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An occupational view of improving mealtimes for people with dementia in acute hospitals: a mixed methods study

by

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Thesis for the degree of Doctor of Philosophy

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ABSTRACT

An occupational view of improving mealtimes for people with dementia in acute hospitals: a mixed methods study

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Background and aims

Poor food and fluid intake in older people with dementia is reported in acute hospitals globally. Poor intake can lead to increased mortality rates and longer hospital stays. Mealtimes are a key component of nutritional care in hospitals and involve complex cognitive processes. Additional sensory, behavioural and physical challenges make the process of eating difficult for people with dementia. There is limited research identifying factors influencing mealtime experience and engagement in the eating process for people with dementia during admission to an acute hospital ward. This research project is the first to explore the phenomena of mealtimes for people with dementia in hospital from the perspective of an Occupational Therapist.

The aims of this research project were addressed in two phases. Phase 1 aimed to describe factors observed to influence mealtime experience and engagement in the eating process. Phase 2 explored hospital staff perspectives of factors influencing mealtime experience and engagement. The research project also aimed to identify any interventions or strategies to improve mealtimes for people with dementia in the participating hospitals.

Methods

A fixed, sequential mixed methods design was applied to the research project, which was conducted in two phases. Phase 1 adopted a concurrent mixed methods design. Structured observations, using Dementia Care Mapping, described levels of well-being and engagement at mealtimes. Qualitative field notes supplemented this data to add depth and meaning to the quantitative coding. Quantitative and qualitative data were merged to present a joint display of the combined findings. Phase 2 was informed by the findings from phase 1. Semi-structured

interviews were conducted with staff caring for people with dementia on the participating hospital wards.

Findings

Participants were observed to experience mealtimes positively and engage well in the eating process for 24% of the time. For 19% of the time people experienced mealtimes negatively and were disengaged from the eating process. Factors influencing experience and engagement at mealtimes derived from a plethora of complex variables. System-driven factors, with a task-focused approach to care, negatively influenced engagement in the eating process. Person-centred care, promoting meals as a meaningful occupation for individuals, encouraged positive experiences and focused engagement in the eating process at mealtimes. The hospital environment is not always conducive to encouraging cognitive access to mealtimes.

Conclusions and implications for practice

The findings were applied to the Person-Environment-Occupation Fit model. The closer the three elements fit, the greater the positive influence on occupational performance, specifically engagement in the eating process. Recommendations are outlined from the findings, which can be applied to the model, to promote mealtimes as a meaningful occupation. These include family and carer visitor involvement in the meal process, the use of volunteers, a separate dining environment, training and education for staff, improving food selection processes and using Occupational Therapy expertise in providing mealtime care.

Table of Contents

Table of Tables

Table of Tables

Table of Figures

Academic Thesis: Declaration Of Authorship

I, Naomi Gallant, 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.

<u>An occupational view of improving meal times for people with dementia in acute hospitals: a mixed methods study</u>

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. None of this work has been published before submission

Signed: Naomi Gallant

Date: 05 April 2019

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Definitions and Abbreviations

Definition of terms

Acute hospital

A hospital offering immediate surgical or medical care to people experiencing a sudden onset of trauma or illness.

Acute hospital ward

An individual unit or department of care within the acute hospital where people will stay for one or more nights.

Cognitive access

Having every opportunity to process, understand and respond to cognitive stimulation in the surroundings

Dementia

A term describing a range of symptoms caused by disease of the brain, including cognitive and functional impairment and behavioural changes (Department of Health 2015)

Eating/drinking or The Eating Process

The cognitive recognition of food or fluid as edible and present; the physical transfer of food or drink to the mouth; the three stages of swallowing from oral through to pharyngeal and oesophageal (Chang and Roberts 2008b).

Eating difficulties

The inability to independently complete any one stage of the eating process, resulting in less than adequate nutritional intake.

Eating episode

A specific occurrence of the act of eating or drinking (Bisogni et al. 2007)

Epistemology

How knowledge of reality (the social world) is constructed and represented (Mason 2018).

Mealtime

A time reserved for an eating episode (Sporre et al. 2015)

Meal process

The process involved in planning, preparing, engaging in, and finishing a mealtime.

Meaningful occupation

An activity with purpose or intention that brings value to an individual. An activity whereby an individual can express identity (Fjellström 2004; Dewing 2008; Wilcock 1998).

Occupational injustice

Restricting individuals from meeting their occupational needs or engaging in meaningful occupation (Durocher et al. 2013).

Ontology

How the nature, character and essence of reality (the social world) is viewed (Mason 2018).

Person-centred care

Care that respects people as individuals and is organised around their needs (Nolan et al. 2004).

Sundowning Symptom

A set of symptoms typically seen in people with dementia, described as disorientation, distress or confusion and occurring late afternoon or evening time (Chang et al. 2017).

System-centred care

Care that is driven by meeting the objectives and tasks prioritised by the hospital system.

Ward Hostess

A member of ward staff employed by the hospital Trust involved in the research project. Their role was described as being solely for the purpose of facilitating the meal processes for patients on the wards. Typically they assist with making menu choices, delivery of meals, and eating and drinking difficulties.

Abbreviations used within the thesis

BCC – Behaviour Category Code (used within the Dementia Care Mapping tool)

CASP – Critical Appraisal Skills Programme

DCM – Dementia Care Mapping

EdFED – Edinburgh Feeding Evaluation in Dementia scale

HCA - Health Care Assistant

HCPC - Health and Care Professions Council

ICF – International Classification of Functioning

ME score – Mood and Engagement score (used within the Dementia Care Mapping tool)

MMAT – Mixed Methods Appraisal Tool

NHS – National Health Service

PD – Personal Detractors (used within the Dementia Care Mapping tool)

PE – Personal Enhancers (used within the Dementia Care Mapping tool)

RCOT – Royal College of Occupational Therapists

TV – Television

UK – United Kingdom

USA – United States of America

Chapter 1   Background

Introduction

As early as 1860 the importance of allowing access to food to people under hospital care was being recognised:

> *"Every careful observer of the sick will agree in this, that thousands of patients are annually starved in the midst of plenty, from want of attention to the ways which alone make it possible for them to take food"* (Aselage and Amella 2010, p.36) quoting Florence Nightingale.

The importance of adequate food and fluid intake, when an older person is in an acute hospital ward, cannot be overrated. Malnutrition among older people with dementia in hospitals has been described as a national scandal, affecting 30 to 50% of older people in rehabilitation or acute hospital settings (Age Concern 2006 ; Young et al. 2018). Still, over a decade later, this scandal continues, with one quarter of staff acknowledging that the nutritional needs of people with dementia are only sometimes met (Corrado et al. 2017). Inadequate food and fluid intake has been associated with increased risk of infections, falls, constipation, pressure ulcers and slower wound healing (Reed et al. 2005; Saka et al. 2010; Heaven et al. 2013; Hooper et al. 2014). Yet, inadequate food and fluid intake are well-documented issues of concern in acute hospitals across the UK (Francis 2013; Corrado et al. 2017).

The research project presented in this thesis aims to add to the existing knowledge of factors influencing inadequate food and fluid intake in people with dementia in hospital. The importance of research to address clinical practice issues is reflected on in the next section. The literature informing the development of the research project is then presented including published literature about dementia, the eating process, and the acute hospital setting. The chapter provides an overview of current policies and guidelines for nutritional care in dementia. The clinical context in which the topic for the research project was developed is introduced as a reflection of practice.

1.1   The Development of the Research Project: A Reflection

When practicing as a Health Care Assistant in a dementia care home, my interest and passion for improving lives for people with dementia was instigated. While practicing as an Occupational Therapist in older person's care, in both mental health and physical health settings, this passion

developed further. I began to observe a need for improvement in the care for people with dementia specifically while inpatients in hospital, when working on medical and rehabilitation wards for older people. Supporting people with dementia appeared to introduce different challenges, requiring a specialist approach. It was not uncommon to see people appearing agitated or aggressive in nature and refusing to eat or comply with care. Staff needed to be vigilant to incontinence in inappropriate or public places, and people walking around disrupting other patients or posing a high risk of falls. These issues seemed worse in the hospital setting and yet there seemed an obvious gap in skills and understanding to provide care for people with dementia. Here I realised a need for work to explore the evidence base and improve the understanding of dementia and care in the hospital setting.

When exploring published evidence to inform my practice as an Occupational Therapist, I began to discover a lack of an evidence base, or knowledge of the evidence base, for interventions used by practitioners. As an Occupational Therapist in a dementia specialist ward setting, the role required me to complete mealtime assessments when people were not eating well. The Pool Activity Level Instrument for Occupational Profiling (Pool 2012) was used to facilitate observational assessments. There was little other guidance for mealtime assessments found, and no literature to provide reasoning for the Occupational Therapist involvement in the assessment. The opportunity to undertake a clinical academic pathway arose, combining clinical practice with conducting research.

In choosing to pursue the path of a clinical academic doctoral fellowship I have been able to continue to develop knowledge and skills, along with a growing passion in working as an Occupational Therapist with older people with dementia. This has been possible while contributing to the evidence base for improving care for people with dementia in hospitals. The continuation of clinical practice was important to ensure an understanding and awareness of research needs in front line care. Through a clinical academic role I could maintain understanding and identify what research questions are relevant to staff and patients in hospitals. In continuing to develop skills in both research and clinical practice the research project has the potential to have a more significant and timely impact on care for people with dementia in hospitals. The findings will influence the changes and improvements needed in nutritional care for people with dementia at mealtimes in the acute hospital setting. The research project presented in this thesis applies an occupational perspective to improving eating and drinking, particularly at mealtimes, for people with dementia in hospitals.

1.2   Key policy drivers to improve nutrition in dementia care

Dementia care as a general concept is recognised worldwide as needing government and strategic influence (The Scottish Government 2017; National Institute for Health and Care Excellence 2018; World Health Organisation 2017). The UK government holds improving hospital care for people with dementia as a national priority (Department of Health 2015; Corrado et al. 2017; Scottish Government 2017). Supporting people with dementia to engage in eating is also recognised as a priority in dementia care by the National Institute for Health and Care Excellence (National Institute for Health and Care Excellence (NICE 2018). These key guidelines also identify the importance of meeting the needs of people with dementia in a way that is in line with person-centred care and considering the individual challenges the disease presents (Department of Health 2015).

Keller et al. (2014) highlight the importance of "government" in influencing eating and drinking for people with dementia. This includes policy and regulation around food and staffing. Policies and guidelines for providing person-centred, nutritional care in hospitals are still limited. Some guidance is recognised within wider documents but generally includes broad statements about ensuring nutritional needs are met (Corrado et al. 2017; NICE 2018). For example, the National Institute for Health and Care Excellence (NICE 2018) states "Encourage and support people with dementia to eat and drink, taking into account their nutritional needs" (p30).

The guidance from the Department of Health (2015) makes more specific suggestions. Guidelines include: considering the room lay out, removing sensory distractions, using contrasting colours for tableware and encouraging appropriate seating posture during consumption of food and drink (Department of Health 2015). The Care Quality Commission (CQC) support this, identifying problems such as, patients not being given adequate physical support, meals being interrupted, and patient needs not being adequately assessed (Care Quality Commission 2013). These have been identified as problems pertinent to the acute hospitals setting (Corrado et al. 2017).

The recent National Audit of Dementia (Corrado et al. 2017) supports suggestions such as protected, uninterrupted mealtimes. It also highlights the importance of availability of finger foods, availability of foods at all hours, and the presence of familiar family members or carers to support at mealtimes. In view of the limited guidance available, individual NHS Trusts and other organisations have developed their own more clinically based guidelines for nutritional care, and meals. An example includes the communication and mealtime toolkit produced by Kellett (2012) within NHS Dumfries and Galloway.

Chapter 1

Overall the key policies both nationally and internationally are vague regarding improving eating and drinking in people with dementia. The World Health Organization (2017) suggested that a lack of understanding of dementia and the implications of the disease is a potential cause for the inadequate care being provided. In order to understand the implications of dementia on eating, the eating process must first be understood as a concept.

1.3   The Eating Process

Eating and drinking is a complex phenomenon in which both hedonic and homeostatic pathways are used in the body to stimulate intake of food and drink (Cipriani et al. 2016). Hedonic processes may involve external cues such as visual or olfactory stimuli, which motivate a person to begin the process of eating or drinking (Malik et al. 2008). Homeostatic processes are primarily known to be regulated by the hypothalamus region of the brain. Hormones and nerve impulses are transferred between the brain and gut to regulate hunger and satiety (Cipriani et al. 2016). Homeostatic pathways can be stimulated by hedonic processes.

Siebens et al. (1986) describe the eating process as "a primitive sense without concern for social niceties" (p193). They describe five stages of the eating process, summarised by Chang and Roberts (2008a) as:

- the cognitive ability to recognise food as edible and present,
- the physical ability to transfer food to the mouth,
- the three stages of swallowing from oral through to pharyngeal and oesophageal.

This process addresses the immediate actions of feeding the body (Watson 1993), but does not acknowledge the complexity of drivers needed to initiate the eating process. Motivation and stimulation to eat is known to go beyond the need for energy homeostasis or hunger satisfaction (Cipriani et al. 2016).

Eating and drinking often occurs at mealtimes; literally defined as a time reserved for an eating episode (Sporre et al. 2015). Mealtimes are a cultural activity varying according to socioeconomic status, geographical situation, ethnicity and culture (Amella et al. 2008; Amella and Batchelor-Aselage 2014). In addressing the complexity of the eating process, the various components of mealtimes should be explored.

Situational factors such as, physical and social surroundings, time of day, time restrictions, and antecedent activities, will also impact engagement in the eating process (Bisogni et al. 2007). In a study among working adults in the United States of America (U.S.A) exploring the situational nature of eating and drinking, Bisogni et al. (2007) developed a conceptual framework describing eight dimension of the eating process as shown in Figure 1. Food and drink is in the centre of this model. Eating goes beyond nutritional intake, food choices have cultural and emotive significance (Hanssen and Kuven 2016).
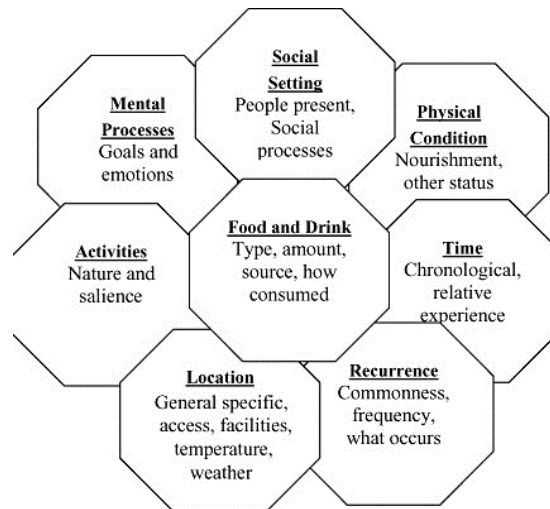
Figure 1: The Eight Interacting Dimensions and Features of Eating and Drinking Episodes (Bisogni et al. 2007)

The framework of interacting dimensions and features of the eating process shows the complexity of the eating process beyond intake for nutritional purpose. In figure 2, The International Classification of Functioning (ICF) model (World Health Organization 2001b) also shows how activities, for example eating and drinking, are the centre of a complex process of impacting factors, including personal and environmental. Cognitive load theory states that a more complex activity, with high levels of interactivity between elements of the activity, increases cognitive load (Paas et al. 2003). Eating is one such activity. Physical elements such as grip and dexterity, lifting food to the mouth, chewing and swallowing, combine with the cognitive demands of eating, for example, recognising food, initiating eating, memory and attention to continue to task, and external sensory influences. This combination of elements of the task creates an activity with a heavy cognitive load (Kaisari and Higgs 2015).
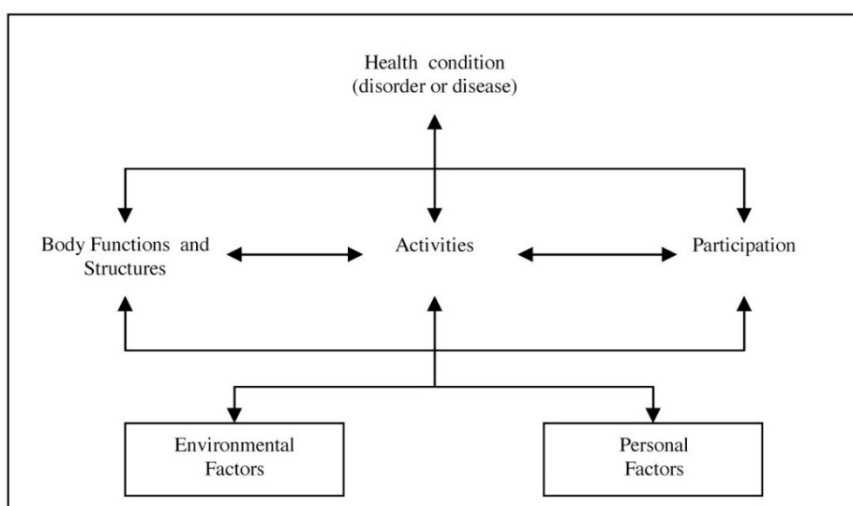
Figure 2: International Classification of Functioning, Disability and Health
(World Health Organization 2001)

It is clear, then, that the "social niceties" alluded to by Siebens et al. (1986) may in fact have an enabling or limiting impact on the eating process. This is particularly true for people with dementia, where symptoms of the disease may limit the ability of an individual to eat and drink independently within the appropriate mealtime occasion (Aselage and Amella 2010; Lin et al. 2010; Liu et al. 2014).

