seemed to be helpful, with a preference for cold drinks identified by some.

> *"So, I started to give her squash and she drunk that."* (Anna)

Anna, like Emma, found that a cold drink seemed to be more readily accepted than tea.

> *"…an icy drink in or I'd buy him a fizzy low sugar drink up there because it was cold."* (Emma)

This change in preference for fluids to cold, sweet drinks has previously been identified (Kai et al., 2015). Emma also sought fun approaches to encourage drinking turning it into a game.

> *"We tried to make a bit of a game of it which sounds quite childish but he is quite childish."* (Emma)

A couple of the participants talked about alcohol. Emma's partner needed to stop drinking because of the medication he was on but he persisted in wanting to drink. She therefore removed all alcohol from the house.

> *"So, we had to throw all the alcohol out"* (Emma)

She used deceit to manage his repeated request for a drink, with acceptance of the non-alcoholic beer described.

> *"We got him a non-alcoholic larger 'oh lovely pint.'"* (Emma)

8.6 Supervise or take over

The decision-making around independence, supervision or taking over food related tasks has been discussed in the context of the need to 'keep safe' (Chapter 7). This represents a factor in complex ethical decision-making. Concern around safety in relation to using the cooker was identified by several participants, with supervision one approach to manage this perceived risk.

> *"I can't leave Trevor because he'll leave the oven on."* (Maria)

Anna felt that when her mother lived with them she was unlikely to try and use the cooker, as she would not know how to.

> *"I think because she was in a place where she didn't know how to work anything she didn't try to put the cooker on or anything anyway so you can lock the cooker."* (Anna)

Locking or disconnecting the cooker was deemed necessary by adult-children when the parent with dementia was viewed by them to no longer be safe to access a cooker when alone.

> *"…there became some risks around that so we did get the cooked disconnected."* (Jo)

However, Jo perceived there was less risk using a microwave.

> *"She was ok with the microwave. You can do a little less harm with a microwave than a gas cooker…"* (Jo)

Such concern about safety with regards to cookers is not unfounded, being one of the more common risks for people with dementia described by healthcare professionals (Taylor et al., 2018).

Taking over was an approach used by participants to reduce perceived risk in the kitchen.

"She would leave pots on the hob. That's where I took over the cooking." (Matthew)

"I interfere fairly heavily even when things are straightforward." (John)

Others chose to swap roles to help mitigate risks yet enable involvement in food related tasks.

"He does the washing up which I did and now I do the preparation of the food." (Maria)

These findings suggest that despite a lack of knowledge or information about strategies around changes in eating and appetite, family carers are resourceful and resilient in adapting to support their family member with eating and keep them safe when engaging in meal related tasks. A trial-and-error approach helped identify effective strategies to support independence with eating and drinking. These findings add new insight to the understanding of family carer lived experiences of eating and appetite in dementia.

8.7   Family carer description of eating and appetite in dementia

Exploration of family carer description of eating and appetite in dementia is relevant for improving communication between family carers and healthcare professionals. This has not previously been well described in empirical research and presents new knowledge. The concept of 'discourse' or language is the penultimate fraction of the life-world and considered as part of the development of thick participant data (Ashworth, 2016). It requires the researcher to reflect on the words or phrases used to describe phenomena, with language being an essential part of phenomenology (Reeder, 2009). Kai et al., (2015) summarise changes in eating and appetite as appetite changes, food preferences, eating habits, swallowing disturbances and 'other symptoms.' The present study identified that whilst some participants did explicitly describe changes in eating and appetite in dementia, most implied or inferred changes by describing observations. The latter is of particular importance for healthcare professionals to note, helping them recognise and understand what is happening. Participants did not seem to particularly understand swallowing or mastication disturbances which can occur as a result of dementia despite describing the need to chew a lot or coughing on certain foods.

As was anticipated, a range of words and phrases were used to describe appetite and eating as the following examples demonstrate:

- Appetite: *appetite increased, her appetite came back massively, appetite not there*
- Eat: *ate better, never been a big eater, picky eater, eat half of it, never ate as well, normally eat anything, don't think I know of anything she wouldn't eat, wanted to eat all the time, happy to eat, not remembering to eat, she's forgotten she's eaten*
- Food: *Loved her food*

Comparison of the language used by participants with that of academics and healthcare professionals is interesting (Keller et al., 20016, Ikeda et al., 20020 and Kai 2015). Appetite is commonly used by professional groups but was infrequently used by participants, with preference instead for qualitative and quantitative descriptions of eating and food. Descriptors of how much was eaten, surrogate measures of appetite through weight change, or observed changes in the way the person looked were also used by participants. Although body weight is a common factor for assessment of nutritional state, it is not generally used by healthcare professionals or researchers as a surrogate to describe changes in appetite (Keller, 2015). Adequate nutritional intake was implied by both Maria and Anna in this way:

"I think it's (weight) level enough." (Maria)

"Surprisingly her weight stayed pretty stable" (Anna)

For Anna, her mother's weight being stable was surprising to her in light of her persistent asking for food and desire to eat. Sarah, Maria and Julia all state how the person they cared for had lost weight. Sarah uses the exact words of "lost weight" in the context of her mum not eating enough, whilst Maria describes the amount of weight lost. Sarah is unable to quantify how much weight was lost using a descriptor of "huge."

"But what I do know is that she lost a huge amount of weight. (Sarah)

Julia's description is interesting. She is the only one who describes weighing her mother.

"…so, we did weigh her as often as we could…" (Julia)

Yet, rather than use the word weight, the effect of the weight loss she sees in her mother is used.

"But you know I could see it in her clothes, you know, you could instantly see" (Julia)

The decision to describe the visual changes in her mother perhaps reflects the power this has as a physical reminder of dementia, and the meaning of this for Julia. Thus, the meaning of words used to describe changes in eating and appetite could provide insight into the psychological impact of such changes on family carers. Careful listening to words and phrases enables insight into not only changes in appetite and eating in the person with dementia but the impact on the family carers. This could provide opportunity for healthcare professionals to follow-up on what is being said and offer support.

The prevalence of inferred changes in appetite was surprising, with description of what was seen with regards to weight or how well clothes fitted:

- *Level enough, weight stayed pretty stable*
- *Put weight on*
- *Lost or losing weight*
- *Lost 2 stone*
- *See it in her clothes*

Such descriptors provided clues as to what is happening with eating and appetite. Changes in appetite were also described through food preferences although these were not as frequent as anticipated.

- *Love for sweet things has increased*
- *Always liked sweet food*
- *He doesn't drink tea any more*
- *He never used to put salt on his food*

An increase in appetite for sweet foods was the most prevalent finding.

"…always liked sweet food but that became even more so." (Julia)

This mirrors the literature where preference for sweet foods, particularly in those with Alzheimer's disease and frontotemporal dementia, is described (Ikeda et al., 2002, Landi

et al., 2016). Emma noticed how her husband was adding salt to his meal, feeling this resulted from a change in his taste.

> *"The amount of salt he puts on his food. He never used to put salt on his food…he, he puts so much salt on his dinner."* (Emma)

Maggie and Emma observe changes in tase with an altered preference for hot drinks.

> *"…and that's another thing George actually increased coffee, loves coffee! …He always used to favour tea…"* (Maggie)

> "…he used to drink tea and he doesn't drink tea anymore." (Emma)

Altered mastication or swallowing was described by participants using the words coughing and chewing:

- *He has been coughing more recently and things tend to irritate his throat*
- *She used to cough a lot and we used to be worried she'd choke*
- *A bit hard, crusty, chewy…he doesn't eat it or I have to soften it in some way*
- *She chews and chews and chews*

Swallowing disturbances were not explicitly mentioned by participants, although an increase in coughing, a need to continually chew food or changes in food texture were described. However, as discussed in Chapter 7, association of these with risk of choking or a need for dietary changes was not always made by participants.

Some participants perceived that for their family member eating was a pleasurable experience, using the words love or happy. Such descriptors are rarely seen in academic discussions where reference is made to low mood, depression or apathy instead (Keller et al., 20016, Ikeda et al., 20020 and Kai 2015). However, is worth noting that these positive terms (love, happy) used by participants did not always mean the effect on eating was perceived as positive by family carers, with difficult eating behaviours described in the same context. Julia describes the effort she would go to cooking food her mother loved but then only half would be eaten. This led to some level of frustration.

"So, I'd cook, she loved roast potatoes, and a piece of chicken… used to eat half of it…" (Julia)

Challenging eating behaviour is only explicitly described one participant.

"Well part of her challenging behaviour was her eating…she'd mess around, put food around, just generally be awkward in all phases." (Matthew)

However, Emma and John both describe what could be considered challenging behaviour when listening to their tone of voice.

"What I noticed, everything I gave him he didn't like." (Emma)

"She was very faddy…" (John)

Matthew expresses exasperation again through his tone of voice on the occasions his wife refuses to eat.

"…you can stick the spoon there but she won't open her mouth." (Matthew)

The data suggests that family carers express challenging behaviour by describing what is happening or infer this through tone of voice rather than using the words challenging or difficult.

8.8   Chapter summary

This chapter describes the strategies family carers use in response to changes in eating behaviour or appetite, and the words and phrases used in relation to these changes. Family carers find their own ways of responding to changes with ability to be resourceful, adapt and reflect on the success of a strategy. Some strategies are mirrored in the literature with such congruence providing assurance of trustworthiness and credibility of the present study findings, both being measures to assess quality of qualitative research (Shenton, 2004, Patton, 1999). Family carers descriptions of what they observe in the person with dementia, context, language and tone of voice all offer insight into eating and appetite changes. Such insight into the way family carers talk about and approach eating and appetite is helpful for health and social care professionals, particularly when considering how best to communicate about this issue. These findings are complimentary

to the findings of Chapter 7. Chapter 9 presents family carer lived experiences of support and information around eating and appetite in dementia.

Chapter 9 Family carers lived experiences of support and resources

This chapter focuses on the findings to answer study objective five - explore family carer views and lived-experiences of resources and support relating to appetite and eating in dementia. Participants were asked if they had received any advice, support or information about eating, appetite, nutrition or diet to support them in their family carer role and how they would access this if needed. They were also asked what advice they would give to other family carers of a person with dementia, what advice support or information they would have liked, and when this should be provided. The findings in relation to these questions are summarised as the following themes:

- Nutritionally I was given absolutely no advice
- Just talking to others is a help
- Have some ice-cream and just enjoy
- An informal, holistic approach is wanted
- Signposting for when things get difficult

Although the questions involved asking about advice, support or information around eating, appetite, diet, weight or nutrition, for ease of discussion the phrase advice about eating will be used.

9.1 Nutritionally I was given absolutely no advice

In response to the question "were you given any advice about eating" all participants responded no or not that they could recall, unless advice was actively sought. Most had attended some form of dementia education course but did not recall any information or discussion about diet, eating, food or nutrition.

> *"I don't remember having any nutrition at Memory Matters."* (Anna)

As identified by Ball et al., (2015) most participants seemed unaware that eating and appetite were likely to be an issue in a person with dementia.

"You were the first person that mentioned that you wanted to talk to me about nutrition and dementia" (Maria)

Advice about diet was felt unnecessary by some participants because they felt they were managing well and believed they could readily find advice if needed.

"…I said I think I can work that out err you know there are plenty of places you can get that sort of information." (John)

The sentiment John expresses is mirrored by others with, for example, Anna describing that without any advice she was able to provide her mother with a "good, balanced diet."

"I felt as though without having any advice from anybody I felt as though she was having a fairly good balanced diet." (Anna)

On asking how she assessed the adequacy of her mother's diet Anna makes reference to health promotion messaging around the main food groups.

"That she's getting all the main food groups. I did used to think about them when I was preparing food it was important." (Anna)

The emphasis of participants' narratives around the need for healthy food, balanced meals and making 'sensible' dietary choices reflects the power of health promotion messaging described in Chapter 7. Such messaging provides dietary knowledge resulted in some participants believing advice or information about diet and eating in dementia is not required.

Advice was described as only being received if explicitly asked fo. Julia recalls how she became very worried about her mother's eating and weight loss and as a result spoke to a doctor.

"Then she was hardly eating… she wanted sweet stuff. And I'd spoken to a doctor and the doctor said look just give her whatever she wants. (Julia)

This sentiment of eating whatever is wanted is the general theme of advice participants received if they sought help. The findings suggest there may be a need to educate healthcare professional in how they provide guidance and education around nutritional

advice for family carers of people with dementia (Hopkins, 2004). In contrast, Bob recalls being given advice by the GP and speech and language therapist.

> *"…we were told by the speech and language therapy and also by the GP to try and do nine hundred – one thousand one hundred calories if we could (pause) for her cause although she wasn't using a lot of the muscles and that, (pause) it was still important from her point of view."* (Bob)

His recalled being told to focus on the amount of calories required, with no mention of other nutritional considerations or dietetic advice. He was also provided with modified texture diet advice by the speech and language therapist.

> *"She'd had thickeners…in all her drink and food…which the GP had put for us…the speech and language therapist brought us a booklet from a company that were a well-known company that did puree foods…"* (Bob)

The participants lived-experiences of advice and support about eating and appetite in dementia is one of having no advice unless specifically sought. Further, some participants believed that they did not need advice being able to provide a 'healthy, balanced diet.' A pilot study of carers of people with Alzheimer's disease identified a lower than anticipated level of knowledge about nutrition, regardless of the carer's educational level (Ryan et al, 2016). This suggests that there is a need to support family carers with advice and information about eating behaviour, appetite changes and nutrition in dementia. With the exception of Bob, advice when sought was limited to supporting the individual to eat as they wished. This is in stark contrast to the healthcare professional perception of being "in it together," with there being a partnership around nutritional care between family carers and healthcare professionals (Mole et al., 2019).

9.2   Talking to others is a help

Talking to other family carers was the most positively described source of advice about eating described by participants. However, this is caveated with the significant lack of other sources of advice. The Dementia Carers Groups were a particularly valued resource.

> *"I know from, you know, talking to other people because I did go to some carers groups and things like that…"* (Jo)

Simply being able to talk with others in the same situation was beneficial in helping to navigate responses to changes in eating and appetite.

> *"…just talking to others at the group is a help."* (Maggie)

Peer support is recognised as important for family carers, with opportunity for emotional support and sharing of experiences and strategies (Lauritzen et al., 2015). Anna elaborates on how the Dementia Carers Group also supports attendees with a folder of information.

> *"…and the groups like we've, got we've got a big folder of information there so if anyone starts talking about this they can say look we've got this information…"* (Anna)

The Internet, the Alzheimer's Society, books or healthcare professionals were also mentioned as sources which participants would use for advice about eating if needed.

> *"Alzheimer's Society or Dementia UK, first call. Possibly the doctor err…if I recognised there was something going on which was causing a problem*." (John)

GPs were mentioned by a couple of participants as providing advice about eating, although advice was usually limited.

> *"Her GP. So, whether it's sweet stuff, fine, just give her whatever she fancies. So, we did that."* (Julia)

Maggie reflects that she likes using books to find information but recognises this may be because this is a preferred information source of a person of her age.

> *"Yeah, I would look in books…probably because of age books are the natural go to."* (Maggie)

However, she goes on to say she would use the Internet to find relevant books as opposed to using the Internet to find advice.

> *"Well, I'd use the Internet to guide me to books."* (Maggie)

Whilst the Internet was used by some participants, a significant limitation was navigating this to find the desired information.

"Well, you'd look and find something, which you'd thought, was to do with dementia and eating and it would go off on different tracks" (Julia)

Some participants therefore found the Internet not particularly helpful.

"I tried to look it up on the Internet but it's a mine field trying to find out if you're feeding someone who has a dementia." (Julia)

The issue of conflicting information was also cited as a problem, particularly when using the Internet, making it difficult for family carers to know which advice to follow.

"And I'd get differing advice, you know it wasn't straight forward." (Julia)

The findings suggest that peer support and talking to others is the most common and helpful form of support about eating and appetite filling the void of other sources of support. The Internet can be difficult to navigate, with challenges in identifying the information needed.

9.3   Have some ice-cream and just enjoy

The overwhelming sentiment of advice participants suggested for others in their situation related to quality of life and having food which is enjoyed. Maggie captures this beautifully.

"So go down the river or out on your bike, or have some ice-cream and just enjoy!" (Maggie)

This echoes the discourse of Hellström et al., (2005) around quality of life and enjoying "lifes little pleasures." There is suggestion that even with adaptions to manage dementia symptoms, there can be moments of pleasure or enjoyment. Giving the person with dementia what they want to eat was a powerful theme running through participants' narratives in this context. This advice mirrors that received by participants from healthcare professional and for some resonated with their own personal meaning of food and eating with pleasure and quality of life for the person with dementia.

"If mum wanted a biscuit she had a biscuit. If that's what they're asking for." (Anna)

Yet, even those who were apparently at ease with this approach presented a caveat of needing a balanced diet.

> *"Um I well I think it is important to try and balance out a diet it's important for the body to work."* (Anna)

Whilst giving the person what they want may be motivated by giving the person pleasure, there were other reasons for this action described by Anna. Firstly, it helped compensate for poor appetite when little else was being consumed.

> *"But my advice would be if somebody with dementia only wants to eat cake, let them. You know if that's all their eating, why not."* (Anna)

It could also help to provide a more peaceful environment within the home.

> *"Um, to give them what they want to eat. Really. If that's all they're going to eat then let them because that's going to be another battle and you don't want another battle. If all somebody wants is rice pudding for their dinner let them have it."* (Anna)

9.3.1   Adapting to 'having ice-cream'

Advice to adapt to new ways of eating was suggested by participants. Such adaptive strategies could to help reduce family carer stress and sense of burden of care but may come at a cost of personal meaning of food. Adapting to allowing unhealthy food choices is presented as a need to 'relax' about eating and food. Maggie had the most to say about this.