1.4   Dementia

Dementia is a term that describes a collection of degenerative symptoms caused by disease of the brain. It results from loss of neurological connections in the brain. Neurological deterioration causes catastrophic cognitive decline, functional decline, and behavioural changes (Ragdale 2014; Collier et al. 2015; Department of Health 2015). There are over 100 types of dementia, the most common being Alzheimer's Disease, Vascular Dementia, Lewy Body Dementia and Fronto-temporal dementia (Ragdale 2014). The speed of neurological decline, and the consequent difficulties vary from person to person and within the different types of dementia. It is estimated that half the population of people with varying types of dementia, eventually experience eating difficulties (Brooke and Ojo 2015).

People with dementia may have difficulties completing the eating process due to sensory, cognitive, behavioural, and physical challenges (Brook 2014; Collier et al. 2015; Department of Health 2015). The challenges around engagement in the eating process can be internal or external to the person with dementia.

1.4.1   INTERNAL: symptoms of dementia

Neurological degeneration impacts motor skills required for eating and drinking. The muscles and nerves, in the mouth, required to complete the eating process lose coordination and function. This loss of function limits chewing and swallowing ability, often referred to as dysphagia. Dysphagia has a prevalence of up to 57% in people with dementia (Rosler et al. 2015). In the later stages of dementia dysphagia becomes more prevalent. The risk of aspiration increases, with aspiration pneumonia being the leading cause of death for people with dementia (Rosler et al. 2015).

Disruption of neurological pathways affects more than physical abilities. Progressive cognitive impairment creates a particular challenge for people with dementia. Cognitive impairment means people may lose an understanding of the purpose or process of eating (Gillick and Mitchell 2002). As a result of impaired neurological systems and cognitive functioning in dementia, it is highly likely that eating and drinking difficulties will progress throughout the stages of the disease (Parker and Power 2002). In the earlier stages people may forget mealtimes, or gradually lose the ability to shop for and prepare food (Ragdale 2014; Douglas and Lawrence 2015). As the disease develops, further cognitive decline and sensory challenges arise. The initial stages of the eating process may become a particular challenge (Chang and Roberts 2008b). There may be confusion over recognition and use of utensils, and recognition of food (Lee and Song 2015) . Cognitive planning needed to bring food to the mouth, and execution of that plan, becomes more difficult (Cipriani et al. 2016). Further cognitive processes such as attention, concentration and memory are essential to repeat and continue the eating process to the completion of a meal (Barratt 2004; Cleary 2007). In advanced stages of dementia people are more likely to experience dysphagia, loss of appetite and apathy typical with end of life (Watson and Green 2006; Chow et al. 2009).

Behavioural and psychiatric symptoms in dementia (BPSD) are also common as a result of neurological degeneration (Ismail et al. 2016). These symptoms can include agitation, depression, anxiety, hallucinations, delusions, aggression and apathy (Sampson et al. 2014; Ismail et al. 2016). Any one of these symptoms can be disruptive to the eating process although apathy and depression have been individually attributed to weight loss in people with dementia (Keller et al. 2014). In contrast to the physical and cognitive difficulties previously discussed, psychiatric symptoms of dementia may not prevent the ability of the person to engage in the eating process, but rather impact their beliefs and choices around eating the food (Chang and Roberts 2008a).

The relationship between dementia and the eating process is complex. There are many symptomatic factors contributing to inadequate food and fluid intake, including physical, psychiatric and cognitive issues. All of these can also be impacted by the person's experience of

the mealtime as a whole. Interaction and relationships with people and the surrounding environment may facilitate or interfere with the eating process (Amella and Batchelor-Aselage 2014).

1.4.2   EXTERNAL: Environment/context

The model in Figure 3 was developed in order to aid understanding of the complexity of the various factors influencing eating and drinking (Keller et al. 2014). It conceptualises the different factors impacting eating and drinking at mealtimes. The model is based on residents in long term care, but can also be applied to the community or hospital setting. There is some consideration of the person with dementia, named "Resident" in the model, and the impact the disease has on the eating process. However, most consideration in this model is given to factors external to the person with dementia: meal quality, meal access and mealtime experience.
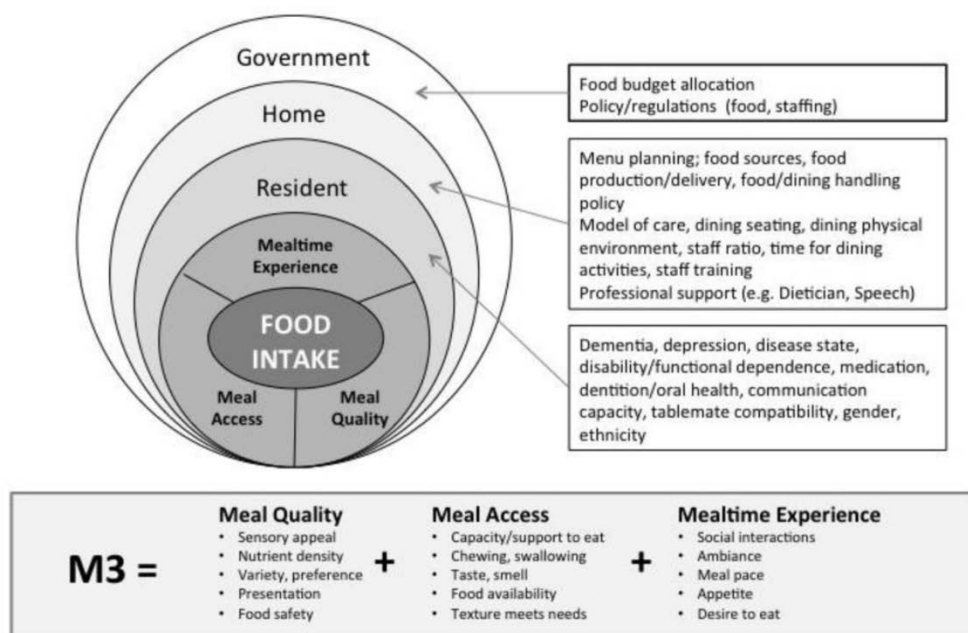
Figure 3: M3 model: Making Mealtimes Matter (Keller et al. 2014)

Access to the meal, and experience of the meal, can be dependent on environmental factors. Physical access may include being able to reach the food, having the ability to chew and swallow the food and having an appropriate texture which meets the needs of the person's disability (Keller et al. 2014). An accessible environment, where a positive experience of the mealtime occurs, may also impact engagement in the eating process for people with dementia (Aselage and Amella 2010). Factors such as noise levels, clutter and adequate lighting have been known to influence engagement in the eating process and mealtime experience (Aselage and Amella 2010; Chang and Roberts 2008b).

The elements of mealtime experience highlighted in the model, namely social interactions, ambiance and meal pace, will vary between care settings according to organisational systems, management and culture (Borbasi et al. 2006). Admission to an acute hospital ward is often a sudden change into an unfamiliar environment, which can impact quality and experience of care for people with dementia (Goldberg et al. 2014; Dewing and Dijk 2016).

1.5 Dementia care in the acute hospital setting

Around one quarter of acute medical beds for older people in hospitals in the UK are occupied by people with dementia (Corrado et al. 2017). In the UK people with dementia are admitted to an acute hospital two to three times more often than other older people (Sampson et al. 2014). People with dementia are often more vulnerable to negative clinical outcomes in an acute hospital due to confusion and the reduced ability to communicate effectively (Borbasi et al. 2006). Admission to hospital for people with dementia is associated with further cognitive decline, reduced independence in activities of daily living, and a higher risk of institutionalisation (Timmons et al. 2016).

In acute medical wards, people with dementia will usually be admitted for reasons other than the dementia diagnosis, often as a result of medical problems or trauma. When a person is admitted to hospital for non-dementia related, medical reasons, the treatment priorities do not lie with the specific needs presented through the dementia (Borbasi et al. 2006; Goldberg et al. 2014; Dewing and Dijk 2016). The constraints of the system, work load, and restraints on time and resources, can impact the ability of staff to see past a patient to the person behind the dementia diagnosis or presentation (Borbasi et al. 2006; Goldberg et al. 2014). As a result, the psychological symptoms of dementia, presenting as distress or agitation, may become burdensome to staff, leading to misunderstanding or unmet needs (Timmons et al. 2016).

Admission to an acute hospital can be a disruptive and distressing time for people with dementia (Timmons et al. 2016). The hospital environment can be unfamiliar, potentially unpleasant,

crowded and noisy (Goldberg et al. 2014). The adjustment to an unfamiliar environment may increase agitation, distress and restlessness; an issue which has been acknowledged for decades (Tolson et al. 1999; Sampson et al. 2014). The hospital environment has even been suggested to be strange, unfamiliar, and therefore unsafe for people with dementia (Borbasi et al. 2006). The disruption and confusion can have a detrimental impact on their ability to eat and drink due to difficulty adapting to the change in circumstances and environment (Nygard et al. 2009). They may hold on to old and familiar routines by way of coping with cognitive changes and the reduced ability to carry out activities (Johansson et al. 2011). Bisogni et al. (2008) (Figure 1) highlight how time, location, physical condition, mental processes and social setting are significant dimensions in the meaning of eating episodes. A shift in mealtime environment or context, leading to a disruption of the meaning and purpose of the mealtime, can create a barrier to engaging in the eating process (Aselage and Amella 2010).

It is unsurprising then that there is interference with the eating process when a person with dementia is faced with admission to an acute hospital ward. Inadequate food and fluid intake during admission could exacerbate negative clinical outcomes or increase mortality rates (Reed et al. 2005). It is essential that dementia care specific to mealtimes is made a priority in policy and guidelines for hospitals both in the UK and globally (Corrado et al. 2017; World Health Organisation 2017).

1.6   Theoretical framework

1.6.1   An Occupational Perspective

The researcher applied a novel approach to research into eating and drinking, and mealtimes, for people with dementia. An occupational perspective was taken in regard to the research presented in this thesis. Engagement in meaningful occupation is considered essential for health and well-being (World Health Organisation 2001). Occupational justice theory states that all individuals have unique occupational needs and capacities; all individuals have a right to exercise the capacity to access meaningful occupation (World Federation of Occupational Therapists 2010; Durocher et al. 2013). Restricting individuals from meeting their occupational needs, engaging in occupation, is described as occupational injustice and impedes on their human rights (World Federation of Occupational Therapists 2010; Durocher et al. 2013).

Occupational injustice can present in five different forms, described by Durocher et al. (2013). Occupational apartheid refers to institutionalised occupational injustice where opportunity to engage in meaningful occupation is offered to some and not others. Occupational deprivation

refers to exclusion from necessary or meaningful occupation due to limited availability or resources and factors outside the control of the individual. Disengagement from meaningful occupation as a result of invisible or unspoken expectation, norms and attitudes, either externally or internally to the individual is described as occupational marginalization. Occupational imbalance describes exposure and engagement in one area at the expense of another. The long-term effects of any form of occupational injustice result in occupational alienation. A lack of meaningful occupation in the long term leads to lack of identity and disconnectedness from an individual's surroundings.

The hospital environment has the potential to promote occupational injustice when considering the rights of a person with dementia to engage in the occupation of eating and drinking at mealtimes. The unfamiliar routines, and the disruption and confusion of a hospital admission, are factors external to the individual (Borbasi et al. 2006). Admission to hospital could reduce the ability and opportunity for a person with dementia to continue their normal ways of accessing resources to engage in eating and drinking (Johansson et al. 2011). Occupational injustice, in many forms, can occur when an individual does not fit the expectations, norms, or resources within hospital care.

Older people, with or without dementia or a cognitive impairment, have been identified as not fitting into one-size fits all approach of the hospital system (Parke and Chappell 2010). Consequently, opportunities for engagement in meaningful occupation are limited. Lack of fit between older people and hospital was displayed by Parke and Chappell (2010) in four dimensions: architectural design features or physical environment, bureaucratic conditions, chaotic atmosphere and hospital employee attitude. All of these have been identified as influencing eating and drinking difficulties for people with dementia (Keller et al. 2014; Liu et al. 2016; Murphy et al. 2017). It is clear, then, that the hospital environment can negatively influence engagement in eating and drinking as meaningful occupations.

1.6.2 Models of eating and drinking difficulties

Various models presenting eating and drinking difficulties for people with dementia have been developed from the published literature (Aselage and Amella 2010; Keller et al. 2014; Liu et al. 2016; Murphy et al. 2017). The models present eating and drinking difficulties for people with dementia as a complex phenomenon. The research presented in this thesis used the models to inform background knowledge and the appropriate methodological approaches to further explore the phenomenon for people with dementia in the acute hospital setting.

A recent study conducted in care homes included the development of a model for the provision of person-centred nutritional care in dementia (Figure 4) (Murphy et al. 2017). Murphy et al. (2017) demonstrate the complexity of factors which influence nutritional care for people with dementia, while keeping the person with dementia central. This was the approach taken in the research presented in this thesis, ensuring the person with dementia was central to methodological considerations and analysis of the data. It is clear from the model developed by Murphy et al. (2017) there are many complex factors surrounding the person, which contribute to nutritional care. They include availability and access to food and drinks, appropriate tools and resources available within a supportive environment, the social element of eating, systematic contribution such as consistency of care and the provision of the right information to people with dementia and those caring for them.
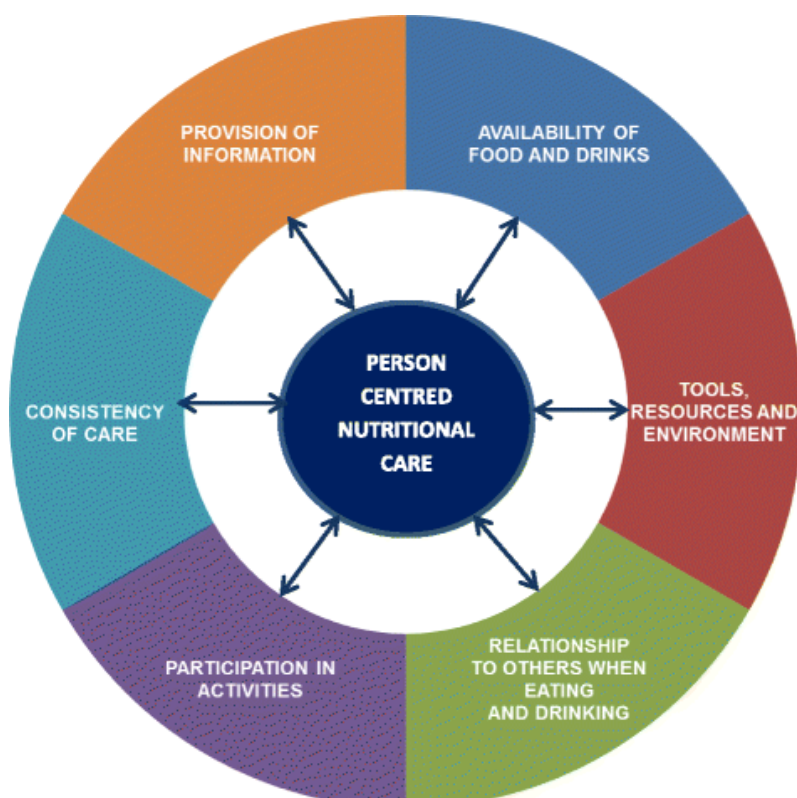
The complexity of factors influencing food intake for people with dementia in care homes has previously been conceptualised by Keller et al. (2014) in a different model, with food intake at the centre. This is displayed in Figure 3 and described further in chapter 1.4. The model was considered essential in framing the knowledge and methodological approaches to the research presented in this chapter. It presents the complexity of factors influencing nutritional care for people with dementia, but with a specific focus on food intake. Factors conceptualised in the model included, the eating environment, the mealtime culture and practices of the care home, and government or policy influence.

The Socio Ecological Model (SEM) (Lui et al. 2016) displayed in Figure 5, has similarities to the M3 model (Keller et al. 2014) (Figure 3) and model of person-centred nutritional care (Murphy et al. 2017) (Figure 4). It highlights social and interpersonal, environmental, and political influences on eating and drinking. At the centre of the model internal factors of the person with dementia, such as cognitive impairment and physical ability, are displayed.