> *"If I could pass any of that on to anybody just to say look relax and find ways of, yes, including things like the chocolate and ice cream and chocolate cake but err you know don't say oh no you can't have that… but err regulate it a bit."* (Maggie)

She alludes to the need to "find ways," in other words adapt. Ability to adapt has been described is part of a resilient approach to providing care and essential for reducing carer stress (Petriwskyj et al., 2016, Papastavrou, 2007). Despite Maggie expressing this need to 'relax,' caveats are given with a need to 'regulate access' to perceived unhealthy food choices.

As illustrated by Maggie there is also a need to adjust to a new normal, with new ways of eating.

> *"Well, he wasn't allowed chocolate cake all the time and now he can have just a half a piece!"* (Maggie)

There may also be a need for negotiation around adaptions in meal-related task, being part the cycle of crisis, adaption and adjustment when changes in ability or function are observed (Patterson, 1988). To help mitigate this, Maggie suggests making small, gentle changes.

> *"First of all, try not to make it into a big anxiety thing you know don't build it up between you.. Introduce small changes gently."* (Maggie)

She gives an example of what she means.

> *"Just make little tweaks like that and err introduce as much err food with sauces which is liquidy and soft…"* (Maggie)

This helps a new normal be less noticeable to the person with dementia (Shatenstein et al., 2008; Wong et al., 2015). A further example of adaptation is using deception, for example, by making portions of desired food look bigger than they are.

> *"Err if they want to eat more of the sweet stuff well portion wise you can arrange it on the plate so it looks more - smaller dish, smaller scoop of ice cream placed in certain ways so it looks the same, yes managing it."* (Maggie)

Further, she suggests a way to encourage eating by presenting food such that it is appealing.

> *"…make the food tasty and colourful, I think it's really important…err but you can still present the food to look nice."* (Maggie)

9.3.2 'Eating ice-cream' together

Eating together with the person with dementia was advocated by several participants. Just as identified by Keller et al., (2015), eating a meal together provides opportunity for socialising and being together.

"…people around. It's just eating as its just social."(Sarah)

However, as Anna describes there comes a point where eating together is no longer possible.

"Try to get them to eat meals with you, which mum did for a long time with us at the table. Until she started to need feeding then she sat in the chair." (Anna)

Even when living apart, Sarah is aware of the importance of her mother eating with company. She balances her own family needs to eat together with those of her mother, dividing her time such that everyone is fed.

"So, I have to separate, allocate time for just us. So, dividing my time. So, um, I do notice if I take food to her so I might take her something I've cooked for us and keep it warm - she's only just up the road. Or I might prepare something there and I will hang around a little bit so I'm so there and can see that she has eaten a little bit." (Sarah)

9.4   A holistic , informal approach is wanted

When asked what advice or support participants would like around eating, description focused on a holistic approach, in a more informal setting, with sign posting for when there is a problem or things become difficult. This presents new insight into how to best support family carers around eating and appetite in dementia. A lack of holistic approach is identified by participants.

"Who takes the holistic approach?" (Emma)

This is compounded by the lack of continuity of health and social care professionals.

"So, its…its difficult because there is no one, um, there no one professional that is engaged with a person with a diagnosis of dementia the whole way through their journey." (Julia)

Having a nurse specialist helps "knit it together," that is to say bring together the different elements of care and advice needed.

"The only person we've got who knits it all together is Tanya...(Pause) And that's wrong. (Pause)" (Emma)

Emma was very measured as she describes this ,and appeared to be containing strong emotional response to her words. The need for someone to "knit it together" was particularly important for participants who had a family member with co-morbidities. Care was frequently in silos of speciality rather than focused on the person.

"So, you've got the diabetic nurse over here, the dementia nurses here, the mental health team over here, the eye department over there." (Emma)

An informal approach to advice was requested by some participants with suggestion that an informal group would work better than an individual appointment.

"Something not quite formal. Something like informal you know so you don't feel like you're dealing with doctors and consultants all the time, where you sit there and think oh I'm just another number...A small group and then each individual has a change to have a say and I know that not everyone can attend the groups either but they've got an option. So that's my feeling that informal groups are much better and you probably absorb more information than big large things or sitting like a doctor across the table." (Anna)

Reference is made to the memory education sessions which Anna felt worked well, except nutrition was not included. There was also a desire for empathy and understanding.

"I think both because when you're speaking to someone, someone can show empathy, understanding. When you've got a piece of paper, great ,refer back to what did it say but there can often be questions and examples outside the remit of what you have written down." (Julia)

In contrast ,some participants wanted a more prescriptive approach from a healthcare professional, detailing what to do, offering reassurance about the care being provided.

" I would say probably a bit more prescriptive and a bit of reassurance I think, that you're doing the right things. If there was a way of, I think also looking at the Internet, we understand that you can't rely on what is said. And I actually wanted

a professional input, I mean I did, I wanted a professional's input. It's all very well

trying to look up but it's conflicting." (Julia)

A similar idea was a 'lifestyle' dietitian, with the proposal being to access the person as problems occurred or advice was needed.

"Well, I think having a lifestyle dietitian, health person in a practice for everybody

would reduce the workload – ok that's more generalistic, um certainly with a

dementia, memory difficulty if there could be someone there to be signposted to."

(Julia)

9.5   Signposting for when things get difficult

Participants were asked how would they like to access information and in what format. As predicted there was no clear consensus. However, signposting was suggested by several participants as a way to avoid being overloaded or even frightened by too much information at once about possible symptoms or challenges.

"To sign post absolutely… I did a three-hour training session about eighteen

months ago now, and again it was really enlightening and terrifying." (Emma)

Suggestion around using a website for signposting was made, providing support for when changes are observed.

"…when you come across those changes here's the website it's on." (Emma)

One innovative idea came from Sarah with the use of scenarios and solutions for family carers to read.

"But I personally wouldn't mind seeing "in these sorts of situations when this is

happening you need to think about…" I think those kind of pointers I would

appreciate…I think um information, just sort of flagging this can happen. These are

the things to watch out for. Um cause I think you know dementia, there's so many

different stages of it…" (Sarah)

9.6 Lived experiences and the NICE guidelines

These findings highlight a gap between national guidance and the reality of family carer lived-experiences. There is limited empirical work demonstrating this, adding to new knowledge about family carer lived experiences of eating and appetite in dementia. The NICE guidelines (2018) for dementia make recommendation about support for carers in section 1.11.1:

- education about dementia, its symptoms and the changes to expect as the condition progresses
- developing personalised strategies and building carer skills
- training to help them provide care, including how to understand and respond to changes in behaviour
- information about relevant services (including support services and psychological therapies for carers) and how to access them
- advice on planning for the future

In section 1.11.2 of the NICE guidelines (2018) suggestion is made that support for family carers is tailored to their needs, designed to help them support people living with dementia, being in a suitable format and at a location which they can easily access. There is also advice that interventions are likely more appropriate if provided as a group session.

The findings of this study highlight that education about dementia for family carers rarely includes nutrition, eating or appetite nor is there evidence that family carers are supported in developing personalised strategies or building carer skills in relation to changes in eating behaviour and appetite. There is little evidence to suggest there is training to help understand and respond to changes in eating behaviour or information about dietetic or speech and language services for those with dementia. Finally, there was no evidence from the study to suggest there was any advice on advanced planning with regards to the person with dementia's wishes about food and eating. This study identifies that family carers would favour informal group sessions for support, training and advice about eating behaviour and appetite. Use of existing dementia carer groups

could be one approach to provide this. Further, there is a request for sign-posting to support with advice on navigating the Internet to find 'safe' sources of advice needed.

9.7   Chapter summary

This chapter identifies a gap between national guidance and family carer lived-experiences in relation to advice, support and information about eating behaviour and appetite in dementia. Participants describe receiving no advice unless specifically sought and found greatest benefit in talking to peers. They describe the importance of quality of life and enjoyment of food with desire for informal, holistic advice and signposting to further support when needed. This is in contrast to the personal focus of participants on providing healthy food choices (Chapters 7 and 8), suggesting a difference between the advice they would give others and their own behaviours. Whilst there is useful information available on the Internet about eating and dementia, the Internet was described as being difficult to navigate, with conflicting information. These findings are complimentary to the major themes in the Chapter 7 and contribute to the overarching theme of daily ethical challenges.

9.8   Summary of findings and discussion

Chapters Seven, Eight and Nine present and discuss the findings of the present study exploring family carers' lived experiences of eating and appetite in dementia. The overarching theme was one of daily, ethical challenges with participants experiencing complex and ethical decision-making throughout the day in relation to food, appetite and eating behaviour. Such decision-making could be linked to a decline in scope for shared decision-making around food and eating, the participant's personal meaning of food and eating, and the influence of health promotion messaging.

The need to make healthy choices dominated participants' views and for some presented a dilemma around what to do in relation to the food provided. Should healthy foods, which brought less pleasure and were not so readily enjoyed by their family member be provided, or rather less healthy but more enjoyable food be offered? Whilst most participants described how they would advise others to provide pleasurable food, some acknowledged that they found it difficult to follow their own advice, with the need to

provide healthy food dominating. The reasons for this were multifactorial and included social pressure and a desire to keep their family member 'healthy.'