Intrapersonal
Comorbidities
Cognitive impairment
Physical capability
Motivation
Mood & behavioral
disturbances

Interpersonal (caregiver/peer resident)
Perceptions
Knowledge/attitude/skills
Communication/interaction
Support/assistance/role
modeling

Environment (Physical and Cultural)
Lighting/noise/table contrast/assistive utensils
Chairs & wheelchairs fit/adaptive seat height
Dining routine/cultural norms
Food delivery/choices

Policy
Staffing (high workload/insufficiency)
Custodial care practice (task-oriented)
Institutional policies (safety)

Figure 5: The Socio Ecological Model (SEM) (Lui et al. 2016)

The three models presented in Figures 3, 4 and 5, represent the current knowledge and understanding of eating and drinking difficulties for people with dementia. They are broad and complex models, which provide a clear framework for developing further research of the topic. A final model considered pertinent to the research presented in this thesis is the model of mealtime difficulty (Aselage and Amella 2010) presented in Figure 6.

Antecedents	Attributes	Consequences
Social considerations Cultural factors Lifelong eating patterns	Mealtime patterns Dyad interaction Mealtime environment Dementia Aversive feeding behaviors	Dyad stress Compromised nutritional status Loss of eating ability Tube vs. hand-feeding Death
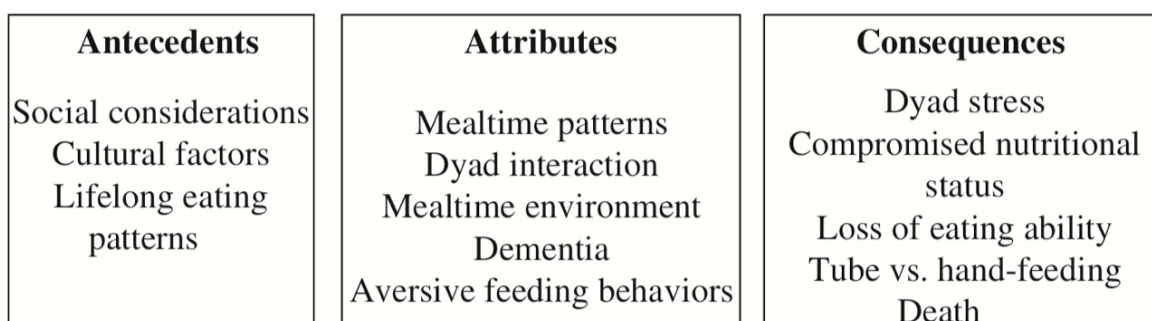
Figure 6: Model of Mealtime Difficulty (Aselage and Amella 2010)

Differing from the other models presented in this section, the model of mealtime difficulty (Aselage and Amella 2010) is a linear model. It considers the time surrounding meals as important when considering factors influencing eating and drinking for people with dementia. It presents the social element of eating, and cultural personal factors of eating, as antecedents to the eating episode at a mealtime. The model of mealtime difficulty also recognises the consequences of eating and drinking difficulty and how these, effect eating difficulties in the long term.

1.7   The research question and thesis outline

This introductory chapter has outlined the current knowledge, and conceptualisation of the theory, of eating and drinking difficulties for people with dementia. The acute hospital setting clearly presents a separate type of difficulty, as outlined in Section 1.5. Combining this underlying knowledge with an occupational perspective of engagement in the eating process for people with dementia inspired the researcher to develop the research project presented in this thesis.

The research presented in the rest of this thesis addresses the question: what influences engagement in, and experience of, mealtimes for people with dementia in acute hospital wards? A good foundation of understanding exists in conceptualising eating and drinking difficulties for people with dementia, but a model is yet to be developed which concentrates on enabling engagement in mealtimes as a meaningful occupation. Further understanding was required of published research investigating what is specifically influencing engagement in the eating process. The following chapter presents a systematic search of existing published research into factors influencing engagement in eating and drinking for people with dementia in hospital.

Chapter 1

The specific purpose of the research project presented in this thesis is determined and presented at the end of the literature review. The thesis then continues in presenting the methodological considerations of the research project, a summary of the significant findings from the data collection, and a discussion of application to the hospital setting. Recommendations for supporting people with dementia to engage in the eating process while in hospital are presented, followed by planned publications and the potential for further research.

Chapter 2   Literature Review

2.1   Introduction

The primary aim of the literature review was to locate published research in order to:

- explore current knowledge of factors influencing mealtimes and engagement in the eating process for people with dementia in the acute hospital setting.

- identify what interventions are used to effectively improve engagement in the eating process for people with dementia.

With an understanding of the current knowledge and evidence base, the gaps for further research could be identified, and aims and objectives for the research project presented in this thesis developed.

2.2   Methods

A systematic search guided by the PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analysis) statement (Liberati et al. 2009) was initially completed August to December 2015. A secondary search was conducted June to July 2018 to identify any new published literature. An initial scoping search was conducted using the platform Delphis from which key databases were identified: the Cumulative Index of Nursing and Allied Health Literature (CINAHL), MEDLINE, PsycInfo, the Web of Science, and the Allied and Complimentary Medical Database (AMED). The Cochrane Library, and reference lists of literature selected for inclusion were also searched for relevant literature. Searches comprised variations of three key areas: Dementia, eating and drinking, and the acute hospital setting. The search terms were identified through MeSH terms and suggested subheadings within data bases. Key words searches were also used. The search terms were combined in various way using Boolean terms "AND" and "OR", and truncation used to broaden the search results. The search strategy is presented below:

Chapter 2

Primary: What is already known about factors influencing eating and drinking for people with dementia in the acute hospital setting?

Secondary: What interventions are effective in managing eating and drinking difficulties for people with dementia in the acute hospital setting?

CINAHL - 06/8/18

S1: MM "Dementia" – subject terms ticked – MH "Dementia, Vascular", MH "Lewy Body Disease", MH "Dementia, Senile", MH "Dementia, Presenile"

S2: "Alzheimer Key word search*

S3: S1 + S2 = 54 314 results

S4: "eating difficul" key word search + subject terms ticked MM "Eating" MH "Eating Behaviour" MH "Food Habits"*

S5: "meal" key word search + subject terms ticked – MM "Meals" MH "Food Assistance"*

S6: "eating N3 drinking" key word search

S7: S4 OR S5 OR S6 = 36 897 results

S8: MM "Acute Care"

S9: Key word search "Acute hospital" OR "Acute setting" OR "Acute ward"

S10: S8 OR S9 = 52 273 results

S11: S3 + S7 + S10 = 9 results

Not enough – S10 is limiting factor

S12: S3 + S7 = 446 results

MEDLINE – 7/8/18

S1: MM "Dementia", OR Suggested Subject Terms ticked -MH "Dementia, Vascular", OR MH "Dementia, Multi-infarct", OR MH "Alzheimer Disease", OR MH "Lewy Body Disease"

= 116 855 results

S2: "Eating difficul" Key word + Subject Terms ticked MM "Eating", OR "Feeding Behaviour"*

S3: "Eating N3 Drinking"

S4: MM "Meals"

S5 "Meal" Key word search*

S6: MM "Food Assistance"

S7: S2 OR S3 OR S4 OR S5 OR S6 = 149 379 results

S8: MM "Hospitals" OR Acute Hospital Key word

S9: Key words search: "Acute Care" OR "Acute setting" OR "Acute ward"

S10: S8 OR S9 = 228 552 results

S11: S1 AND S7 AND S10 = 6 results

Not enough – limiting factor is Acute care S10

S12: S1 AND S7 = 490 results

PsychInfo – 7/8/18

S1: MM "Dementia", Subject terms: DE "Vascular Dementia", OR DE "Senile Dementia", OR DE "Presenile Dementia", OR DE "Semantic Dementia", OR "Dementia with Lewy Bodies", OR DE "Alzheimer's Disease"

= 66 277

S2: Suggest Subject Terms for "Eating difficul" –DE "Eating Behaviour" (includes "Eating") OR DE "Activities of Daily Living"*

S3: "Eating N3 Drinking"

S4 "Meal" Key word search*

S5: Suggested Subject terms search "Food Assistance" – subject terms ticked DE "Food Intake"

S6: S2 OR S3 OR S4 OR S5 = 49 855

S7: MM "Hospitals" OR Subject Terms ticked DE "Hospital Environment" OR DE "Hospitalized patients" OR "Hospital Admission"

S8: Key word search: "Acute setting" OR "Acute ward" OR "Acute care"

S9: S7 OR S8 = 49 027

S10: S1 AND S6 AND S9 = 59 results

S11: S1 AND S6 = 2620 results

Web of Science – Key word Search – 7/8/18

S1: "Dementia" OR "Alzheimer"*

S2: "Eating N3 Drinking" OR "Eating difficul" OR "Meal*" OR "Eat*"*

S3: "Hospital" OR "Acute Hospital" OR "Acute setting" OR "Acute ward" OR "Acute Care"

S4: S1 AND S2 AND S3 combined in Web of Science = 113 results

S5: S1 AND S2 combined = 1324 results

AMED – Key word search - 7/8/18

S1: "Dementia" OR "Alzheimer"*

S2: "Eating N3 Drinking" OR "Eating difficul" OR "Meal*" OR "Eat*"*

S3: "Hospital" OR "Acute Hospital" OR "Acute setting" OR "Acute ward" OR "Acute Care"

S4: S1 AND S2 AND S3 = 3 results

S5: S1 AND S2 = 44 results

Cochrane Library – Cochrane Reviews – Key word search 7/8/18

S1: "dementia OR Alzheimer" AND "Eat* OR Meal*" = 6 results*

Total: 5025

Duplicates = 4440

*Total to screen Title and Abstract = **585** (579 Endnote, 6 in Cochrane)*

Inclusion/Exclusion criteria:

Add primary research (?empirical research) protocols and conference data to inclusion
Add non-research papers e.g. magazine articles to exclusion

Exclusion: dysphagia - physiology of swallow difficulties
- community based
- non-oral food intake – e.g. PEG, NG
- hyperphagia – this study is looking at undereating

Interventions studies kept as a resource of information but are summarised in recent intervention literature reviews.

As seen in the search strategy the acute hospital setting was a limiting factor in the search. The search was broadened by removing the acute hospital factor, which included the terms "acute hospital", "acute setting" and "acute ward". The results, which were found from acute hospital specific search terms mostly focused on fortification of food, non-oral intake, or were studies not specific to dementia care, so did not fit the inclusion criteria.

Inclusion and exclusion criteria were used to identify literature relevant to the aims. This is identified in Table 1. The search aimed to be as inclusive as possible in including a wide range of dementia types. Initially all types of dementia were included, however, it is apparent in the literature that people with frontal temporal dementia types often have distinct eating difficulties from other dementia types. The issues are more likely to be a lack of control of eating, binge eating, eating inedible objects and weight gain (Piguet et al. 2011; Aiello et al. 2016; Cipriani et al. 2016). This review aims to explore lack of engagement, leading to under eating and under nutrition, for people with dementia. Studies specific to difficulties experienced by people with frontal temporal types of dementia were therefore excluded.

Table 1 lists "all care settings" to be included in the search, despite the research project being set in acute care. More generic papers were included to gather a broad understanding of eating and

drinking difficulties in dementia. Studies conducted worldwide added to the depth of understanding through exploring multiple cultural aspects within different health systems. No date restrictions were used to ensure publications from past decades, which have impacted more recent work, were not missed. As a result some studies identified were published more than ten years ago, but still contained relevant material to inform current understanding of eating and drinking processes in dementia.

The publications selected included qualitative and quantitative, and mixed methods studies, using a variety of research methods. This integrative approach is inclusive of diverse methodologies and research designs. It is used to assist in finding a broad, comprehensive evidence base, from varied research perspectives, not constrained to specific study types (Whittemore and Knafl 2005). As shown in Table 1, published literature reviews were included in the search. This was to add to conceptualisation of the research topic, and to reduce duplication of other literature reviews.

Table 1: Inclusion and exclusion criteria for published literature identified for review	
Inclusion	Exclusion
- all types of dementia except frontal lobe/frontal temporal - eating, drinking and feeding difficulties - all care settings - world wide - multi-profession - systematic reviews - no date restrictions - qualitative, quantitative and mixed methods studies	- Frontal temporal types of dementia - end of life ethical issues - non-oral feeding - fortified foods and supplements - nutrition as a risk factor in developing dementia - physiological dysphagia - links with dementia, learning disabilities and Down's syndrome - pharmacological studies - discussions about tools for measuring eating and drinking difficulties - nutritional screening tools

Throughout the screening process it became evident that recent literature reviews existed exploring interventions used for improving nutritional intake for people with dementia. Research studies of specific interventions, already included in these recent literature reviews were then excluded. The literature reviews exploring effective interventions were included. This was to meet

the aim of identifying what interventions are used to effectively improve engagement in the eating process for people with dementia. Other reasons for exclusion throughout the screening process were studies not reporting empirical research, or not being relevant to answering the aims the review set out to explore.

Once the relevant literature had been identified, an integrative review methodological approach was used for analysis of the findings presented the selected papers (Whittemore and Knafl 2005). The integrative approach includes qualitative, quantitative and mixed methods studies and so is appropriate for exploring complex phenomenon such as health related topics (Souto et al. 2015) . With the inclusion of such variety in theoretical and research approaches, and study methods, there is a risk the literature review lacks rigour or format. To overcome the risk, and add structure to the quality appraisal, the Mixed Methods Appraisal Tool (MMAT) (Hong et al. 2018b) was used.

The MMAT is a recently developed tool, designed to meet the growing demand for a rigorous, reliable tool to review studies of varying methodologies (Pace et al. 2012; Souto et al. 2015). The original tool was critically appraised by research graduates, experienced mixed methods researchers, and members of the Cochrane Collaboration. Their feedback was used to produce the 2011 MMAT (Pace et al. 2012). This was further developed in a doctoral study through a literature review of critical appraisal tools, interviews with MMAT users, and a Delphi study with international experts in the field (Hong et al. 2018a). The most recent MMAT - The 2018 MMAT (Hong et al. 2018) (Appendix B) - is used to critically appraise the empirical research in this literature review.

Each category of study design listed in the MMAT has 5 five guiding questions. The answer to these can be "yes", "no", or "can't tell" with further space in the tool for other comments. The tool developers discourage overall scores of rating studies, rather they encourage description of the quality of the research (Hong et al. 2018). Standardised quality criteria were not applied to the studies because of the mixed study designs, diverse methodologies, and recommendations of the MMAT. The MMAT is only for use with empirical studies but excludes literature reviews. Analysis of literature reviews found in the search was guided by the Critical Appraisal Skills Programme (2018) (CASP) systematic reviews checklist. The results of the literature search included other types of review in addition to systematic. The CASP (2018) systematic reviews checklist principles were used to appraise these.

A table of study characteristics and summary of analysed publications is shown in Appendix C. Tabulated processes of using the MMAT and CASP tools are displayed in the notes in Appendices D and E. Findings from each publication were compared and searched for emerging themes (Whittemore and Knafl 2005). The findings were divided to fit the two aims of the review:

research into factors influencing eating and drinking, and interventions to improve eating and drinking for people with dementia. The findings are presented in a narrative format of emerging themes from the literature, with some quality assessment of the published literature included to strengthen the themes presented (Grant and Booth 2009).

2.3 Findings

A total of 585 papers were found after duplicates were removed. Titles and abstracts were screened according to the inclusion and exclusion criteria, leaving 91 eligible for full-text screening. Following full text screening, 55 further publications were excluded, leaving 36 papers for review. The selection process can be seen in the PRISMA diagram in Figure 7 (Liberati et al. 2009).
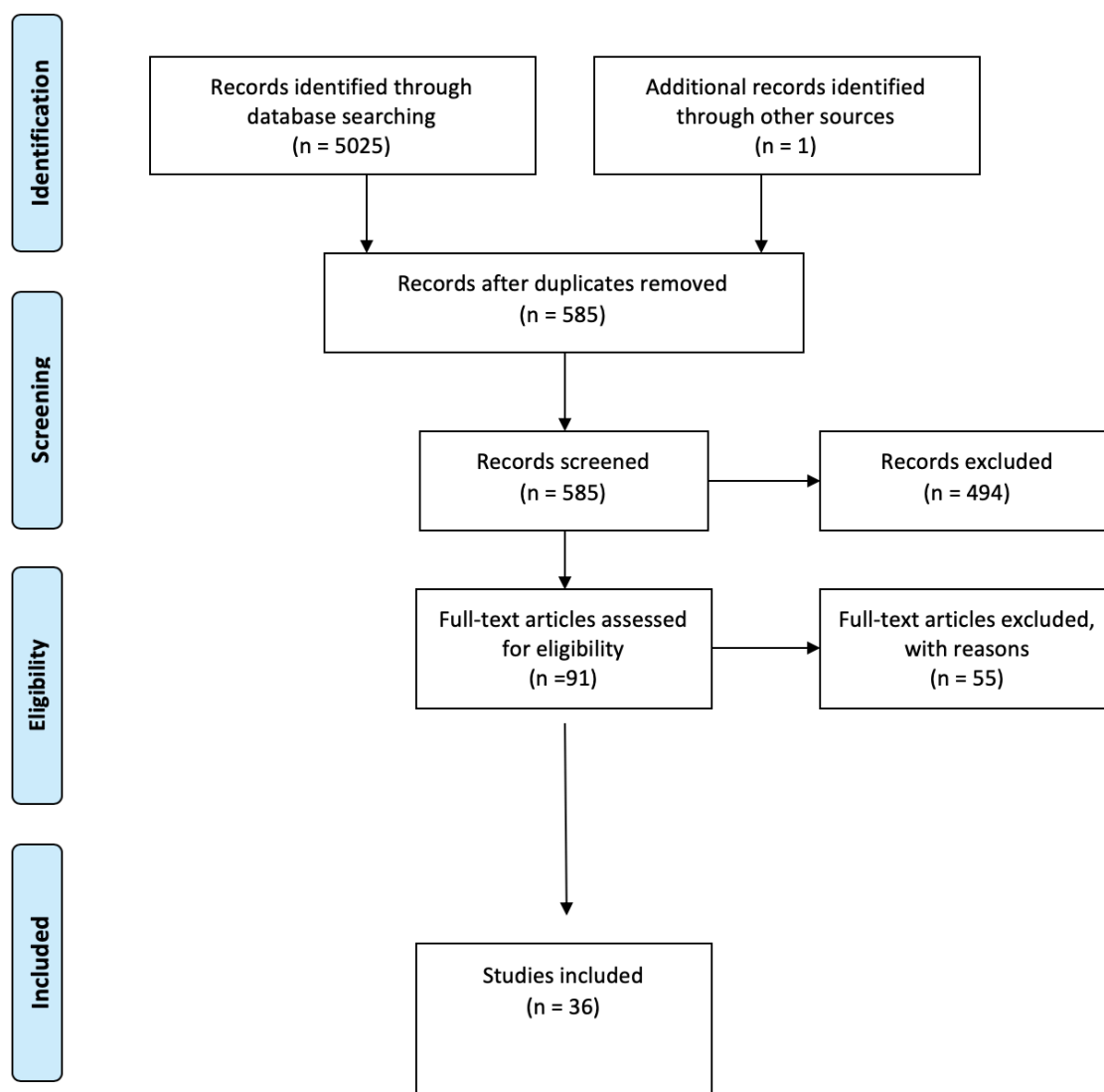
Figure 7: PRISMA 2009 Flow Diagram

The characteristics of the 23 papers that were empirical research can be seen in the table in Appendix C. The empirical research described studies conducted in a variety of countries, including the United States of America (USA), Taiwan, Japan, Canada, New Zealand, South Africa, Norway, and the United Kingdom (UK). Despite such a varied study population, similarities were found across all the studies of factors influencing the eating process for people with dementia. The other 13 papers identified for review were published literature reviews relevant to the aim of the literature review presented in this thesis.

The language used to define eating, feeding or mealtime difficulties appeared in the literature to be varied and complex. Swallowing difficulties, the lack of ability to self-feed, or dependency in eating, have been used to describe the phenomena of eating and drinking difficulties for people with dementia (Watson and Deary 1997; Chang 2012). In an attempt to conceptualise eating difficulties, and examine the instruments used to assess mealtimes, Aselage (2010) summarises the descriptions found in their literature review under three domains: "meal behaviours", "feeding behaviours" and "eating behaviours". These were then combined and conceptualised as "mealtime difficulties". "Feeding behaviours" is a term used when a caregiver is actively assisting a person who may be exhibiting resistive or psychological behaviours. "Eating behaviours" refers more specifically to food intake whether a person is independent or needing assistance, and relates to behaviours to do with nutritional intake. "Meal behaviours" includes the elements of eating or feeding behaviour, but includes a wider consideration of the social and environmental aspects of mealtimes. The language used within this review reflects the language of the authors within the literature being discussed, but all indicate the general concept of eating and drinking difficulties for people with dementia.

The review of the published literature revealed some knowledge and understanding of factors influencing eating and drinking for people with dementia. These included factors involving the presentation and situation of the person with dementia, factors which were environmental, and factors which were influenced by staff and organisational structures or cultures. It was also evident that a variety of assessment tools have been used to attempt to understand and conceptualise the difficulties faced by people with dementia when engaging in the eating and drinking processes.

2.3.1   Assessment of eating difficulties for people with dementia

Various tools were used across the publications analysed for this review. Observation tools included: the Edinburgh Feeding Evaluation in Dementia (EdFED) (Watson 1994; Amella 2002; Chang and Roberts 2008b; Lin et al. 2010; Chang 2012; Batchelor-Murphy et al. 2017), the Chinese

Feeding Difficulty Index (Ch-FDI) (Chang et al. 2017), the Structured Meal Observation (Reed et al. 2005), and the Formal Caregivers' Behaviours in Feeding Dementia Patients Observation Checklist (Chang et al. 2006). Aselage (2010) completed a review to examine the quality and feasibility of mealtime assessment tools used to date, discussing twelve tools which had been developed since the 1990s. The EdFED was reported to have the most extensive testing for reliability and validity (Aselage 2010). It was recommended as best for use in clinical practice due to its length and the relatively short time required to complete (Aselage 2010). Chang et al. (2017) added the Ch-FDI to the EdFED to include chewing, swallowing and attention to eating which the EdFED reportedly missed. The tools used in the studies analysed for this review were used to measure and identify eating difficulties for people with dementia. From this factors influencing the eating process were identified.

2.3.2   Factors influencing the eating process

It is clear from the published empirical research, and the published literature reviews, that influences on eating and drinking in older people with dementia are complex and multi-factorial. Themes emerged from the analysis of the publications, which described factors influencing the eating process: environmental factors, person factors, and staff factors and organisational factors. Examples of factors which contributed to the themes, and the publications in which they were identified, are displayed in Table 2.

Table 2: themes describing factors influencing the eating process

Theme	Examples within the published literature	References of publications in which the theme was identified
Person factors	- Severity of dementia. - Comorbidities - Cultural significance of food. - Personal, familiar routines. - Behavioural dementia symptoms, e.g. Sundowning syndrome. - Time required for eating. - Person-centred care approach. - Knowing the patient.	McGillvray and Marland (1999); Amella (2002); Reed et al. (2005); Aselage and Amella (2010); Lin et al. (2010); Slaughter et al. (2011); Edahiro et al. (2012); Slaughter and Hayduk (2012); Gilmore-Bykovski (2015); Lee and Song (2015); Cipriani et al (2016); Hanssen and Kuven (2016); Liu et al. (2016); Nell et al (2016); Chang et al. (2017); Lea et al. (2017); Liu et al. (2017)
Environmental factors	- Physical dining environment,	Reed et al. (2005); Chang et al.

Theme	Examples within the published literature	References of publications in which the theme was identified
	e.g. noise, light levels, stimulation, - Social aspects of eating. - Positive social interactions.	(2006); Watson and Green (2006); Chang and Roberts (2008); Aselage and Amella (2010); Hun and Chaudhury (2011); Slaughter et al. (2011); Chang (2012); Slaughter and Hayduk (2012); Douglas and Lawrence (2015); Bunn et al (2016); Hanssen and Kuven (2016); Leah (2016); Nell et al. (2016); Chang et al. (2017); Lea et al. (2017); Liu et al. (2017); (Herke et al. 2018)
Staff and organisational factors	- Level of staff support (verbal/physical prompting etc). - Activity levels during the day and the mealtime. - Flexibility of kitchen staff. - Different groups of staff working together. - Staff education and attitudes. - Staff to resident/patient interactions and relationships. - Care givers feelings of guilt and responsibility within the resources. - Task centred approach. - Staff rushing meals or giving too big spoonfuls. - Feeding techniques.	Amella (1999); McGillvray and Marland (1999); Reed et al. (2005); Chang et al. (2006); Watson and Green (2006); Chang and Roberts (2008); Aselage and Amella (2010); Hung and Chaudhury (2011); Douglas and Lawrence (2015); Gilmore-Bykovski (2015); Liu et al (2015); Bunn et al (2016); Hammar et al. (2016); Leah (2016); Liu et al. (2016); Nell et al. (2016); Batchelor-Murphy et al. (2017); Lea et al. (2017); Murphy et al. (2017)

2.3.2.1 Person factors

The severity of dementia and cognitive impairment was suggested to have an impact on the need for eating assistance, and functional ability with eating and drinking (Reed et al. 2005; Slaughter et al. 2011; Edahiro et al. 2012; Lee and Song 2015; Chang et al. 2017). Reed et al. (2005) conducted a large study of 407 residents across 45 care facilities in four different states in the USA. The study concluded, through rigorous statistical analysis using logistic regression, that the prevalence of eating difficulties was higher in a nursing care facility where the severity of dementia and dependency were higher. There were other factors in the nursing facility which could also contribute to prevalence of eating difficulties, such as the dining environment and availability of staff to assist, which could question the overall conclusion that severity of dementia is directly linked to prevalence of eating difficulty. Despite this, the statistical analysis is presented in the paper showing that severity of dementia has an influence on eating difficulty. The study was based only in the USA, but other more recent studies worldwide support the findings. Research was conducted in Taiwan (Chang et al. 2017), Japan (Edahiro et al. 2012), Korea (Lee and Song 2015), and Canada (Slaughter et al. 2011). The conclusion from all the studies, that severity of dementia is a confounding factor influencing engagement in eating, is strengthened by the consensus of statistically significant findings.

In older people with dementia, the severity of dementia is complicated by other symptoms of aging (Aselage and Amella 2010). Slaughter et al. (2011) and Slaughter and Hayduk (2012) conclude that comorbidities, not related to the dementia diagnosis, can contribute to up to half of the eating disability seen in people with dementia. A major limiting factor to the study, described in both publications, was the assumption that lack of eating meant a lack of ability to eat. There are many other factors which influence engagement in the eating process, beyond assessing the ability to move food from the plate or bowl to the mouth. The published literature revealed the importance of a person-centred approach to mealtime care, namely: considering persons' food preferences, the time of day and related dementia symptoms individual to each person, the meaning and cultural significance of food to that person, and the presence of familiar people at the mealtime (Lin et al. 2010; Gilmore-Bykovskyi 2015; Hanssen and Kuven 2016; Nell et al. 2016; Chang et al. 2017; Lea et al. 2017; Murphy et al. 2017).

A person-centred approach has been known to reduce behavioural symptoms of dementia at mealtimes which has the potential to influence engagement in the eating process (Gilmore-Bykovskyi 2015). The findings from a time series analysis in a study published by Gilmore-Bykovskyi (2015) revealed behavioural symptoms at mealtimes were 19 to 21% more likely to occur after task-centred actions from staff. The study concluded that person-centred care actions

were significantly related to a reduction in behavioural symptoms of dementia at mealtimes. The assessment tools used were the Pittsburgh Agitation Scale and Person-centred and Task-Centred Inventories (Gilmore-Bykovski 2015). They showed 82 to 92% accuracy of inter-rater reliability, but the description of the tools and the specifics of what they were measuring were not stated clearly in the paper. The study described by Gilmore-Bykovskyi (2015) was a quantitative study with statistical analysis, but the small sample size limits generalisability of the results. Twelve residents and eight Certified Nursing Assistants were observed over 33 observations. Transferability of the results to other settings is limited by the study being conducted in one setting only. Still, there is potential application to practice, providing scope and justification for further research into the benefits of person-centred care approaches at mealtimes for people with dementia.

Other publications identified in the literature search supported the value of person-centred mealtime care in improving eating performance. Interviews and focus groups were recently conducted with residential home care givers in New Zealand (Nell et al 2016), the UK (Murphy et al. 2017) and Australia (Lea et al. 2017). All acknowledged the importance of factors such as considering people's food preferences, flexible mealtimes to suit people's normal routines, knowing a person individually, and consideration of individual people's dementia symptoms. In particular Sundowning symptoms were suggested to influence evening meals. The symptoms were described as disorientation, distraction and distress. Considering the symptoms of individuals, and meeting their individual needs, was described as a solution to improve mealtimes for people with dementia (Nell et al. 2016; Change et al. 2017). The qualitative studies, although individually with small sample sizes and in specific care settings, were collectively rich, in-depth and applicable to people with dementia in care homes in a wide geographical area.

Murphy et al. (2017) developed a model, which is presented in the background chapter of this thesis. The centre of the model is person-centred care, with other factors feeding into the provision of person-centred care. Limitations of the study include the risk of bias in choosing sections of data to analyse. The data were transcribed verbatim, but only the pieces of data considered relevant to the research question. The findings do, however, fit with the findings from other similar studies (Nell et al. 2016; Lea et al. 2017). A confounding limiting factor, present within all these studies, is that they are single method research studies. Methods across the studies include focus groups and individual interviews. The studies are also limited in that they miss the vital element of observing or talking to people with dementia at mealtimes. They describe person-centred mealtime care, but perspectives on factors influencing eating and drinking are purely represented by the staff caring for people with dementia, and do not consider the view of the person with dementia.

Part of a person-centred approach is to involve people who are familiar to the person with dementia in mealtimes within the institution they are based. Lin et al. (2010) noticed a significant difference in food intake when the frequency of family visits increased. This study collected data from 477 residents in nine long-term dementia care facilities in Taiwan. The data was collected using the EdFED observational tool (Watson 1994), a reliable and well used tool for measuring feeding difficulties in people with dementia. With such a large sample size, clear outcome measures and reliable tools for data collection the study has much promise for application to practice. The limiting factor for generalisability is the context of the study being restricted to Taiwan, but the strength and clarity of it allows for replicating the study in other contexts and cultures.

A person-centred approach is presented, in the publications analysed for this review, as a factor in influencing eating and drinking for people with dementia. This is described as an approach which considers, the cultural importance of food to an individual, a person's symptoms of dementia and physical symptoms of aging, and individual preferences, familiarity and routine. In addition, external factors were also presented as influencing eating and drinking for people with dementia.

2.3.2.2   Environment factors

Contextual factors, such as the surroundings and eating environment, were widely considered to be significant in influencing mealtimes for people with dementia (Reed et al. 2005; Chang et al. 2006; Change and Roberts 2008; Hung and Chaudhury 2011; Slaughter et al. 2011; Chang 2012; Hanssen and Kuven 2016; Nell et al. 2016; Chang et al. 2017; Lea et al. 2017; Liu et al 2017). Environmental considerations could fit into one of two categories: the physical environment and the social environment.

Eating in a communal dining area with a positive social eating environment, was considered more effective in encouraging food and fluid intake, and suggested as an improvement to mealtimes for people with dementia (Reed et al. 2005; Lea et al. 2017). In a study by Nell et al. (2016), the majority of staff participants mentioned positive social interactions as facilitating residents to eat and drink well. Murphy et al. (2017), although not directly measuring the impact to eating and drinking, identified the importance of relationships during the mealtime as integral to person-centred mealtime care. The studies discussed are limited in that they only consider the perspective of the care givers of people with dementia and exclude people with dementia themselves (Nell et al. 2016; Murphey et al. 2017). Reed et al. (2005) observed the whole setting rather than interviewing staff, but measured food intake rather than experience of the meal. Still, they found that people eating in a communal dining area were significantly less likely to have low

food intake. This supports the views of care staff in the other studies (Nell et al. 2016; Lea et al. 2017; Murphey et al. 2017).

Simply sitting in a communal area, however, was not adequate in promoting engagement in eating at mealtimes. Studies by Chang and colleagues (2006; 2008; 2012; 2017) all emphasised the importance of the physical nature of the dining area. Factors such as, noise, light levels, sensory stimulation and distractions within the dining environment impacted eating and drinking. Chang et al. (2017) found that illuminance level and sound volume significantly influenced food intake. Lower illuminance and a higher noise level correlated to higher eating difficulty and lower food intake. The cross-sectional research showed promise of identifying factors associated with eating difficulties; there was a clear sample size calculation with more participants than needed, to account for drop-outs (Chang et al. 2017). There was a high risk of selection bias among the care facilities, limiting the implications of the research findings. People with dementia were only considered eligible if they were identified as having eating difficulties, which excluded people who could demonstrate how elements of the environment could positively influence mealtimes, and engagement in the eating process.

Several qualitative studies, which involved interviewing care facility staff, found that carers for people with dementia considered physical environment impacts mealtimes (Hung and Chaudhury 2011; Nell et al. 2016; Lea et al. 2017). Participants described noise from music or television as over stimulating and with the potential to cause distraction from the eating process. Others reported the same could create a calming environment and help residents to relax if managed in a way that was individual to the person with dementia (Hung and Chaudhury 2011; Nell et al. 2016). Hung and Chaudhury (2011) focused on the personhood and dining experiences, so were not directly looking to explore factors influencing engagement in the eating process. They did, however, provide particularly rich findings through their combination of data collection methods: conversational interviews, observation field notes and focus groups. Multiple researchers analysing the data added validity to the findings, and there was evidence of continuing the data collection until theoretical and data saturation were reached. The consensus of findings with other studies add value to their implications of environmental impact on eating. The qualitative studies, identified above, provided in-depth and insightful understanding into the experiences of mealtimes for staff in residential care facilities, caring for people with dementia.