Keeping their relative safe by managing risks in the context of food-related tasks, nutritional intake and eating added a further layer of complexity to participants' decision-making. When to step in, take over, or even prevent participation in food-related activities, as well as how to best support family members to eat could create challenges for participants. The need to keep relatives safe in the context of food and eating is not surprising, with keeping family members safe described as an essential part of the hierarchy of family carer needs in dementia (Pini et al., 2018). The consequences of changes in eating behaviour and appetite for the participants were wide ranging and included personal, relational and financial costs. Such costs can contribute to carer burden and ability to take care of oneself, this being of foundational importance in the hierarchy of family carer needs in dementia (Pini et al., 2018). Such costs can contribute to feelings of burden and adversely impact quality of life, both being risk factors for a person with dementia needing residential care (Schölzel-Dorenbos et al., 2010).

The language used by family carers around eating and appetite tended to describe changes they observed rather than the specific words of appetite or weight being used. Listening for such descriptions may help healthcare professionals' to better understanding the changes in eating, appetite or nutritional state. Participants' understanding about the connection of observed changes in eating behaviour and appetite with that of dementia was variable and influenced response to these. Such participant responses or strategies included eating together, altering calorie intake, using pictures or prompts to support food related activities and making adaptations to eating or drinking. A need to supervise or take over food related tasks or support eating was a further response described by most participants.

Variance in participants making connections between dementia and the changes in eating behaviour and appetite was apparent. This likely resulted from the lack of support and advice received by participants about eating, appetite and nutritional care. Consequentially, many described a 'trial and error' approach with participants' expressing distress or uncertainty about what to do as they observed changes in eating in their

family member. This can contribute to feelings of carer burden, being a risk factor for a person with dementia being moved to residential care (Schölzel-Dorenbos et al., 2010). To fill this void in information and support many participants relied on peer support and talking to others in a similar situation to themselves. Most participants stated they would welcome advice about eating and appetite, describing preference for an informal, holistic approach to nutritional care and signposting to support and advice for when 'things got difficult.' Using these findings, the final chapter describes the implications for clinical practice, limitations of the present study and future research recommendations.

Chapter 10   Conclusion

This final chapter considers the implications for clinical practice of the new knowledge resulting from the present study, the limitations of the study and recommendations for future research. The overarching finding of the essence of family carer lived-experiences of eating behaviour and appetite in dementia was identified as daily ethical challenges encompassing the three superordinate themes:

- Complex ethical decision-making around eating behaviour and appetite in dementia
- Recognition of the impairment effects of dementia on eating behaviour and appetite
- The cost to family carers of eating behaviour and appetite in dementia

Such experiences may contribute to the ability of family carers to meet their own needs as well as the person with dementia (Pini et al., 2018). Further, the contribution of these experiences to carer burden may impact ability to continue providing dementia care in the home (Schölzel-Dorenbos et al., 2010). The present study found that family carers showed resourcefullness and resilience in their responses to changes in appetite and eating behaviour. However, there was variable understanding about the effects of dementia on these functions and the consequences of such changes. A lack of information and support for family carers received was clearly identified. Despite this, many participants expressed confidence in their own ability to provide nutritional care with a strong emphasis on their provision of 'healthy' food. This power of health promotion messaging dominated, influencing participants decision-making around food, making it difficult for any messaging to be heard about adapting diet as changes in eating and appetite occurred. These findings have implications for practice and are discussed in the following section.

10.1   Implications for practice

Three implications for practice were identified from the study findings:

- The impact of changes in eating behaviour and appetite in dementia on family carer needs could inform a concept model for practice-based education
- Communication with family carers about eating and appetite in dementia
- Countering health promotion messaging through improved support, advice and information for family carers

10.1.1 The impact of changes in eating behaviour and appetite in dementia on family carer needs – a concept model for practice-based education

Mole et al., (2019) suggested that health and social care professionals were not always confident in providing support and advice about nutrition and eating to family carers. It was also evident from the present study that such support for family carers was lacking. This identified a gap between recommendations of NICE (2018) and the experiences of participants in the present study. Improving knowledge and understanding of health and social care professionals about the effects of dementia on eating and appetite and the relevance of this for family carers might improve confidence in offering advice and support. Demonstrating relevance to practice may help to engage health and social care professionals in learning about this phenomenon.

One such approach to supporting health and social care professionals understanding of the impact of eating and appetite in dementia on family carers is to use existing models used to such as 'the consequences of unmet need in dementia' (Schölzel-Dorenbos et al., 2010). The findings of the present study suggest that the daily ethical challenges which family carers face in relation to eating behaviour and appetite may affect their ability of to meet their own needs as well as those of the person with dementia. Ultimately such daily ethical challenges around eating and appetite have implications for the continuation of care at home (Figure 19).
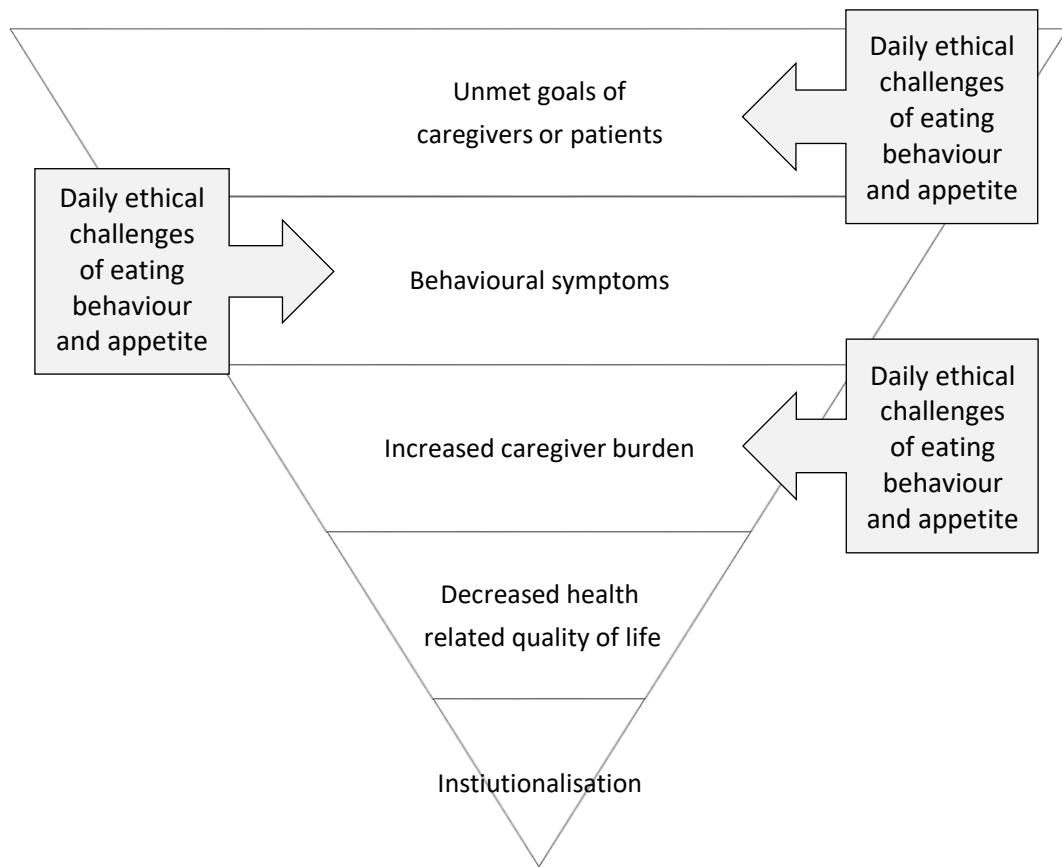
Figure 19 Model of the consequences of unmet need in dementia adapted from Schölzel-
        Dorenbos et al., (2010)

Such an adapted model may help bring alive the relevance of this essence of family carer experience for health and social care practitioners. Mapping the essence of the present study onto the model of consequences of unmet need in dementia provides a way of illustrating the effects of eating behaviour and appetite in dementia. This provides clear rationale for health and social care professionals to develop understanding of the effects of dementia on these functions, and the importance of providing family carers with support. Further, such learning could improve confidence in engaging with family carers and developing strategies for providing local support and advice about eating and appetite in dementia. Such support could improve the confidence of family carers in responding to the daily ethical challenges of eating and appetite in dementia, reducing feelings of burden whilst becoming better equipped to meet their own needs and those of their family member. Using the theoretical modelling of Schölzel-Dorenbos et al., (2010) this may increase the length of time those with dementia can remain in their own home.

Key points:

- Using an adapted model of carer need can illustrate the importance and relevance of eating and appetite in dementia care and may better help to engage health and social care professionals in developing understanding about this.
- Improving health and social care professionals' knowledge may improve their own confidence in providing support for family carers.

10.1.2 Communicating with family carers about eating and appetite in dementia

Effective communication is essential to understand family carers concerns about eating behaviour or appetite changes in dementia. It is also necessary to provide effective information that is relevant, accessible, understood and used by the intended audience. The findings of the present study illustrate that the range of words and phrases used by family carers to describe and discuss eating behaviour and appetite contrast with those more commonly used by healthcare professionals. This offers a starting point to consider how to improve communication with family carers about this topic. Advice on writing for patients is available and includes using simple words and avoiding jargon (NHS Digital, 2021). As this study demonstrated the word appetite, whilst not considered jargon, is commonly used by healthcare professionals but infrequently used by participants. Rather, there was preference for participants to describe the consequences of changes in eating behaviours and appetite such as changes in appearance or behaviour.

Accessibility of information particularly through the Internet may be improved if words better reflected common lay language. Using familiar terms to communicate with family carers about eating and appetite will likely help to improve understanding, accessibility of information and engagement. Equally, health and social care professionals may find listening for alternate words or inferred changes of eating or appetite helpful in better understanding family carers experiences. Further, consideration of how family carers search for information on the Internet is needed to improve access using language which is more meaningful or familiar to family carers.

Key points:

- Communication of health and social care professionals with family carers could be improved by using words or phrases more commonly used in lay language.
- Improving awareness of inferred changes in eating or appetite may help health and social care professionals to better understand of family carers experiences.
- Better provision and access to information, support and advice about eating and appetite for family carers is needed.

10.1.3 Countering health promotion messaging through improved support, advice and information for family carers

The findings of this study have highlighted the limited information and advice family carers have about eating and appetite, with infrequent mention by health and social care professionals, support workers or at dementia education sessions. Similar findings were identified by Ball et al., (2015). Perhaps as a consequence of this, health promotion messaging seems to dominate with participants often using this as their primary reference point for dietary advice. This study suggests that this continues regardless of the stage of dementia, eating behaviour or appetite changes being experienced by the person with dementia. This suggests a need for timely and appropriate advice. To help counter the power of health promotion messaging, provision of Information on the effects of dementia on eating behaviour and appetite, and ideas around responses to are needed. Signposting to specialist services are also likely beneficial. Further, advice on planning for the future should include discussion of eating and appetite. This would provide a more comprehensive approach to family carer support. These concepts are informed from the findings of the present study and fit within the NICE (2018) guidelines describing dementia carer support and information (Table 4).

Table 4 Recommendations for support and advice for family carers using the NICE guidelines (2018) and study findings

NICE guidelines (2018) section 1.11.1	Recommendations for support and advice for family carers based on study findings
Education about dementia, its symptoms and the changes to expect as the condition progresses	Information about recognising the impairment effect of dementia on eating and appetite.
Developing personalised strategies and building carer skills	Support perhaps through group sessions around how to respond and adapt to changes in eating behaviour and appetite developing resilience as a family carer
Training to help them provide care, including how to understand and respond to changes in behaviour	Information about responses to changes in eating behaviour and possible strategies
Information about relevant services (including support services and psychological therapies for carers) and how to access them	Information about specialist services related to eating and appetite and how they can help Signposting to support access to dietetics and speech and language services
Advice on planning for the future	Planning for the future to include discussion of eating and nutritional care

The NICE guidance (2018) provides a framework for development of advice, support and information for family carers in relation to eating behaviour and appetite in people with dementia.

The present study also identified that family carers want information and advice about nutrition and eating provided from a holistic perspective, with consideration of the whole person with dementia rather than a silo, disease specific approach. Sign posting to information for when things become more difficult is favoured, as it can be overwhelming and frightening to have all the information at one time. Empathy and sensitivity is wanted by family carers when discussing eating and appetite related issues.

Key points:

- Information about the impairment effects of dementia on eating behaviour and appetite needs to be provided by health and social care professionals in an empathetic, supportive approach.

- Sign-posting needs to be clear for family carers to know where and how to find support and advice about eating behaviour and appetite, or specialist services as they are needed.

- Peer support and groups are favoured by family carers as a way of sharing information. Health and social care professionals could look to utilise these approaches to share information and offer support about eating behaviour and appetite in dementia. Novel approaches in the provision of information and advice about eating and appetite in dementia may need to be considered.

- Supportive information and advice about eating and appetite in dementia needs to be incorporated into existing information pathways for family carers of those with dementia.

10.2   Limitations of the study

This study has three limitations identified. The first relates to the transferability of findings to a wider population of family carers. Participants of the study were all Caucasian and living in the Southern England, with limited ethnic or cultural diversity. Whilst this was appropriate for the method chosen, lived experiences of family carers in other localities or with different cultural or ethnic backgrounds may not be the same. Commonalities amongst the participant group were identified, some of which resonated with the albeit scant empirical evidence. This suggests the findings of the present study may be more widely applicable. However, this would need to be tested. A second limitation relates to the method. Whilst IPA provides an in-depth analysis of a small number of participants, a less in-depth approach such as thematic analysis would have supported a larger participant group. This may have resulted in different findings or conferred greater confidence in applicability of findings to a wider population. However, the in-depth analysis of the present study would not have been possible and associated findings may not have been identified. A third limitation was the challenge in recruitment both in terms of accessing the sample group, and the enforced two-phase approach to

recruitment because of personal illness. The latter disrupted engagement with gatekeepers with momentum of the recruitment process lost. As a result, the original study plan was curtailed.

10.3   Recommendations for future research

This thesis has presented new knowledge of relevance to family carers of people with dementia, people living with dementia and those working with such individuals. The essence of family carer lived experiences around eating and appetite in dementia is daily ethical challenges with a need for daily, complex ethical decision-making. Further, family carers often lack knowledge and understanding about the effects of dementia on eating behaviour and appetite. Limited provision of or access to information, advice and support to help in responding to changes in these functions was also identified. However, this study was small and exploratory in nature with limited prior work in this field. Therefore, the first recommendation for future research is to explore experiences of family carers from a wider, more culturally and ethnically diverse background. This would offer opportunity to confirm the present findings and add further to new knowledge in this field.

The second recommendation for future research relates to exploration of why family carers are not accessing current information provided about eating and appetite in dementia. Much of this is available through the Internet, being an increasingly common way of communicating information particularly since the recent COVID pandemic. The findings of the present study describe difficulty in navigating the Internet, with conflicting or irrelevant information found. A potential research question could therefore be, 'what are the barriers to family carers accessing information and support about the effects of dementia on eating and appetite?' Engagement of key stakeholders ideally at a national level reflecting cultural and ethnic diversity should be sought. A scoping exercise of barriers to accessing existing information could be undertaken. This could inform future work around improvement in accessibility to information, revision of existing resources to better meet the needs of family carers, and if needed, development of new resources. Whilst it is recognised that there are sources of information available in the form of leaflets and on websites, the present study highlights these are not being readily accessed

with navigation of the Internet seen as being difficult. Thus, there may be benefit in the improving signposting, reviewing search terms for websites or the language used in existing information on the Internet. This work needs to be undertaken at a national level and would help to demonstrate achievement of the NICE guidelines for Dementia, section 1.11.

The third recommendation for future research involves exploration of current education of health and social care professionals, support workers and relevant organisations . Specifically, there is a need to provide training about the effects of dementia on eating behaviour and appetite and the consequences for both family carers and people with dementia. Thus, a research question could be:

> How confident do health and social care professionals and support workers feel in providing beneficial information to family carers about the effects of dementia on eating behaviour and appetite and response to these changes.

Follow on questions could include:
> What are the barriers to confidence in providing this?
> What support, education or training would be helpful?

A scoping exercise could be used to identify existing and desired training needs, gaps in knowledge and a way forward. This would involve identifying key stakeholders including relevant higher education organisations, professional bodies and support workers of people with dementia. There could be exploration of what education already exists in this domain and how this could be shared more widely. This work could help inform future steps to improve awareness about the effects of dementia on eating behaviours and appetite of those involved in supporting family carers of those with dementia, and where support and advice can be found. This could contribute to the achievement of the NICE guidelines (2018) recommendations about providing family carers with information and support.

10.4   Concluding thoughts

To conclude, this thesis has demonstrated that family carer lived experiences of eating and appetite in dementia is that of daily ethical challenges. Using a novel approach to explore this phenomenon has provided new knowledge and insight, with implications for practice, family carers and those with dementia. Applicability of findings to an existing model of family carer needs has illustrated how the study's findings are relevant for practice. Findings can also be used to help inform a framework for the delivery of NICE guidelines (2018) in terms of support and advice for family carers about eating and appetite. This study has shown a mismatch between these guidelines and lived experiences of family carers, with scope for improvement of support and information around understanding of and response to changes in eating and appetite in dementia. Health promotion messaging dominates, often making it difficult for family carers to recognise benefits of dietary adaptations in response to changes in eating or appetite, or consider a change in emphasis to food being a source of enjoyment, adding to quality of life. The need for, and importance of support and information for family carers about eating behaviour and appetite changes is clearly demonstrated through this study. Family carers' ability to meet their own needs and those of the person with dementia are implicated if the daily ethical challenges of eating and appetite become overwhelming. This can effect health, wellbeing, quality of life and even continuation of care in the home. This study has shown that family carer lived experiences of eating and appetite in dementia really are so much more than just about eating.