2.3.2.3 Staff and organisational factors

Implications of the environment on staff, were seen through observations in a study conducted in Taiwan (Chang and Roberts 2008b). The dining environment was too crowded and noisy, meaning staff were unable to provide what they considered best practice. Examples provided included,

standing to feed people or having to talk louder to overcome the other noise, adding to the noisy environment (Chang and Roberts 2008b). Organisational factors involving staff, such as flexibility of the kitchen staff and systems, staff education and attitudes, time allowed for mealtime care, and staff relationships with people with dementia, were reported to influence eating and drinking (Amella 1999; Reed et al. 2005; Chang et al. 2006; Chang and Roberts 2008b; Hung and Chaudhury 2011; Gilmore-Bykovski 2015; Hammar et al. 2016; Liu et al. 2016; Nell et al. 2016; Batchelor-Murphy et al. 2017; Lea at al. 2017; Murphy et al. 2017).

Caregivers of people with dementia described meaningful activities throughout the day and at mealtimes as a potential to stimulate appetite, and improve engagement and experience of meals (Nell et al. 2016; Murphy et al. 2017). These were staff views but they also considered the organization structures and cultures as a restricting factor in being able to provide this optimal care. Reported barriers included low staffing numbers, limited training and education, and poor attitudes of senior staff in accepting changes to care (Lea et al. 2017). In order to enable care givers to provide care they consider is best practice, they require permission and confidence through the hierarchy of the care systems (Hammar et al. 2016).

Staff have also reported feeling abandoned to provide skilled care without support, and described the weight of responsibility of nutritional care at mealtimes (Hammar et al. 2016). It is possible this is the culture of the one nursing home included in this small mixed methods study. The care givers were from different units within the nursing home to encourage discussion between potential different ways of working, but ultimately they were under the same management.

Staff were considered to have a negative impact on mealtimes through, mixing feeding with other tasks, rushing the mealtime, offering too much food on the spoon or fork, poor communication, and relationships between caregivers and residents (Amella 1999, 2002; Chang et al. 2006; Chang and Roberts 2008b; Hung and Chaudhury 2011; Gilmore-Bykovskyi 2015). Inconsistencies in practice, and impact of carer interaction on mealtimes, highlighted staff's training needs. The lack priority given to providing the training was also considered a barrier (Hammar et al. 2016). In contrast, Watson and Deary (1997) found no causal relationship between nursing intervention and eating difficulties, but recognised that looking at one small element of the overall problem may not provide the best answer. The conclusion was subject to a risk of bias, or pre-conceived judgements, as research observers were nurses working on the wards.

The findings from the review of published literature describing factors influencing eating and drinking identified person related factors, environmental factors and organisational factors which create barriers to eating and drinking for people with dementia. The published literature presents a paucity of factors that have a positive influence on eating and drinking. Recent literature

reviews exploring effective interventions to improve eating and drinking for people with dementia were also examined.

2.3.1   Interventions

There is a clear need for effective interventions to manage poor food and fluid intake and improve clinical outcomes for people with dementia (Ullrich et al. 2014). Recent literature reviews have been conducted on the effectiveness of current interventions (Watson and Green 2006; Whear et al. 2014; Liu et al. 2015; Abdelhamid et al. 2016; Bunn et al. 2016) . Studies identified in these reviews use various outcome measures for effectiveness of interventions in supporting people with dementia to eat and drink. The main outcome measures identified in these reviews are: food consumption, weight or Body Mass Index, motor function and time taken to eat.

There is a distinct lack of interventions that show statistically significant improvement in outcomes for people with dementia at mealtimes. Reviews of effective interventions reveal a lack of Randomised Control Trials and strong evidence for individual interventions (Watson and Green 2006; Leah 2016). Liu et al. (2014) completed a comprehensive systematic literature review providing a summary of whether current interventions are effective in tackling the problem of reduced intake for people with dementia. Their thorough search of recent literature and rigorous analysis of the studies, showed a lack of theory based interventions being used in practice. Lui et al. (2014) identified a plethora of studies testing interventions such as environmental adaptations, playing music at mealtimes, and educating care staff, with little statistical significance in their results to provide an adequate evidence base for practice guidelines. Many of the studies described as "strong" in the review showed a use for nutritional oral supplements in the diet of those with inadequate food and fluid intake. Interventions can include direct changes to the food (Abdelhamid et al. 2016), however, there is still little strength in the evidence for interventions to improve and maintain independence in the eating process. Whear et al. (2014) support the need for further empirical research into the topic when exploring interventions for behavioural and psychological symptoms of dementia at mealtimes. Despite an in-depth search of 15 databases they report weakness in the current evidence due to a lack of statistical significance for individual interventions tested.

Mixed interventions to improve nutritional care have been identified as more effective in improving outcomes for people with dementia (Bunn et al. 2016; Leah 2016). Changes to the dining environment, education and training of people with dementia and their care-givers, assistance with eating, behavioural interventions and exercise, have all been identified in recent literature reviews as interventions currently used to improve eating and drinking in people with

dementia (Bunn et al. 2016; Leah 2016). The reviews had clear and rigorous search strategies which included 5-12 of the most prominent databases. They selected only randomised control trials (RCTs), controlled clinical trials (CCTs) or time series studies with comparisons between time frames. Despite rigorous methods and searching, as in earlier reviews (Whear et al. 2014; Lui et al. 2015) there were limited studies identifying individual interventions as "strong". Multi-component interventions appeared to have the most positive outcomes, however, only one study with mixed interventions was described as "strong" (Liu et al. 2014). The most recent reviews of current literature acknowledge that a person specific assessment is needed to create care plans of mixed interventions for most improved outcomes, there cannot be a 'one size fits all' approach to nutritional care in dementia (Leah 2016).

2.4   Discussion

2.4.1   Gaps in the research

Although there is some understanding of correlates to undernutrition, there appears to be little significant evidence, and few rigorous studies, to support existing interventions. The lack of evidence highlights the need for further research, not only in effectiveness of specific interventions, but in conceptualising the bigger picture of underlying reasons for eating and drinking difficulties. The review of published literature identifies that eating and drinking difficulties for people with dementia is a complex process. Various reasons are presented to describe what is known about why people with dementia may disengage from the eating process.

Literature conceptualising the issues has significant gaps to be addressed in further research. These are summarised as:

- Exploring eating positively was not identified in the published literature or assessment measures used for conceptualising eating difficulties. It may be beneficial in adding to the knowledge base to consider what is positively influencing eating and drinking for people with dementia, not only selecting participants identified with an eating difficulty.
- There is a limited amount of published research in the acute hospital setting, which has been identified as having a need for understanding dementia and mealtime care (Naithani et al. 2008; Gladman et al. 2012; Goldberg et al. 2014; Ottrey et al. 2017)
- Published literature is limited in presenting the perspective of people with dementia and how they experience mealtimes, particularly those unable to communicate their views verbally.

- Many publications focused on eating behaviours and food intake, but less on engagement in the eating process (Chang et al. 2006; Chang and Roberts 2008b; Chang 2012; Edahiro et al. 2012; Gilmore-Bykovski 2015; Chang et al. 2017).

- There was a lack of mixed and multi-method studies in the published literature reviewed. Considering the complexity of factors influencing engagement in eating and drinking with people with dementia, multiple or mixed methods studies would provide a greater breadth of understanding the concept.

These gaps in the research identified through the analysis of published literature are expanded and discussed under the following headings: assessment of eating difficulties for people with dementia, acute hospital setting, patient perspectives and experiences, and exploring mealtimes positively.

2.4.1.1 Assessment of eating difficulties for people with dementia

All the tools identified in the publications analysed for the literature review focus on the difficulties experienced and expressed by people with dementia, or their care-givers. Understanding mealtimes for people with dementia has not been explored fully from a positive perspective – observing and discussing what works well, as well as difficulties. The tools also consider the focused time frame in which meals are happening. An understanding of what is happening in the time around the mealtime to influence both positive and negative eating behaviours is needed in order to develop the current understanding of the multi-factorial and complex nature of engagement in the eating process for people with dementia.

2.4.1.2 Acute hospital setting

Much of the research identified has been carried out in long term care settings, with the exception of two publications (Watson and Deary 1997; Edahiro et al. 2012). There is limited research specific to acute hospital care. Despite some similarities in the institutional nature of care settings, it is still questionable how much the research in long-term care settings is applicable to care planning and clinical practice in acute care. There are distinct differences between community, long-term and acute care, which will have implications to patient experience and the care provided (Holmes 2008; Ullrich et al. 2014). Ullrich and colleagues (2014) started to explore the differences between long-term and acute settings. Mealtimes, particularly, were very different experiences in each setting. In acute care settings the time was chaotic, fragmented and mixed with other duties such as patient observations and administering medication. They identified further research of mealtimes is needed in specific care settings due to differences in organisational structures and processes effecting care provision during the eating process. The

dining environment was an overall theme in the findings presenting factors influencing eating and drinking for people with dementia. Therefore, research into different care settings is essential for application to practice in individual settings.

2.4.1.3 Patient perspectives and experiences

Hung and Chaudhury (2011) emphasise the necessity of the person being central to care. They discussed factors that influence experience, but still primary data collection was interviews and did not include people who could not express their verbal opinions or experiences. There is a paucity of published research that observes or questions people with dementia, investigating their experiences of mealtimes. This is perhaps due to the potential difficulty of including people with dementia in research who cannot consent or verbally communicate their views. Including people with dementia without identified eating difficulties could also expand the general understanding of the impact of various factors identified, such as physical environment, on people with dementia at mealtimes.

Barnes et al. (2013) acknowledged the importance of including people who were unable or unwilling to express their views about mealtimes in their observational study of residential homes. Although not dementia specific, the study was not exclusive of people with dementia and used an adapted version of the Dementia Care Mapping tool (University of Bradford 2006). It is not clear from the published report of the study what proportion of participants did not have capacity to consent or would be considered unable to express their views. Some research has been conducted with appropriate study designs, analysis and useful findings of patient perspectives and experiences (Reed et al. 2005; Naithani et al. 2008; Barnes et al. 2013; Hanson et al. 2013). These studies are limited in number, with methods focusing on interviewing people with dementia who can communicate their views verbally and their families.

Research which investigates the experience and views of people with dementia is needed. It is acknowledged that this can be difficult as people with dementia may not be able to give informed consent, or express their needs verbally, due to cognitive and communication difficulties. Excluding them from the research can leave them vulnerable and powerless (Hanson et al. 2013). Most studies identified in the literature review did not seek to explore the views of those who were unable to express their opinions verbally.

2.4.2 The need for a conceptual model for the acute hospital setting

The paucity of research specific to acute hospitals means it is unclear how much the current conceptual models can be applied to such a unique setting (Keller et al. 2014; Liu et al. 2016;

Murphy et al. 2017). An investigation of eating and drinking at mealtimes in the acute setting is needed, producing a relevant conceptual model which can be used to influence practice.

The factors influencing eating and drinking in dementia are considered independently in this review of the published literature: person, environment, staff and organisation. Published models of eating difficulties include them all as important (Keller et al. 2014; Liu et al. 2016; Murphy et al. 2017). The current models, and published literature, are limited in showing the inter-related nature of eating and drinking difficulties. The complexity of various factors is clear, but there are no models that conceptualise the difficulties and portray how different influencing factors interact with each other. The current models are all static with factors presented in different separate sections. There is a need for a model that shows the dynamic nature of the complexity of meals, and how influencing factors fit together.

Most of the research in the published literature, and the research involved in the development of the current conceptual models, were single method studies. Further mixed methods research would be useful to both quantify the problem, and to understand experiences, meanings, and engagement in the eating process, at mealtimes.

2.5   Purpose of the research project

The purpose of the research presented in this thesis was to add to the current knowledge of what influences engagement in eating and drinking for people with dementia, and to begin to address gaps identified in the literature review. The research was the first which aimed to approach exploration of mealtime difficulties for people with dementia by considering the positive elements of what works well, as well as identifying where improvements are needed. Seeking to understand mealtime experiences from the perspective of the people with dementia, even those who could not verbally express their views, was an approach which is limited in the current literature. As an Occupational Therapist, the researcher provided a novel view of the issue of mealtimes for people with dementia. The research project is the first to have a focus of occupational performance and engagement. A key difference to the research presented here, and the literature identified in the review, will be the context. The research project presented in this thesis was conducted in the acute hospital setting, on medical wards for older people.

The research findings could be used to inform practice development, and education and training, for people caring for people with dementia in the acute hospital setting. The research project was conducted in two phases; as separate studies, but one overall project.

Chapter 2

PHASE 1 AIM:

- To describe factors observed to influence engagement in the eating process at mealtimes, and experience of the mealtimes, for people with dementia in the acute care setting.

OBJECTIVES:

- Use Qualitative field notes and Dementia Care Mapping (DCM) observations to record how people with dementia engage in the eating process and express behaviours and well-being within the ward environment.
- Use the emerging themes from the findings as a framework to develop the next phase of the research study.

PHASE 2 AIMS:

- To understand the perspective of hospital staff who care for people with dementia on what influences engagement and experience for people with dementia at mealtimes.
- To understand what policies, interventions and strategies are currently practiced in the acute hospital setting to improve mealtimes for people with dementia.

OBJECTIVES:

- Use semi-structure interviews, framed by the findings from phase 1, to discuss mealtimes for people with dementia in the acute hospital setting.
- To provide recommendations to improve practice at mealtimes in the acute hospital setting.
- Combine the findings from both phases of the research to inform the development of a conceptual model of factors influencing mealtimes for people with dementia specific to the acute hospital setting.

Chapter 3   Methodological considerations

Introduction

This chapter outlines the philosophical approaches underpinning the research project and discusses the methodological considerations in qualitatively driven mixed methods research. The setting of the research project is also an important methodological consideration when conducting research – this is described to give context to the research project presented in this thesis. Ethical considerations for both phases of the research project are presented at the end of this chapter, before the presentation of methods used and findings from each phase of the research project.

3.1   Research design

Mealtimes in an acute hospital setting are complex. As such, both quantitative and qualitative data was required to gather a fuller understanding of the experiences and engagement of people with dementia during these times. A fixed mixed methods design was employed, meaning the timing and elements of qualitative and quantitative data collection were pre-planned and implemented intentionally (Creswell and Plano-Clarke 2018). A convergent mixed methods design was employed in the first phase of the research. The merged quantitative and qualitative results informed the interview schedules in the second, pre-planned, qualitative phase.

The methods chosen for phase 1 of the research were semi-structured qualitative field notes combined with structured quantitative observations of people with people with dementia who were patients in the hospital. The qualitative and quantitative observations of people with dementia were collected in parallel, with the integrated findings guiding the content for semi-structured qualitative interviews in phase 2. The interviews were conducted with staff participants. This added methodological triangulation to strengthen the overall research project (Finlay and Ballinger 2006). Using interviews was beneficial in widening and affirming the observation findings. Staff could discuss situations and experiences beyond the timings of the observation periods, providing a greater breadth to the overall research project. The chosen methods were determined in line with the philosophical world view and approach to research held by the researcher.

Chapter 3

3.1.1 Philosophical assumptions: Ontology and Epistemology

In mixed methods research there arises a philosophical debate around research paradigms. Some traditionalist will argue that the two paradigms are not compatible to be combined in any way (Doyle et al. 2009). The world views attached to qualitative and quantitative research arguably contradict in their ontological and epistemological approaches to reaping knowledge and understanding of the context being researched (Brannen 1992).

Positivism, primarily associated with quantitative research, is an epistemological position which seeks objective knowledge; one truth about the world which is independent of the interpretation of individual perceptions and meanings (Finlay and Ballinger 2006). Typically the positivist approach is used by researchers holding a Realist belief. Realists believe there is an external reality for scientists to focus on, made up of structures that have cause-effect relationships (Finlay and Ballinger 2006; Bryman 2016). The ontological position of Objectivism also resonates with the positivist, natural science model, asserting that social phenomena have meaning external to the individual's perception or understanding (Bryman 2016). As such, researchers with these ontological and epistemological world views will be more likely to conduct scientific, deductive research, testing theory and seeking objective truth about a phenomenon.

In contrast, interpretivism is more aligned to qualitative research. It respects differences and influences between people and the social world and suggests there is a subjectivity to truth and knowledge (Bryman 2016). The interpretivist epistemology is guided by the beliefs of Wilhelm Dilthy in the 1860s and 1870s (Ritchie and Lewis 2003). His approach to learning about the world emphasises the importance of understanding people's lived experiences within a context. This approach was developed and continued by Max Weber into the 1900s in his principle of 'Verstehen': empathy and interpretive understanding of individual experiences in order to explain social phenomena (Bryman 2016). Research from an interpretivist position seeks meanings and interpretations, constructed through social, cultural and historic factors of an individual's life. The researcher also acknowledges their own influence and identity in undertaking the research and understanding the findings (Finlay and Ballinger 2006; Mason 2018). The ontological position of Relativism, as opposed to Realism, is often aligned with the interpretivist approach. Although a context or phenomena may be real, the understanding, experience and interpretation of that is relative to individuals (Finlay and Ballinger 2006).