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Appendix A   Ethical approval

A.1   University of Southampton approval

Approved by Research Integrity and Governance team - ERGO II 30523.A3
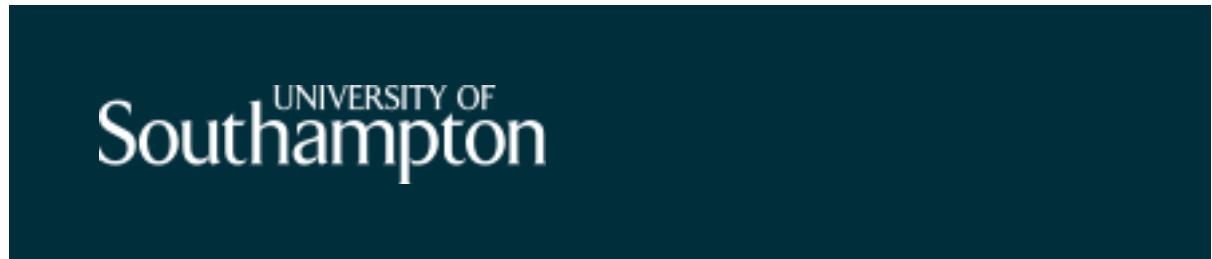
ERGO II – Ethics and Research Governance Online https://www.ergo2.soton.ac.uk

Submission ID: 30523.A3
Submission Title: Carer experience of appetite changes in people with
dementia living at home. (Amendment 3)
Submitter Name: Emily Walters

The Research Integrity and Governance team have reviewed and approved
your submission.

You can begin your research unless you are still awaiting specific Health
and Safety approval (e.g. for a Genetic or Biological Materials Risk
Assessment) or external ethics review (e.g. NRES/HRA/MHRA etc).

TId: 23012_Email_to_submitter___Approval_from_RIG Id: 126359
erw2v07@soton.ac.uk coordinator

A.2   Health Research Authority approval

NHS
Health Research Authority

> **Please note:** This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval
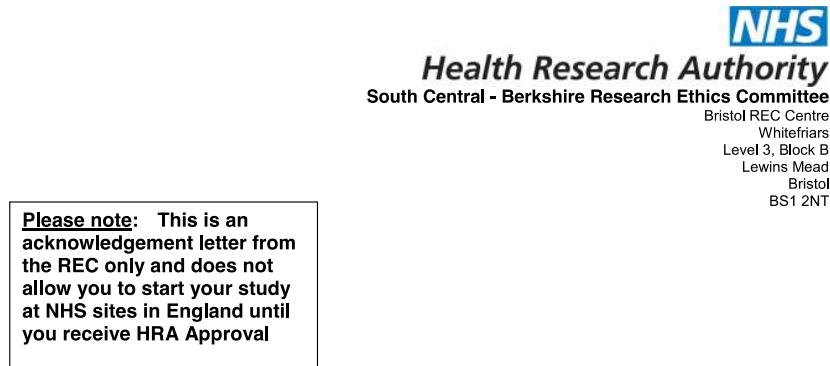
16 May 2018

Miss Emily Walters
NIHR CLAHRC Doctoral Fellow
University of Southampton
Faculty of Health Sciences, University of Southampton
University Road
Southampton
SO17 1BJ

Dear Miss Walters

Study title:	**Carer experience of appetite changes in people with dementia living at home**
REC reference:	**18/SC/0213**
IRAS project ID:	**239827**

Thank you for your letter of 16 May 2018. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 01 May 2018

Documents received

The documents received were as follows:

Document	Version	Date
Participant consent form [CONSENT FORM v2 02052018 changes highlighted]	2	02 May 2018
Participant information sheet (PIS) [Participant Information Sheet v2 02052018 changes highlighted]	2	02 May 2018

A Research Ethics Committee established by the Health Research Authority

the "   "

and capability (e.g. provision by you of a 'green light' email, formal notification following a site

A.3   HRA approval for amendments

Amendments
From: hra.amendments@nhs.net <noreply@harp.org.uk>
Sent: 13 May 2019 11:19 AM
To: Walters E.R.
Subject: IRAS 239827. Amendment categorisation and implementation information

Amendment Categorisation and Implementation Information

Dear Miss Walters,

IRAS Project ID:	239827
Short Study Title:	Carer experience of appetite changes in people with dementia
Date complete amendment submission received:	02 April 2019
Amendment No./ Sponsor Ref:	ERGO 30523
Amendment Date:	16 November 2018
Amendment Type:	Non-substantial
Outcome of HRA and HCRW Assessment	**This email also constitutes HRA and HCRW Approval for the amendment,** and you should not expect anything further.
Implementation date in NHS organisations in England and Wales	35 days from date amendment information together with this email, is supplied to participating organisations **(providing conditions are met)**
For NHS/HSC R&D Office information	
Amendment Category	A

Thank you for submitting an amendment to your project. We have now categorised your amendment and please find this, as well as other relevant information, in the table above.

Appendix B   Consent form

Study title: Carer experience of appetite changes in people with dementia living in their own home

Interview about carer experience of appetite changes in dementia

Researcher name: Emily Walters   Ethics committee: Berkshire (18/SC/0213)

Please initial the boxes if you agree with the statements:

I have read and understood the participant information sheet (version 2, 2 May 2018) and have had the opportunity to ask questions about the study.	
I understand that that the research will require me to talk about my experiences of being a carer. There is a small risk that this may cause me to have new questions or concerns or cause distress. I agree to speak with my GP or other healthcare professional about these or if I continue to feel distressed.	
I agree to take part in this research and for my data to be used for the purpose of this project and the researcher's doctoral thesis.	
I understand that my interview will be audio recorded and I agree to this.	
I understand that I may be quoted directly in reports, presentations or discussions of the research but my name will not be used.	
I understand that information collected about me during my participation in this study will be stored in a locked cupboard at the University of Southampton and also on a password-protected computer. This information will only be accessed and used for the purpose of ethically approved research studies.	
I understand that the information collected about me may be anonymised and used in future ethically approved research studies.	
I understand my participation is voluntary and I may withdraw at any time for any reason without my medical care or rights being affected.	
I understand that I can withdraw my data up to one week after it has been collected.	
I agree to my confidentiality being breached if I disclose something that puts the safety of others or myself at risk.	

Optional: please only initial if you agree with the statement

I agree to being contacted by the researcher to discuss participating in the second phase of the research – the development of a resource or intervention about appetite changes in dementia to support carers.	

Name of participant (print name)   Name of researcher (print name)

…………………………………..   …………………………………………
Signature of participant   Signature of researcher

…………………………………..   …………………………………………

Date: ………………………………   Date: …………………………………

Appendix C   Patient information

C.1   Plain English summary

Study title: Carer experience of appetite changes in people with dementia living in their own home

Aim of the study

This study explores how carers manage and respond to appetite changes in people with dementia living at home and the type of support they would find useful. We will use what we learn to improve support for carers.

About appetite changes in dementia

Not everyone with dementia will have a change in appetite. However, studies have shown that these often occur as the dementia progresses. Some people eat less than normal, others more and in rare cases try to consume non-food items. Symptoms can include not finishing meals, changes in food choices, eating at different times, looking for food, feeling hungry more hungry or changes in weight.

Why are we doing this study?

Appetite changes in people with dementia can sometimes cause stress and anxiety for carers. By better understanding carer experience we aim to improve carer support.

What does the study involve?

The study has two parts. In the first part we will ask you questions about your experience as a carer of a person with dementia, focusing on mealtimes, eating, appetite and support. With your permission the discussion will be recorded (audio). It is likely to last between 1 and 2 hours. The second part of the study is optional. The researcher will develop a resource or intervention for carers about managing appetite changes in people with dementia. You will be invited to join a small group of carers and share your thoughts and ideas about this as it develops.

Can I take part?

To take part you need be or have been a carer of someone with dementia living at home for at least 6-months. You need to be aged 18 years or older, able to understand and speak English and give consent.

Researcher contact: Email: erw2v07@soton.ac.uk   Mobile:07864084218

Lay Summary [version 1] [1 September 2017]   [Ethics number:]

C.2 Patient information flier / poster

Carer experience of appetite changes in people living with dementia

Are you a carer of a person living with dementia?

Would you be interested in taking part in research and talking about your experience?

People living with a dementia can experience changes in appetite. They may not want to eat, eat more food than usual or rarely try to eat non- food items. This can be a cause of carer stress and anxiety. There has been little research about carer experience of appetite changes in dementia. We are interested in hearing about your experience to help us improve support for carers.

Ethics approval: Berkshire Research Ethics Committee (18/SC/0213)

C.3   Patient information sheet

Participant Information Sheet

Study Title: Carer experience of appetite changes in people with dementia living in their own home

Researcher: Emily Walters   **Ethics committee**: Berkshire   **IRAS number:** 239827

Please read this information carefully before deciding to take part in this research. It is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This research explores how carers of people with dementia living at home manage and respond to appetite changes. It will also ask about what support carers would find useful. We will use what we learn to help us improve the support we give to carers about appetite changes in dementia. This will include developing a resource or intervention for carers. We will involve people with experience of caring for someone with dementia in the development of this. Berkshire Research Ethics Committee (18/SC/0213) reviewed this study.