The research presented in this thesis adopts a pragmatic paradigm, commonly associated with mixed methods research (Creswell and Plano-Clarke 2018). The emphasis of this world view is on the research question and answers, employing a "what works" (p37) approach to getting an answer (Doyle et al. 2009; Creswell and Plano-Clarke 2018). The researcher abandoned the idea of

paradigms opposing, of a forced choice between positivism and interpretivism, and adhered to the view that approaches can complement rather than compete (Doyle et al. 2009). As described by Bazeley (2018) all phenomena have both qualities and quantities. Quantities can still have quality and meaning, while qualities can be quantified. The researcher realised the importance of qualitative research methods in understanding behaviours, thoughts and feelings as determined by the context they are in (Gillham 2000). On the other hand counting and evaluating the numerical data in order to increase confidence in the results could not be undervalued (Bazeley 2018).

The ontological position of the researcher falls between the opposing positions of realism and relativism to adopt a subtle realist approach (Finlay and Ballinger 2006). Subtle realism supports the mixed methods design in that it states the different methods will produce different pictures of the phenomena being studied (Duncan and Nicol 2004). The subtle realist attempts to acknowledge both the subjectivity and objectivity of knowledge, without aligning fully to either end of the realism-relativism spectrum (Seale 2004). Although an objective knowledge is being sought in exploring factors influencing experience and engagement at mealtimes, the researcher acknowledges that the subjectivity of the participants means there can be no absolute truth determined. Multiple realities will be considered and then combined to understand a collective experience and understanding of the mealtime phenomena. This approach is summarised by Hickson (2008):

" although phenomenon is experienced uniquely by each person, there exists an underlying unifying meaning of the experience that is essential and invariant for all people." (p.55)

3.1.2 Methodological approach: Sequential Mixed Methods

The philosophical paradigms adopted by the researcher are conducive to mixed methods research. For the overall project a sequential mixed methods design is followed. Creswell and Plano-Clarke (2018) developed the concept of the sequential two-phase approach, introducing two types of sequential design to distinguish whether qualitative or quantitative methods are first in the sequence. The explanatory sequential design uses qualitative data to explain and broaden the initial quantitative phase; the exploratory sequential design begins with qualitative data then builds on it with quantitative methods. Neither of these specific descriptions fit the overall design of the research. The first phase contained the mixed quantitative and qualitative methods, used in parallel, which were then explored and expanded by the second, qualitative, phase. The current research, therefore, draws on earlier mixed methods descriptions and is considered a general sequential model, using sequential triangulation (Morse 1991). Elements of the explanatory

sequential design were applied, in that a second, qualitative, phase was used to expand and broaden the findings from the initial mixed qualitative and quantitative phase.

Figure 8 depicts the sequential mixed methods design applied to the overall research project. It shows the parallel mixed methods used in phase 1, with the findings informing the interview schedule used for phase 2.
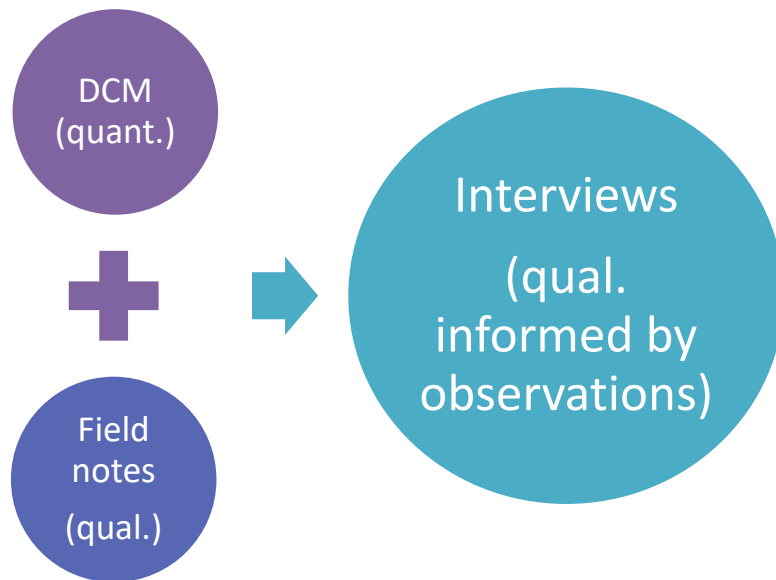
Figure 8: Visual display of the sequential mixed methods design applied to the research project

A convergent mixed method design was used in the first phase of the research. This involved the integration of both qualitative and quantitative observation methods where the data sets were collected in parallel. The purpose of this approach was to triangulate data collection to obtain different but complimentary data of the same phenomenon, to be compared and contrasted during analysis (Creswell and Plano-Clarke 2011). The two data sets were merged to reveal different perspectives of the experience and engagement of people with dementia at mealtimes (Creswell 2014). Seale (2004) illustrates the benefits of combining opposing paradigms in this mixed methods approach through the description of stories and facts. The qualitative element tells a story of experience and meanings, acknowledging the story will be impacted by the researcher. Facts seen in the quantified codes underpin and give evidence to the story. Conceptual triangulation contributes to overcoming the opposing paradigm assumptions, so the research followed the recommended steps in the conceptual triangulation process (Tolson et al. 1999):

1) Conduct qualitative and quantitative research

2) Distinguish pertinent results within each method

3) Examine confidence within the results

4) Construct one or more conceptual models.

Further description of using these steps are presented in the data collection and analysis sections for each phase of the research (Chapter 4.2 and 6.3).

Mixed methods designs have different typologies, depending on the priority and emphasis of the research questions, and philosophical approach of the researcher. The typology of mixed methods used in the research gives priority to the qualitative data (Mason 2016). This is in line with the overall research aims, seeking to understand meanings, and experiences of people with dementia, of the mealtime phenomenon (Doyle et al. 2009; Creswell and Plano-Clarke 2018). The study is partially mixed methods as, although the quantitative and qualitative methods are used in parallel, the data is not merged until the analysis and interpretation stages (Doyle 2009). The data collection is concurrent (convergent) and the qualitative data is dominant, making it what Doyle et al. (2009) describe as a partially mixed, concurrent, dominant status design.

The dominant status of the qualitative data is evident where the research is exploratory and naturalistic, observing the naturally occurring phenomenon of mealtimes in acute hospitals as opposed to setting up an experiment (Doyle et al. 2009). Detailed recordings and interpretation of the mealtimes allowed for the construction of theory rather than testing a pre-supposed hypothesis. Interpretation and understanding of the meaning of events was essential to answer the research question. The interviews were used to reconstruct a group of subjective viewpoints, using individual stories and interpretations in order to begin formulating wider answers (Flick 2014). The quantitative data was secondary to the qualitative data, aiming to strengthen, support and quantify the qualitative data.

A mixed methods design is not simply collecting data using multiple methods. Methodological triangulation of data collection methods is a strength of mixed methods research. The use of different types of observation, as well as interviews, added validity to the study in comparing different perspectives of the same phenomena. As well as validating the different sources of data, triangulation of methods added breadth to provide a fuller understanding (Finlay and Ballinger 2006). Mixed methods design goes beyond methodological triangulation through merging and integrating the qualitative and quantitative data. Conclusions are drawn from the different data sets combined in a single study. The merging of data in this study took part at the analysis and interpretation stage of the research (further explained in section 4.2 Data Analysis of phase 1). This merging and combining of the different data sets, from different methodological and

individual perspectives, provides a more complete and comprehensive picture of the mealtimes (Doyle et al. 2009).

A mixed methods approach adds value to the research neutralising the weaknesses of using just qualitative or quantitative methods alone (Robson and McCartan 2011). Doyle (2009) suggests this is of particular use in health care settings where hard evidence can be presented to policy-makers, while understanding the complexity of the situation. Seale (2004) suggests that good quality research comes from quantifiable facts being applicable to and in conjunction with theory and claims made from qualitative exploration.

The quantitative element of the data was to describe presentation of behaviour, well-being and engagement systematically through alphabetical and numerical coding, using the Dementia Care Mapping (DCM) tool (University of Bradford 2005). Qualitative data provided in-depth and detailed field notes expanding on the quantitative data, allowing for interpretation and understanding of behaviour and experiences. Quantitative data alone would miss this crucial element, not allowing for interpretation or analysis of meaning and experiences. Although the research aims were primarily qualitative in nature, the systematic coding was important in adding strength and structure. Qualitative data alone may be considered too subjective and provide only "soft" data. The quantitative coding allowed for "hard" descriptive data to be used to back up the researcher's interpretation of events through the field notes (Creswell 2014). The alphabetical and numerical codes were essential for allowing comparisons and investigation of relationships in the data.

3.1.3   Quality criteria

An aim of using a convergent mixed methods design is to combine the strengths, and off-set the weaknesses of individual quantitative and qualitative methods (Creswell and Plano-Clarke 2018). Usually there are specific standards for measuring the quality of quantitative and qualitative research. Quantitative research is often evaluated through criteria such as reliability, validity and generalisability (Finlay and Ballinger 2006).

Reliable research refers to the accurate and repeatable nature of the methods and results, the idea being if somebody else repeated the study the same results would be found (Finlay and Ballinger 2006). This is addressed to a degree in the research through a second observer coding a small portion of the DCM observations, and inter-rater reliability co-efficiency scores achieved before and throughout the observation period. This is explained in context and in further detail in Chapter 4. It was considered important to include this criterion as reflexivity was considered throughout; the researcher acknowledged that as a health professional their views and approach

had the potential to influence the overall findings. Validity and generalisability were more difficult to achieve with the dominant status of qualitative approach in the research. It was also not considered completely necessary as the exploratory, naturalistic, rich and in-depth property of the research aims are not conducive to the need to meet all the quality criteria of quantitative research. Qualitative research adheres to different quality criteria, considering the credibility and trustworthiness of the research (Bryman 2016).

It is evident that the ontological and epistemological approaches of the research influence the quality of the research. In mixed methods it is important to consider both criteria, but it can be difficult to satisfy the traditional quality criteria fully for all elements of the study. The philosophical underpinnings and methodological decisions may differ from traditional studies. The convergent parallel timing of collecting data in the observations made it difficult to meet both criteria. A statistical sample size power calculation may add validity to the study, but to take qualitative field notes for that many participants would be time consuming and produce a large amount of qualitative data, without adding quality to the qualitative element (Creswell and Plano-Clarke 2018). This meant that using a separate set of quality standards for mixed methods research was more appropriate and useful (Creswell and Plano-Clarke 2018). O'Cathain (2010) suggests a framework set of evaluation criteria for mixed methods research, presented in Creswell and Plano-Clarke (2018) (p.280-281) as shown in Table 3.

Table 3: Evaluation criteria for mixed methods research, and explanations.	
Criteria	**Explanation**
Planning quality	The extent that the initial study plan is feasible, transparent, and situated in existing literature
Design quality	The extent that the study design is described in detail, suitable for the study purpose, and employs methods that complement each other
Data quality	The extent that the methods of sampling, data collection, analysis, and integration are appropriate, adequate and rigorous
Interpretive rigour	The extent that findings emerge from methods, the inference align with the findings, inconsistencies are explained, and others could reach the same conclusion
Inference transferability	The extent that conclusions can be applied to other settings, groups and times
Reporting quality	The extent to which the study is successfully completed, clearly reported, and yields understanding more than the separate parts
Synthesizability	The extent that the study is worthy of inclusion in a synthesis of evidence
Utility	The extent to which the results are usable by consumers

O'Cathain (2010) acknowledges this as a vast set of criteria and proposes a bespoke selection to meet the researcher's philosophical approaches. The research question would be relevant in deciding the appropriate criteria to follow. The researcher used these criteria to ensure rigour and quality was included and portrayed throughout the research. Challenges and solutions to ensure quality throughout the project are described in the methods section for each phase of the study

(Chapter 4 and Chapter 6). Limitations to the study are discussed following presentation of the findings, interpretations and implications.

3.2   Contextual considerations

The data collection was undertaken in two NHS hospitals in the UK. Across the two hospitals a total of eight hospital wards were included in the research: five from hospital site A and three from hospital site B. The wards selected were specifically for the medical care of older people. The patients on these wards were generally over the age of 65 years and had an acute medical or trauma diagnosis requiring admission to hospital. In these wards a dementia diagnosis was secondary to a medical reason for admission to hospital. Despite being across two hospital sites, the wards in which the research was conducted held many similarities.

Typically there were two qualified Nurses and four Health Care Assistants for a ward of 26 patients. The therapy, dietetic and speech therapy team generally covered the whole hospital, with one to two Occupational Therapists and Physiotherapists covering one ward. The Dietitians and Speech and Language Therapists were more thinly spread, covering more than one ward per person. The two hospitals appeared to have slightly different approaches to the supervision and allocation of patients to nursing staff. In both hospital sites the wards were designed in bays, with four to six beds per bay. In Hospital Site A nursing staff and health care assistants were allocated to set bays for their shift. When patients were considered at high risk of falls, or required higher levels of observation a staff member was allocated to remain in the bay. This was described as a cohort bay. At Hospital Site B, all nurses and health care assistants were responsible for all the patients across different bays. Still, cohort bays were created when more than one patient was considered to require constant supervision.

Each hospital had a dedicated Dementia Specialist team covering the whole hospital. The staff within the teams consisted of a Band 7, Band 6 and Band 5 nurse and two Health Care Assistants. The Dementia Specialist team at hospital site A took referrals from all wards for advice or intervention required for people with dementia. The team at hospital site B had a screening process for every person with dementia who was admitted to the hospital. The senior nurses in both teams had an integral part in assisting the researcher to recruit participants for mealtimes observations and staff interviews.

Mealtimes were similar in both hospital sites, with identical food delivery processes. The meals would appear on the wards, at a set mealtime, pre-prepared in a kitchen on site. Patients would have ordered food the day before for a mid-day meal, and that morning for an evening meal. At hospital site A each ward was allocated a Ward Host(ess) whose role it would be to take menu

choices, deliver hot drinks and meals, and provide mealtime assistance if asked by the nursing staff. At hospital site B the mealtime processes fell to the Health Care Assistants to carry out, including collecting menu choices.

Both hospitals had the option of a Finger Food menu, for people assessed by nurses and dietitians and identified as being unable to, or not eating, full meals using utensils. Other food related policies across the two hospital sites were shared with the researcher by the Nutrition and Dementia Specialist Nurses. These included, a red tray system to identify patients requiring maximum assistance at mealtimes, and availability of adapted equipment such as plate guards and large grip cutlery. Both hospitals held an official protected mealtime policy disallowing clinical staff which were non-essential to be on the ward at mealtimes. This included therapy and medical staff. The aim of the protected mealtime policy was to reduce the risk of distractions at mealtimes.

3.3   Ethical considerations

The research proposal was submitted to the University of Southampton Research and Governance Office, the Health Research Authority for the appropriate Trusts for ethical and governance approvals. Research Ethics Approval was gained on 30th January 2017. The dignity, rights, safety and well-being of research participants are of utmost importance when conducting the research (Department of Health 2005).

As the researcher is also an Occupational Therapist, registered with the Health and Care Professions Council (HCPC), adherence to ethical standards set out by the HCPC and Royal College of Occupational Therapists is required when carrying out the proposed research (Royal College of Occupational Therapists 2015; Health & Care Professions Council 2016). Key ethical areas were raised through the ethical approval process: risk of bias, access to the wards, dignity and respect, risk of harm to patients, and anonymity and confidentiality.

3.3.1   Risk of bias

Many may regard entering the field of data collection without preconceived theoretical ideas as impossible (Robson and McCartan 2011). As an Occupational Therapist the researcher may approach the data collection and analysis with preconceived judgements of other professionals. The observation notes, and interpretation of interview data, could be influenced by the clinical view of the researcher. The researcher is familiar with a setting where nurses and other health professionals frequently disclose what it is like working in the stressful busy environment with a lack of time. This may induce sympathy from the researcher, which would impact the notes taken

during observations. The researcher used the data management software NVivo 11 (QSR 2016) Memo notes to write reflections throughout the data collection period. These included an acknowledgement of how having the approach of a health professional could create potential bias. Subjectivity is important to consider when using qualitative methods (Borbasi 2006). Effort was made to reduce bias, and be factual and deductive when taking field notes, conducting semi-structured interview conversations, and analysing the qualitative data.

3.3.2   Access to wards

Approval from the Research and Development departments at each hospital was gained as part of the Health Research Authority ethical approval. Gatekeepers were identified at each hospital to gain physical access to the wards and participants. The key gatekeepers were the Dementia Specialist Nurses and Clinical Nutrition Specialist Nurses. Ward Matron and Sister's meetings were attended before the research began to make the researcher known among staff and start to build working relationships with the sites. The consultant for older people's care was met, and the project discussed, gaining their approval for access to the participants who were patients under their care.

3.3.3   Dignity and respect

During the observations participants undergoing personal care or procedures behind curtain were not directly observed during those time frames. The researcher judged DCM coding from the sound of conversations and activities, or coded the timeframe as the participant being absent from the room. If a participant was located in a side room, the researcher sat in a communal space with a view of the person being observed but within view of other people.

For the sake of dignity, respect and privacy staff interviews were conducted in private rooms off the wards. If an interview was disrupted by other people entering a room the participant was given the opportunity to discontinue the interview.

3.3.4   Risk of harm to participants

The Code of Ethics and Professional Conduct for Occupational Therapists (Royal College of Occupational Therapists 2015) states there is a duty of care to ensure every reasonable action is taken to ensure the health, safety and welfare of any person involved in any activity for which the Occupational Therapist is responsible. The safety or well-being of a participant must take priority over any other loyalties, this includes a research project. Precautions were considered and plans made prior to the data collection starting.