Why are we doing this study?

Studies have shown that appetite changes in people with dementia can be a cause of stress and anxiety for their carers. We know very little about carer experiences of appetite changes in dementia. We would like to talk to carers and ask them about these. This will help us to better understand their needs.

What do we mean by appetite changes in people with dementia?

Not everyone with dementia will have a change in appetite. However, studies have shown that appetite in those with dementia can increase or become less. Very rarely some people with dementia try to eat or drink non-food items. Symptoms of appetite changes can include not finishing meals, changes in food choices, eating at different times of day or night, feeling hungry all the time or changes in weight.

Who can take part in the research?

To take part you need to be or have been a carer of someone with dementia living at

home for at least 6-months. You must be aged 18 years or older and able to understand and speak English. If you are interested in taking part we will ask you some questions to see if you are eligible.

What will happen to me if I take part?

Consent is needed before you can take part. We will explain and discuss the research with you. You can ask questions to help you understand what is involved. You may decide you do not want to take part. This will not affect your treatment, care or support. If you are happy to take part you will be asked to sign a consent form and given a signed copy to keep. This shows that you understand what the research involves and that you are happy to take part. A copy will also be kept in a secure cupboard at the University of Southampton for our records. The study has two phases. You can take part in just phase 1 or phase 1 and 2.

For phase 1 we will arrange to meet with you at an agreed place and time, where our conversation will be confidential. We will ask you to tell us a little bit about you and the person you are caring for. This gives us demographic data needed for the research. For example your age, how long you have been a carer for and the type of dementia the person you are caring for has. We will then ask you some questions and listen to your experience. This will be recorded (audio) with your permission. Confidential notes may be made. This is so we don't miss or forget any part of the discussion. The visit is expected to last for 1- 2 hours.

If you are happy to take part in the second part of study we will contact you, arrange to meet and go through the consent process. We will then invite you to participate in the development of a resource or intervention to support carers about appetite changes in dementia. This will require you to attend 2 meetings and share your ideas and opinions with a group of carers and the researcher.

Are there any benefits in my taking part?

If you decide to take part in the research you will be helping us contribute to improving carer support and care of those with dementia. For agreeing to take part in phase 1 we will offer you a supermarket voucher to the value of £10 in recognition of you sharing your experience and time. Similarly, we will offer you a £5 supermarket voucher for each of the meetings you attend in phase 2. We are also able to contribute to any parking or travel costs you may have as a result of taking part in either phase of the research, up to the value of £10. A receipt for travel or parking costs will be required before payment can be made.

Are there any risks involved?

The study asks you to tell us about your experience of being a carer of a person with

dementia, and to contribute to the development of a resource for carers. There is very little risk to you. However, these activities may cause you to have new questions or concerns, or cause you to recall difficult memories, which may result in anxiety or distress. We would advise you to discuss these with your GP or other healthcare professional.

Will my participation be confidential?
All written records, forms, notes and audio recordings will be stored on a password-protected computer or in a locked cupboard at the University of Southampton. Only the researcher, research supervisors and approved transcriber will have access to the original data. The audio recording will be transcribed (written down) by the researcher or a commercial transcriber contracted through the University of Southampton. The audio version will be deleted as soon as transcribing and analysis has been completed. Every effort will be made to remove information that could identify you from the transcribed interviews. This includes your name and names of people you mention. Participants will be referred to by identification codes or pseudonym (false name) instead of their name. The results of the study will include quotes from participants referred to by their identification code or a pseudonym (false name). There is a very remote chance that someone may be able to link you to the quote. The content of any interview will be treated in confidence. However, should any safeguarding issue arise such as concerns about the welfare of the person with dementia or the carer-participant, the researcher is required to inform an appropriate body. This research complies with the Data Protection Act and the University of Southampton's regulations relating to data protection.

Who is funding the research?

Funding for this research is from the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC). The study is part of a doctoral student project at the University of Southampton.

What should I do if I want to take part or find out more information?
If you would like to take part or discuss the study please contact the researcher, Emily Walters, on the mobile phone number or e-mail address below. Please provide your contact details. The mobile phone is a dedicated number for this research and only accessed by the research team. The e-mail is a University of Southampton address, password protected and only accessed by the researcher.

Mobile phone: 07864084218   **E-mail:** erw2v07@soton.ac.uk

What happens if I change my mind?
You are able to withdraw from the study at any point. You do not need to give a reason. This will not affect your care, treatment or support. You may request that information collected about you is withdrawn from the study up to one week after your interview

with the researcher or attendance at a group meeting.

What will happen to the results of the research?

The anonymous results will be used to help us develop a resource or intervention to improve support for people with dementia and their carers. This and other findings of the research will be shared through articles, presentations, posters and discussions, and may be presented through various forms of media. The researcher will also use them in her doctoral thesis. The anonymised data will be available to other researchers through the University of Southampton's institutional repository, to support or inform future research.

What happens if something goes wrong?

If you wish to raise a concern or complaint please contact:

The Research Integrity and Governance Manager, University of Southampton

Telephone: 023 8059 5058   E-mail: rgoinfo@soton.ac.uk

Support or advice can also be obtained from the following services:

- Patient Support Services, University Hospital Southampton NHS Foundation Trust, C level, Centre Block, Southampton General Hospital, Tremona Road, Southampton, SO16 6YD

   Telephone: 023 8120 6325   E-mail: patientsupportservices@uhs.nhs.uk

   Visit: Monday to Friday 9am to 4pm

- Patient Advice and Liaison Services (PALS) and Complaints, Southern Health NHS Foundation Trust, 5-6 Sterne Road,   Tatchbury Mount, Calmore, Southampton, SO40 2RZ

   Telephone: 023 8087 4065

   Visit: To make an appointment please call 023 8087 4065

Advice and support for people affected by dementia

For general advice and support about dementia please contact:

- The National Dementia Helpline telephone 0300 2221122
- The Alzheimer's Society at www.alzheimers.org.uk

The Alzheimer's Society also produce a fact sheet about eating and drinking which is available on their website.

Please discuss any concerns about dementia or the person you are caring for with your GP or healthcare professional.

Thank you for taking the time to read this information sheet and consider taking part in the research.

Appendix D   Eligibility

D.1   Eligibility criteria

- Aged 18 years of age or older.

- Capacity to give consent.

- Ability to understand and converse in English to a level that enables participation in an interview without the need for translation in to another language.

- Non-salaried family carer for at least 6-months of an individual with a dementia diagnosis living at home / in a domestic home environment. The participant does not have to currently be providing such care at the time of interview i.e., the care recipient may now be in residential care or deceased.

- The care recipient must not have a concurrent malignancy or other condition, which is reported or anticipated to have significant impact on appetite as determined by the researcher for the time period the participant provided care at home.

D.2 Eligibility screening

```
                          How old are you?

      Under 18 years old -          18 years or
         NOT ELIGIBLE                  older

                    Have you looked after an individual with dementia
                    at home for 6-months or more without payment
                           (excluding carers allowance)?

         NO - NOT ELIGBILE                    Yes

                      Has the person with dementia had cancer while
                      you've cared for them?  Do they have any other
                      diagnosis significantly effecting  their appetite?

         YES - NOT ELIGIBLE                     No

                   Based on researcher conversation with the individual - does the
                    individual appear to have the ability to speak and understand
                       English to a level which would enable participation?  (
                             Subjective decision made by researcher)

          NO - NOT ELIGIBLE                     Yes

                     Does the individual have capacity to give consent? (Subjective
                        decision made by researcher following conversation with
                                         individual)

          NO - NOT ELIGIBLE                   YES - ELIGIBLE
```

Appendix E   Interview guide

Setting the scene for the interview

➢ Welcome participant and ensure they are comfortable

➢ Consent: check the consent form is signed and ask if the participant has any questions prior to beginning the interview

➢ Remind the participant that the interview and recording can be stopped at any time at their request and this will not be detrimental to them or their care in any way

➢ Check the participant is happy for researcher to make notes during the interview

➢ Check the participant is happy for audio recording and ready to begin the interview

Start audio recording

State at the beginning of the recording:

➢ Date

➢ Time

➢ Study title: Carer experience of appetite changes in people with dementia living at home

➢ Researcher name

➢ Participant study identification code

Demographic data collection prompts

➢ What is your relationship with (*the name of the person being cared for*)?

➢ When was (*the name of the person being cared for*) diagnosed with dementia?

➢ Do you know what type of dementia they have?

➢ How long have you been their carer for?

➢ Are you the only / main carer?

➢ Would you describe the care needed as 24hour?

The interview has four themes to help guide the interview.

Theme 1: Mealtimes

"Tell me about mealtimes with the person you are caring for"

PROMPTS: How have mealtimes have changed?

What is it like to eat out or go to friends or family for meals?

How have these changes affected you?