Any observed malpractice by staff, which puts the participant at risk of harm, would be questioned at the time and reported according to local procedure. Interview participants were informed at the outset of the interview that any practice reported which constitutes as abusive, putting the subject at significant risk of harm, or serious neglect, would be reported outside of the interview following local procedures (Royal College of Occupational Therapists 2015).

Due to the nature of observing participants at mealtimes, risk of choking was raised as a potential risk of harm which could be observed. If a participant was seen to be choking, or otherwise unwell, to the point of needing immediate intervention, as a registered Occupational Therapist the researcher had a professional duty to intervene and call for help.

3.3.5 Anonymity and Confidentiality

The research data collected was not personal data. Management of information about the hospital wards, and personal data on Consent forms, was in line with the General Data Protection Regulation (GDPR) published in 2018 (Information Commissioner's Office 2018). As identified in the principles of GDPR, collection of personal data was purpose limited and kept to a minimum, so only collected when necessary, in order to prove consent to be involved in the research. The storage of personal data maintained the principle of integrity and confidentiality in that it was made secure against unauthorised access (Information Commissioner's Office 2018). Paper consent forms were scanned and saved on a password protected, University of Southampton issue laptop computer. The paper copies were then shredded, minimising data storage (Information Commissioner's Office 2018).

Any identifiable information about the participants was treated as confidential (Health & Care Professions Council 2016). Hospital names and wards are also kept anonymous throughout the research process. Participants, and their families if applicable, were assured of their anonymity throughout the research process unless there is evidence of a person being put at risk through malpractice. In this case anonymity may have needed to be broken in the reporting process. Any identifiable information in the interview transcripts was removed, and interview participants were given the opportunity to choose their own pseudonyms.

Observation data was collected and recorded initially on Dementia Care Mapping raw data sheets provided by the University of Bradford (University of Bradford 2005). The raw data sheets had no patient identifiable information on them. Rather than the use of participant names, codes were used for each participant on the Dementia Care Mapping raw data sheets. The data was input to a password protected Excel spreadsheet at the soonest possible opportunity. Interviews were recorded on an audio-recorder and uploaded as a file to a password protected computer at the

earliest possible time. The interview was then deleted from the audio recorder. When transcribed, interviews were transcribed onto a password protected document.

Chapter 4   Methods used in phase 1 – mixed methods observations

The specific methods of data collection and analysis are described in this chapter. The analysis and interpretation of the findings from phase 1 informed the semi-structured interviews used for phase 2. This methods chapter is, therefore, followed directly by the findings from phase 1. A full description of the methods used in for phase 2 of the research is described following the findings of phase 1.

4.1   Data Collection

4.1.1   The use of observations

Observations were used to collect data for the first phase of the study. Semi-structured interviews have been used in other research to gain patient accounts of mealtimes and difficulties (Naithani et al. 2008; Hickson et al 2011; Johansson et al. 2011). An assumption of interviewing is that people have self-knowledge, ordered in such a way that they can express it adequately (Gillham 2008). The participants in this study included people in moderate to later stages of dementia who may not have been able to express their needs verbally, views or opinions. These can be the people most likely to experience difficulties engaging in the eating process (Gillick and Mitchell 2002). To use an interviewing method would be to exclude these participants from the study. Observations allow for the natural setting to be observed, not relying on memory or expression of thoughts to explore the characteristics of the participant group (Creswell 2014).

The observations provided both qualitative and quantitative data. Semi-structured field notes were used to record first-hand the presentation and behaviours of participants at mealtimes. The field notes were also used to describe activities and interactions around the ward, which may have influenced engagement in the eating process. Dementia Care Mapping (DCM) (University of Bradford 2005), a structured observation tool, was used to measure well-being at mealtimes and engagement in the eating process.

4.1.2   Dementia Care Mapping

Dementia Care Mapping (DCM) was developed by the University of Bradford to measure well-being and the perspectives and lived experiences of people with dementia. DCM also collects data to depict what is positively affecting engagement. The most recent version of the tool, DCM 8

(University of Bradford 2005), was used in the research project to measure and quantify engagement and experiences of people with dementia at mealtimes in the participating hospitals. In order to become a Dementia Care Mapper with qualification to use the tool in the research project, the researcher undertook a standardised four day course delivered and licensed by the University of Bradford. The course consisted of teaching and assessment exercises to understand and apply the observation coding, including use of the operational rules, analyse and interpret the results, and feedback to the relevant people within the organisation being assessed. At the end of the four days the research was assessed and judged to be a reliable assessor.

The tool involves assigning alphabetical Behaviour Category Codes (BCCs) and numerical Mood and Engagement (ME) scores to every five-minute time frame over a set observation period. These are recorded into a raw data sheet (Appendix F). There are 23 alphabetical BCCs. They describe the presentation and behaviour of the person during a five-minute time frame. There is clear guidance within the DCM User's Manual (University of Bradford 2005) as to which BCC to use. When two or more behaviours occur within one five-minute time frame there are operational rules which help the researcher to make a decision about which code to assign. The rules help ensure the coding is systematic and consistent among all researchers using the tool. Some BCCs have a higher potential for well-being, as outlined by the DCM Process and Application guide (University of Bradford 2014)

Mood and Engagement scores are a second code to apply within a five-minute time frame. They represent the level of well-being and level of engagement or focus during a time frame. Mood is interpreted by the researcher through observing the expressions and body language of the participant, which indicated well-being or ill-being. Indicators of well/ill-being are listed in Table 2 (University of Bradford 2014).

Mood and Engagement are noted as one combined code. Scores are odd numbers on a scale ranging from -5 to +5. A neutral presentation, displaying no overt signs of positive or negative mood, is scored as +1. Extreme well-being or ill-being would be scored as +5 or -5. A mood score of +5 suggest the person is the happiest, most relaxed, most content or most comfortable they could be. The opposite end of the scale, -5, is where a person displays extreme distress, discomfort, anxiety, anger or unhappiness. Moderate or considerable positive or negative mood are scored as +3 or -3, where the observer judges that the participant has the potential to display more extreme positive or negative mood (University of Bradford 2005).

Table 4: Indicators of well-being and ill-being (University of Bradford 2014)	
Well-being	**Ill-being**
- Assertiveness - Bodily relaxation - Sensitivity to the needs of others - Responding to and use of humour - Creative self-expression - Showing pleasure - Helpfulness - Initiating social contact - Showing affection - Signs of self-respect - Expression of a range of emotions - Positive mood - Positive engagement and occupation	- Unattended despair - Intense anger - Unattended grief - Anxiety - Fear - Boredom - Physical discomfort - Bodily tension - Agitation - Apathy - Withdrawal - Cultural alienation - Difficulty withstanding powerful others

Engagement describes how focused or connected a person is with another person, an activity or an object. Engagement in an activity can be on a sensory level, a social level, or an occupational level. Sensory engagement may include eye focus or tracking, listening or smelling. Social would include others in an activity. Occupational level suggests an activity with a purpose (University of Bradford 2005). The same numerical scale as measuring mood applies in measuring engagement levels but an engagement score cannot be below -1. This would portray somebody as disengaged from their surroundings. A person's level of engagement is observed through their focus, attention and distractibility. As with BCCs, operational rules are provided to discern the best Mood and Engagement score to apply to a time frame.

4.1.2.1   Reliability and Validity

A list of all the literature using DCM was taken from the DCM, University of Bradford website. This includes all studies which have used DCM and all literature evaluating DCM as an observational tool. The literature evaluating the tool as an observation tool for well-being and engagement, and as a research tool, were selected in order to evaluate its use in this research project.

Despite guidance through operational rules and the list of indicators, measuring Behaviour Category Codes and Mood and Engagement scores can still be considered subjective. The list of indicators for well/ill-being is not an exhaustive description of how people express their experiences. Earlier literature identifies the need for empirical testing of inter-rater reliability and internal consistency (Thornton et al. 2004; Brooker and Surr 2006). These concerns have been addressed more recently by Sloane et al. (2007) and Algar et al. (2016) who reported good inter-rater reliability rates for DCM, commending it as a research tool. Sloane et al. (2007) acknowledge the development of the most recent version of the tool, DCM 8, negates some of the concerns from their evaluation of DCM version 7 (Brooker and Surr 2006).

In order to be used reliably as a research tool researchers must complete observations with other mappers to establish inter-rater reliability (Beavis et al. 2002). Inter-rater reliability is examined by calculating a concordance co-efficient. The number of times researchers agree on coding is divided by the possible agreements over the full observation time period. A percentage is then calculated to represent the concordance co-efficient. The comparison findings must have a concordant co-efficient score of at least 80% for the researcher to be considered competent to be completing reliable observations independently.

The DCM tool was piloted in a local care home by the researcher and an experienced Dementia Care Mapper before data collection for phase 1 of the research project began. This gave opportunity for the researcher to become familiar with the tool. It enabled initial inter-rater reliability examination, providing the evidence of the researcher achieving at least 80% concordant co-efficient score required for completing the DCM training. The training and the pilot use of the tool helped reduce variability in recording when collecting data for the study. During the research project, the researcher conducted inter-rater reliability observations with another Dementia Care Mapper throughout the study, achieving concordant co-efficient score of 86%. Differences appeared to result from Mapper's time frames not matching up when using slightly differing clocks.

Test-retest reliability has been recognised as difficult to measure in a tool for measuring well-being for people with dementia (Algar et al. 2016). The variability of subjects and environmental influences to mood and behaviour create problems when re-testing the tool at a later time. This can be more pronounced in the acute care setting where medical condition changes and impacts well-being and engagement; a person may become better or worse for reasons independent from the environment or care (Beavis et al. 2002). Reliability and internal consistency in DCM has been known to vary most when comparing BCCs than Mood and Engagement scores, but is still considered a "good level" (Fossey et al. 2002). Studies into DCM as a research tool have identified

strong enough test-retest reliability to promote the tool being used in observational research into well-being for people with dementia (Fossey et al. 2002; Algar et al. 2016).

There is a consensus amongst the literature that DCM has strong face and content validity in that it is accurate at measuring what it sets out to do. Good face validity and content validity has been attributed to the time dedicated to developing, evaluating and adapting the tool, which has clear theoretical underpinnings from the work of Tom Kitwood (Kitwood 1997; Beavis et al. 2002; Algar et al. 2016). It has been described as a good measure for engagement (Beavis et al. 2002). This gives additional value, compared to other quality of life and well-being measurements, for the purpose of this research, namely to explore experiences and engagement in the eating process.

Brooker and Surr (2006) found concurrent validity between versions 7 and 8 of DCM with strong similarities in how coding was employed. When validating the tool Brooker et al. (1998) interviewed 260 staff members who had experienced DCM observations in their unit throughout three cycles, to see if they felt it would be a useful tool to improve care. 88 to 100% of staff in each cycle agreed. DCM is identified as a useful tool for practice development and has considerable promise as a research tool (Algar et al. 2016; Surr et al. 2018).

4.1.2.2   Reflections on Using Dementia Care Mapping

In the acute hospital wards, DCM observations were completed for three-hour time periods. Lunch time observations were from 11:00 to 14:00, and tea time from 16:00 to 19:00. This was to capture antecedents, the actual mealtime and consequences (Amella and Aselage 2010). The coding was used to measure mealtime experiences and engagement in the eating process. It was useful for describing and interpreting experiences of mealtime care (Cooke and Chaudhury 2013), but the use of DCM in addressing the research aims was not without challenges.

In their analysis of the DCM tool, Cooke and Chaudhury (2013) discuss how the operational rules for deciding BCCs and MEs can result in inaccuracy in the overall portrayal of a particular time frame. This became evident during observations for this study. The rules list BCCs with a higher potential for well-being. These are to be used above codes with lower potential, however long the behaviour presented during the time frame. If a participant were eating it would be coded as F. If the behaviour changed for most of the time frame to a lower potential behaviour - such as passively watching others (B) - the rules would stipulate using F. This was not always the best way of answering the research question and highlight distractions from engagement in the eating process. Where it was deemed more useful in providing valuable data for the research, the code which portrayed the predominant behaviour of the time frame, as opposed to the higher potential code F, was used. The second operational rule for BCCs is that if two or more high

potential codes occur in a five-minute time frame, then the longest occurring code is used. As the tool already stipulates codes can be assigned based on the proportion of the time frame, the validity of the tool was not undermined.

The rules for ME scoring needed minor adaption in the event of coding disengagement from the eating process. A code of -1 can be used with any BCC for describing mood, but for engagement should only be applied to behaviour category C which describes complete disengagement or withdrawal from a person's surroundings. As the research question is exploring engagement in the eating process, use of ME score -1 has been used to describe disengagement from the eating process, as well as signs of ill-being. For the purpose of the research it has been used along-side the BCC of F (food). When F -1 is coded in the data, it shows that there is a potential for engagement in the eating process but something is creating a barrier, possibly incorporating signs of negative mood. Any other minus scores with F indicate considerable signs of ill-being.

Applying ME scores as one combined score could be difficult. At times mood and engagement were different, for example, somebody was fully engaged in eating (+3) but showing considerable signs of ill-being such as grimacing or crying (-3). Another situation observed was somebody showing considerable signs of well-being though talking and laughing with another person (+3) but easily distracted and intermittently engaging in eating (+1). The ME score could also change within a time frame, often depending on the actions or responses of other people. The operational rules are clear in these situations. Where the ME scores differed between positive and negative, the negative mood must take precedence in the time frame score (University of Bradford 2005). Although not portraying engagement, this was a valid rule to adhere to as the research aimed also to explore mealtime experiences, of which well-being was the outcome measure being used.

DCM proved to be useful as one research tool for the purpose of this study. Where the operational rules restricted the quantitative data from answering the research questions clearly, qualitative field notes added breadth, depth and understanding to the description of events. In order to best meet the research aims, the additional use of qualitative semi-structured field notes in understanding the DCM coding was essential.

4.1.3 Field notes

The field notes were used as a way of describing the activities and interactions, external to the participant, which may be influencing engagement in the eating process. DCM, with field notes, is considered a useful tool for reflecting how mood and engagement can be impacted by the care provided (Cooke and Chaudhury 2013). Without the use of field notes to describe what is

happening to influence coding, the meaning and interpretation of the data is limited. Field notes provide the opportunity for capturing experiences at the moment it occurs. The occurrence can then be preserved for later deeper reflection and understanding (Emerson 1995). Field notes can never be purely objective description of the facts; however much the researcher attempts to be factual and objective there is always interpretation of what is significant enough to write down (Emerson 1995). The use of field notes parallel to the DCM coding assists in reducing the risk of subjective selection of what is written.

DCM promotes the use of structured observational field notes along-side coding. The field notes suggested by DCM are based around whether care provided is meeting 5 psychological needs described by Kitwood (1997): Comfort, Identity, Attachment, Occupation and Inclusion. The potential for well-being and engagement is based around these 5 psychological needs being met. The DCM field notes capture Personal Enhancers (PEs) and Personal Detractors (PD) to a person's needs being met. PEs and PDs have the potential to uphold or undermine any of these psychological needs. PEs are interactions and actions which go above and beyond the normal care expected, they enhance a person's well-being. PDs are those interactions and actions that appear to have a direct negative impact on a person's well-being. A list of PEs and PDs is provided in the DCM User's Manual (University of Bradford 2005). Additional descriptive field notes were used to capture observations of behaviours and interactions when PEs and PDs were not being observed.

The field note structure presented by DCM of capturing PEs and PDs emphasise counting phenomena. This does not provide enough detail for understanding all the DCM coding when PEs and PDs were not present. The scope for understanding meanings and reasons for the behaviours and well-being required a less structured approach to writing field notes (Gillham 2008). The researcher wrote objective, descriptive, semi-structured notes, capturing the events of the observation period without assumption of what would be seen. To ensure focus within the field notes the research question of what may impact well-being and engagement at mealtimes was kept in mind. The researcher was guided by the Structured Mealtime Observation tool (Reed et al. 2008) in describing characteristics and observations of the participants. As well as staff interaction and environmental context the Structured Mealtime Observation tool included consideration of alertness, utensil use, postural stability and movement. These factors were considered when observing engagement in the eating process.

While completing the observations a similar process as outlined by Ritchie et al. (2014) was followed, as presented in Table 5. Field notes were adapted as the data collection developed to manage emerging themes. The researcher initially wrote more detailed descriptive notes of what was happening throughout the complete timeframe. As the data was analysed and the

researcher's experience developed the notes became more concise and focused on the research question. It was still important to remain exploratory and capture what was happening before during and after the meal period. It became clear that what was happening during the actual mealtime was of greater significance than other events before or after. Towards the end of the data collection period the researcher was much more aware of familiarities and themes emerging from the data and could be more mindful of this when writing the notes.

Table 5: Phases of Participant Observation (Ritchie et al. 2014 p.248)	
Type of observation	**Description**
Descriptive observation	Provides the researcher with orientation to the field and its complexity.
Focussed observation	Narrows the perspective of the researcher to focus more specifically on the research question
Selective observation	Towards the end of the data collection this is used to further evidence processes or practices found throughout the data collection.