Theme 2: Changes in eating

"Can you tell me about any changes you've noticed in the type of food eaten or frequency of eating?"

PROMPTS:　　Can you give me examples?

　　　　　　What effect has this had? i.e. on you, how you shop or cook?

"Have you noticed anything different or unusual in food or drink choices or eating behaviour?"

PROMPTS:　　Can you tell me more about this? Give me some examples?

　　　　　　Why do you think these change(s) have happened?

　　　　　　Have you made any changes as a result? i.e. changed the foods you buy, cook differently, measures to manage unusual behaviour

　　　　　　What effect have these changes you've made had?

　　　　　　How do you feel about making these changes?

T

heme 3: Carer concerns about appetite changes in dementia

"Do you have any concerns about appetite, eating, food or nutrition?"

PROMPTS:　　Can you give me some examples?

　　　　　　Have you made any changes as a result? i.e. changed your behaviour, activities

　　　　　　What effect have these had?

　　　　　　How do you feel about making these changes?

　　　　　　Have you talked to anyone or looked for information about your concerns?

If weight is not an issue raised*: "Do you think the person you are caring for has had a change in weight?"*

PROMPTS:　　Why do you think this has happened?

　　　　　　Have you made any changes as a result?

　　　　　　Have you talked to anyone about this or looked for information?

Theme 4: Support and resources for carers about appetite changes in dementia

"What do you know about appetite changes in dementia?"

PROMPTS:　　Tell me about where you read or heard about this?

　　　　　　What did you think about it? Was it useful?

'Where do you go for advice about nutrition in dementia? Is this useful?'

"If you were to give / have you given advice about appetite and dementia to someone in your situation what would it be?"

"What sort of support or resources about appetite and dementia do you think would be most helpful to carers?"

Wrap up of interview

"Is there anything else you would like to tell me about?"

Advise to contact GP or the dementia team looking after their relative if there are any further concerns or worries.

"Thank you for your time and participation"

Check travel or parking costs

Offer supermarket gift voucher

Turn off audio recording

Appendix F Lone worker interviewing

UNIVERSITY OF
Southampton

Research and Enterprise Services Office

RA3 Lone Interviewing Checklist

Management of Health & Safety At Work Regulations 1999 - principles include:
(i) avoiding risks
(ii) evaluating risks which cannot be avoided
(iii) combating risk as source
(iv) replacing the dangerous by the non-dangerous or less dangerous
(v) give appropriate instruction to employees
The points below are to be completed by the researcher(s) with their research team/line manager/principal investigator/supervisor as appropriate.

Discussion Point	Notes & Actions from discussion	Date Complete
Research Design:		
Take general risk assessment into account when designing project: Is lone working necessary? Are home interviews necessary? What time of day will interviews take place? Is it possible to complete during daylight? Clarify circumstances in which home visit is necessary (vs. more neutral environment) Could researchers conduct interviews in pairs?	Home visit if there are practical issues with participant travelling, identification of alternative environment and/or availability of alternative care for individual with dementia.	31.7.2017
Take general risk assessment into account when costing project proposal.	Participant travel costs factored into budget and agreed with Jackie Bridges. Budget is not able to cover additional care costs.	1.9.2017
Training:		
Researchers/Research Teams should consider whether any of the following training or other training may be required/appropriate to the research project team members: First aid Equity and Diversity Deescalating Aggressive or Challenging Behaviour for specific groups such as; Alcohol or drug users, or those affected by mental health, poverty, discrimination or social exclusion.	No additional training identified. If there is aggressive or challenging behaviour researcher will exit from the environment. Research Governance office or supervisor will be notified and advice sought. If there is an emergency situation the police will be called on 999. If there is a need for immediate medical care 999 will be contacted.	31.7.2017
Pre Fieldwork Checks:		
Organise team meeting to agree on general level of risk, systems and responsibilities	Discussed at supervision. Follow lone worker policy. Risk assessment discussed and agreed.	31.7.2017

Research and Enterprise Services Office

RA4 Lone Interviewing Contact Procedure & Location Form

IMPORTANT

If you have any queries please contact your supervisor/principal investigator

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Prior to your first interview/visit:

Please ensure that you have read the **Lone Interviewing Risk Assessment Guidance (RA2)** and completed the **Lone Interviewing Checklist (RA3)** with your supervisor/principal investigator (PI) and completed a **Location Form (RA4)** for the first interview. Please bring the Location Form and your completed Checklist to the Research and Enterprise Services Office (RESO) for review **before** you start your fieldwork.   A copy of your Location Form must also be given to your agreed contact person (if the interviews will take place outside office hours (08.30-16.00).

Prior to each subsequent visit/interview:

Complete a new **Location Form** and hand it to the Research and Enterprise Services Office or your agreed contact person if the interview/visit will take place outside office hours.

On the day of the visit/interview:

Before the interview

The researcher should call the Research and Enterprise Services Office (if during office hours) or the agreed contact person (if outside office hours) to let them know they are about to start the interview.

After a visit/interview

The researcher should call the Research and Enterprise Services Office once the interview/visit is complete (if during office hours) or the agreed contact person (if outside office hours). It is preferable that the researcher speaks to someone in person instead of leaving a message.

If THREE hours have elapsed since the start of the researcher's interview/visit the following procedure should be followed by the Research and Enterprise Services Office /agreed contact person:

- Phone the researcher on the main contact number they have provided (preferably a mobile).

- If they are still interviewing, ask the researcher to telephone the Research and Enterprise Services Office/agreed contact person when they leave.

- If no answer, try other contact numbers.

- If contact has still not been made, phone the interviewee

- If the interviewee says that the researcher is there, ask to speak to him/her personally and check everything is well.

- If the interviewee says that the researcher has left recently (within 10 minutes), wait another 10 minutes. If there is still no contact, instigate emergency procedure (see below).

- If there is no answer from the interviewee, commence emergency procedures.

Emergency Procedures

The Research and Enterprise Services Office or agreed contact person (if outside office hours) should inform the researcher's supervisor/PI and then phone the police (Hampshire Constabulary central call number is 0845 045 4545)

If the researcher should find themselves in an uncomfortable situation:

Leave immediately: Make an excuse to return to the car, taking car keys, and leave.

If the researcher is unable to leave the household:

- Use the telephone to contact someone, preferably the Research and Enterprise Services Office. If this is difficult, explain that the office will be alerted if you do not return.

- If you are able to make an emergency call relay a pre-decided emergency message (e.g. "Please tell my supervisor that the interview is going well")

- If the Research and Enterprise Services Office or agreed contact person hears this phrase, they should contact the police and researcher's supervisor/PI immediately.

Notes:

- *If you feel THREE hours is too long or too short a time, please indicate your time preference on the Location Form.*

- *Please take into consideration how long your interview might take to complete and bear in mind that if the interview finishes outside office hours then the agreed contact person will be responsible for checking the researcher back in and instigating emergency procedures if necessary.*

- *The researcher may also choose to add an additional 'check-in' if they are travelling a long distance before and/or after the visit/interview.*

- *If a visit is happening outside office hours or is likely to finish outside office hours, the agreed person will replace the Research and Enterprise Services Office as point of contact. The agreed person should be a reliable person who you know will be available at the time of the interview e.g. a family member/spouse/partner.*

Appendix G   Supporting information

Arthur J. Gallagher

24th July 2017

TO WHOM IT MAY CONCERN

We, the undersigned Insurance Brokers hereby certify that we have place the following Insurance:

VERIFICATION OF INSURANCE

Unique Market Reference:	B1262FI0671217
Type:	Clinical Trials Insurance, Professional Indemnity and Medical Malpractice
Insured:	University of Southampton and/or University of Southampton Holdings and/or Subsidiary Companies
Period:	From: 01st August 2017 To: 31st July 2018 Both days inclusive at Local Standard Time.
Interest:	This Policy will indemnify/cover the Insured in respect of their Legal Liabilities arising out of the Insured's activities and as more fully disclosed within the Policy Wording.
Limit of Indemnity:	GBP 20,000,000Any One Claim and GBP 20,000,000 in the Aggregate, including costs and expenses GBP 10,000,000Any One Claim and GBP 10,000,000 in the Aggregate, including costs and expenses for Medical Malpractice
Excess:	GBP 12,500 Each and Every Claim, including costs and expenses GBP 5,000 Each and Every Claim, including costs and expenses for Medical Malpractice
Territorial Limits:	Worldwide including USA and Canada Worldwide Excluding USA and Canada for Medical Malpractice
Underwriter:	50.0000% Newline Syndicate 1218 50.0000% NVA Syndicate 2007

This document is for information only and does not make the person or organisation to whom it is issued an additional Insured, nor does it modify in any manner the Contract of Insurance between the Insured and the Insurers. Any amendment, change or extension to such Contract can only be affected by specific endorsement attached thereto.

Should the above mentioned Contract of Insurance be cancelled, assigned or changed during the above policy period in such manner as to affect this document, no obligation to inform the holder of this document is accepted by the undersigned or by the Insurers. The information provided is correct at the date of signature.

Authorised Signatory
Arthur J Gallagher.

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