4.1.4 Recruitment

4.1.4.1 Sampling

In accordance with the concurrent mixed methods design, the same group of participants was used for both the qualitative and quantitative elements of data collection. In qualitative research a small number of participants can provide rich data, whereas quantitative research generates large sample sizes to produce generalisability (Creswell 2014). The integration of research methods resulted in challenges when considering sampling strategy, in ensuring the quality of the research was maintained (Collins et al. 2007). The parallel convergent nature of the mixed methods data collections meant validity was more likely to be compromised through different sample sizes (Creswell and Plano-Clarke 2018). The aims of the research question favoured a qualitative dominant design. Considering the concurrent timing of the data collection a qualitative sampling strategy was considered most appropriate for the research project (Creswell and Plano-Clarke 2018).

Purposive sampling was used to ensure selection of people with the best characteristics to meet the needs of the study (Creswell 2014; Flick 2014). To ensure quality observations, up to four

participants could be observed at one time. When more than four people were identified as eligible participants, randomisation of the identified eligible participants was used. This supports the mixed methods sampling framework, with what Collins et al. (2007) describe as random purposeful sampling: selecting random cases from a purposefully selected sample.

The participant group had a homogenous element (Ritchie et al. 2014). A diagnosis of dementia, and being patients in the Acute Medicine for Older People hospital wards, were particular phenomena which linked all the participants. Heterogeneous sampling (Ritchie et al. 2014) was used within the dementia diagnosis category to allow for as much representation of the wider population of people with dementia in acute hospitals as possible within the study. Participants were chosen to have a variety of age, dementia type and stage, and gender.

Table 6 outlines the inclusion and exclusion criteria used to select eligible participants. People with other specialist conditions impacting eating and drinking were excluded from the study as additional conditions may add applications to the eating process. These included people with complex neurological conditions impacting swallow, or people being cared for on an end of life pathway. People who were fully dependent on non-oral nutritional input were also excluded as they may not be able to engage in the eating process. One participant had a nasogastric tube but was being re-introduced to soft food and was observed engaging in the eating process. Identification of potential participants was completed by the Dementia Nurse Specialist at each hospital based on the inclusion and exclusion criteria provided by the researcher, in Table 6.

Table 6: Inclusion and Exclusion criteria for participants	
Inclusion	**Exclusion**
- Inpatients on medicine for older person's ward with diagnosis of dementia prior to admission. - All types of dementia except frontal lobe/frontal temporal. - Any stage of dementia. - All ages.	- People with undiagnosed cognitive impairment. - People with frontal lobe/frontal temporal dementia. - People with medically induced delirium but no dementia diagnosis. - End of life care. - Other specialist conditions which impact eating and drinking. - People dependent on non-oral nutritional interventions.

The qualitative orientation of the research aims, namely exploring meanings and experiences, sought to produce rich, in-depth findings using a small sample size. The sample size was initially calculated based on the time frame of the data collection rather than probability calculation typical with quantitative research. Over a four to six month time period allocated to data collection for observations, it was deemed realistic to include up to 60 participants. They could be observed up to three times. The final sample size was determined on the principle of data saturation (Pope et al. 2000). The recruitment and observations finished when collecting fresh data created no new emerging patterns or themes.

4.1.4.2   The recruitment process

The participants were all inpatients on Medicine for Older Persons wards from two National Health Service (NHS) acute hospitals in England. One hospital had five wards and the other three, amounting to eight different sites for observing participants. Meetings took place at each hospital with the Matrons for Older Person's Medicine, and the ward Sisters. The Matron from each hospital sent a letter of permission for observations to take place on each of their wards. Verbal permission, and discussion of the project took place with the medical Consultant for older people. The Dementia Specialist Nurses had a database of people with dementia admitted to the hospital, meaning they were the key point of contact for the recruitment process.

The recruitment process:

1. On the day of observations the Dementia Nurse Specialist would select a ward for observations to take place, ensuring all wards were evenly covered as practically possible, across the data collection period.
2. The Dementia Nurse Specialist identified patients with dementia on that ward. A bay was chosen based on having two or three people with dementia. If more than one bay met the criteria a randomising application on the researcher's iPhone (Burnett 2016) was used to select an index participant and determine the selected bay. Eligible participants were numbered from one to the maximum number being randomised. The application then randomly generated a number from one to the maximum number.
3. The Dementia Nurse Specialist approached the eligible participants to inform them fully of the research and the implications of taking part. A Participant Information Sheet (PIS) (Appendix G) was available if eligible participants wanted further information. At this point the Dementia Nurse Specialist assessed the mental capacity to be able to understand the research and make an informed decision to participate.

4. If the person was deemed to have capacity, verbal permission was sought from the eligible participant for the researcher to approach to take consent. The process for a person who lacks capacity to consent is outlined below.

5. The researcher then approached to request the participant sign a consent form (Appendix H).

6. When the researcher returned the same day to complete observations they approached the participant and clarified continued consent through verbal permission to start the observation.

4.1.4.3   Consent

The study included people who lacked capacity to consent to participating in the research. The level of cognitive impairment for some participants meant they were unable to verbally communicate their needs, wishes or feelings. The Mental Capacity Act (Department of Health 2005) stipulates that in order to be deemed to have capacity to make a decision a person must be able to understand, retain and weigh up the information given them. They must also be able to communicate their decision. The Dementia Nurse Specialist completed a mental capacity assessment when approaching each participant for recruitment. No formal capacity paperwork was completed, but the Research Ethics Committee approved the process on the basis that the Dementia Nurse Specialists are expert and experienced in completing capacity assessments.

When a person was deemed not to have capacity to make the decision to participate in the research, the process outlined in the Mental Capacity Act (Department of Health 2005) was followed. Consultee agreement was sought from a family member or next of kin engaged in the care or interested in the welfare of the person. In the absence of a family or friend consultee a key nurse was asked to act as a professional consultee. The Dementia Nurse Specialist approached the consultee, face to face if they were visiting or over the telephone. Consultees were offered a Consultee Information Sheet (Appendix I) and were required to sign a Consultee Agreement Form (Appendix J).

Attention was also given to ongoing consent throughout the observation period. Capacity is known to fluctuate (Department of Health 2005). If the person lost capacity after signing the consent form, consent was assumed to continue from the decision to participate when they understood and could consent to participating. Any indication that the person did not wish to continue was considered withdrawal of consent (Department of Health 2005). The PIS and Consent Form outlined the participant's right to withdraw from the research. For people unable to communicate their wishes or feelings verbally, their reactions and responses to the researcher's presence were monitored. The research protocol stipulated that if any participant

showed signs of ill-being as a direct result of the researcher's presence then the observation should stop. This was monitored throughout the observation periods but did not present as an issue needing action in the duration of the research project.

4.2   Data Analysis

The analysis of the data was in line with the convergent mixed methods design of the project. Confusion can arise when combining and integrating the data and relating the qualitative and quantitative elements (Doyle et al. 2009). In the research project presented here, the integration of quantitative and qualitative data begins at the analysis stage.

Quantitative and qualitative data sets were used to validate each other (Creswell 2014). The two data sets, DCM coding and field notes, were analysed separately then combined for side-by-side comparison and contrast. When dominant BCCs had been identified, and descriptive statistics produced, the significant time frames were cross-referenced with the qualitative field notes. Joint display tables were used to present the integrated data and side-by side-comparison (Guetterman et al. 2015). Conclusions and interpretations were drawn from the combined data sets, which is the essence of mixed methods research, and increased the validity of the mixed methods research project (Creswell 2014; Bazeley 2018; Creswell and Plano-Clarke 2018). The conclusions drawn from qualitative analysis are strengthened through combination with the quantitative data, introducing a more 'scientific attitude' to the research (Robson and McCartan 2011).

4.2.1   Qualitative analysis

As in other studies using DCM and field notes (Goldberg et al. 2014; Barnes et al. 2013), thematic analysis was used to analyse the field notes. Thematic analysis is an open and accessible way of analysing across an entire data set (Braun and Clarke 2006). Braun and Clarke's Thematic Process was used as a framework for the analysis:

1. Familiarising yourself with your data
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

Field notes were transcribed, and the data managed, in qualitative data analysis software NVivo version 11 (QSR 2016). This initially aided in Braun and Clarke's (2006) Stage 1 of thematic

analysis, the researcher familiarising with the data. The software also enabled the researcher to label and code the data and organise codes into visual representations. The field notes were coded in NVivo 11 and then codes and patterns reviewed for developing themes. A theme was considered a patterned idea relating to the research question which had meaning and significance across the data set as a whole (Braun and Clarke 2006; Robson and McCartan 2011). Themes do not necessarily need to be significant through quantifiable measures but rather considered by their importance to the research question. However, the comparison of the qualitative data findings to the DCM coding allowed for some quantification of the ideas emerging through the thematic analysis. A second researcher, trained in qualitative methodology, completed coding for 10% of the field notes. Themes were identified independently then researchers compared and discussed the results.

An abductive approach was used to group the data into codes and broader themes. This approach combines and switches between inductive and deductive analysis techniques; finding new and unanticipated themes and drawing from preconceived theory (Braun and Clarke 2006; Doyle et al. 2009; Timmermans and Tavory 2012). An inductive approach is typical to qualitative research but deductive principles can also be applied at various stages of the analysis (Ritchie and Lewis 2003). Deductive approaches are often used to test theory rather than purely deriving theory from observation of the world. The researcher approached the observations and analysis aware of preconceived ideas of what may impact the mealtime, taken from the review of the published literature. Current models of theory were applied using the M3: Making Mealtimes Matter model (Keller et al. 2014) as a grounding for what may be observed in the hospital wards. In addition to the current knowledge, taking factual objective field notes could aid in discovering new themes and findings. Interim, preliminary, analysis was conducted after the first twenty participants had been observed. Summary sheets for each participant were created, and preliminary findings were used to guide further data collection (Robson and McCartan 2011). This followed the model outlined in Table 5: Phases of Participant Observation (Ritchie et al. 2014) for conducting field notes. It meant the second half of the data collected was more focussed and selective, using a deductive approach to build on the ideas created through the initial inductive observations.

4.2.2   Quantitative analysis

The Dementia Care Mapping coding was analysed using Microsoft Excel to produce descriptive statistics. The descriptive statistics included basic summarising such as counts, percentages, means, modes and medians. Summaries of percentage proportions of time in each Behaviour Category Code (BCC) and Mood and Engagement (ME) score were calculated for each individual participant and the whole data set. As the timing of the observations were based around the

model of eating difficulties (Figure 6) (Amella and Aselage 2010) the coding was broken down into before, during, and after, the period of time the food was in front of the participant. Group summaries were calculated to show the time participants spent displaying certain behaviours, or engaging in certain activities, on the wards.

The summary of BCCS and MEs separately were useful for the purpose of answering the research aims. They provided understanding of the overall common behaviours and activities before during and after the meal as well as the collective experience of well-being and ill-being during the observation periods. In order to explore further the experience of mealtimes, the BCCs and MEs in each five-minute time frame needed to be considered together. Additional descriptive statistics were calculated to summarise the percentage of time in each ME within each BCC. This was then combined with the qualitative analysis to integrate the quantitative and qualitative data.

In order to interpret the data as mixed methods results it was essential to merge and integrate the DCM results with the findings from the qualitative analysis of the field notes in order to be true mixed methods results (Creswell 2014). Comparison of the data determined similarities and contrast between quantitative codes and qualitative themes. Common patterns of behaviour, activities or presentation of well-being, derived from the field notes were compared to the quantitative coding to provide a quantifiable evidence base for the findings. This analysis process, completing side by side comparison and merging of quantitative and qualitative data, produced discussion of findings and interpretations of the results. Further questions were then identified and compared with the literature to generate future research needs as presented in Chapter 8 of the thesis (Creswell and Plano-Clarke 2011).

Chapter 5   Findings from phase 1

5.1   Introduction

This chapter presents the data collected through structured observations (DCM) and semi-structured qualitative field notes. The quantitative and qualitative data are presented separately, then combined to allow for further discussions and insight into implications of the findings. Data saturation was reached across both hospitals, and the researcher did not feel there were new phenomena being observed. The Mann-Whitney U Test was used to compare the sites, and ascertain if there was a significant difference between sites which would warrant further analysis. The Mann-Whitney U Test showed no significant difference between the codes at each hospital.

The Dementia Specialist Nurses approached 51 patients in total, with three refusing to participate in the research. Across approximately 40 meal times 49 participants were observed. The total number of five-minute time frames coded was 1695, equating to 141.25 hours of observation data. Demographic data including their age, gender, dementia diagnosis, and number of observations conducted, is shown in Table 7. Participants for the phase 1 were unequally distributed between sites with 31 from Site A, and 18 from Site B. As the data was not gathered simultaneously between sites, and data saturation was reached, there are fewer participants at Site B.

Participants had a range of dementia types, determined from medical notes collected by the Dementia Nurse Specialists. One quarter of the participants did not have a type specified in their notes but could have been any of the types of dementia observed or other types. The most common type of dementia observed was Alzheimer's disease, with almost 40% of the participants having a diagnosis. Vascular dementia and mixed dementia were the next most common types observed. These figures are in line with the national figures showing prevalence of each dementia type, released by the Alzheimer's Society (2017).

Table 7: characteristics of participants taking part in observations

Characteristic	Overall		Hospital			
			1		2	
Participants	49		31		18	
Age - mean (SD)	86.7	(5.9)	86.1	(6.9)	87.8	(3.5)
Gender						
Male	26		17		9	
Female	23		14		9	
Type of Dementia						
Alzheimers	19		10		9	
Vascular	9		7		2	
Mixed	4		3		1	
Lewy body	2		2		0	
Alcohol related	1		0		1	
Young onset	1		1		0	
Unspecified	12		7		5	
Number of observations per participant						
1	33		17		16	
2	14		12		2	
3	2		2		0	

5.2   Dementia Care Mapping

5.2.1   Summary of complete observation time period

The observations structured by Dementia Care Mapping (DCM) provided a descriptive quantitative summary of participant behaviours, well-being and experience at mealtimes. The description provides insight into the influence of the ward environment on participant experience and engagement during the observations. The DCM data also revealed when mood and engagement scores reflected described signs of well-being or ill-being in the qualitative field notes.

Table 8 shows the group summary for the total percentage of time spent in each Behaviour Category Code (BCC) and Mood and Engagement (ME) score for the whole data set. This includes data from each two to three hour observation period, before, during and after the meal. A brief description of what each BCC and ME represent are included in the Table.

Table 8: Percentage of time spent in each Behaviour Category Code (BCC) and Mood and Engagement (ME) stated over the entire observation period

Behaviour Category Code (BCC) and description	Total % of time spent in BCC
A: Interaction with live person or animal	12.1
B: Passive engagement/watching	12.5
C: Withdrawn, no engagement	3.5
D: Self-care	1.5
E: Expressive or creative activity	0.0
F: Food related activity	24.7
G: Reminiscence	0.2
I: Intellectual	0.3
J: Exercise or physical sport other than walking	0.0
K: Walking, standing, moving independently	2.6
L: Leisure	4.4
N: Sleeping/dozing	17.7
O: Attachment or engagement with an object	4.0
P: Physical assistance	8.7
R: Religious activity	0.0
S: Sexual activity	0.0
T: Direct, intentional engagement of the senses	1.2
U: Un-responded to	2.7
V: Vocational, work related activity	1.6
W: Repetitive self-stimulation	0.5
X: Use of the toilet, out of view	0.7
Y: Interacting with self or imagined person/hallucination	1.2
Mood and Engagement (ME)	**Total % of time spent in ME**
+ 5: extreme signs of well-being, focused and concentrating on behaviour or activity	0.1
+ 3: moderate or considerable signs of well-being, focused and concentration on behaviour or activity	13.4
+ 1: neutral – no particular signs of well/ill-being, partially engaged but possibly distractible	62.4
-1: moderate signs of ill-being, disengaged from task or activity	22.0
- 3: considerable signs of ill-being	2.0
- 5: extreme or severe signs of ill-being, anger, distress, discomfort or unhappiness	0.0

The highest percentage of BCCs was food related activities, with almost one quarter of the time being coded as F. This was to be expected with the observation period occurring over a mealtime. The other higher percentages of behaviours and activities included interactions (A), passive engagement or watching the environment (B), sleeping or dozing (N), and physical assistance (P).

There is a selection of BCCs not recorded in the entire observation period: expressive or creative activity (E), exercise other than walking (J), religious activities (R) and sexual activities (S). These BCCs have therefore been removed from the following results tables. Creative, expressive, sexual and religious activities would not be expected to be commonly observed in a hospital setting. The timing of the observation period could provide reason for lack of exercise and movement, as physiotherapists were least likely to provide interventions around mealtimes. Other than these un-used codes, there is a general spread of BCCs with most representing less than 5% of the overall codes.

The least commonly observed categories with high potential for well-being were: reminiscing (G), intellection activities (I), self-care (D) and vocational activities (V). The combination of these BCCs made up less than 6% of the overall codes. There is a clear prominence of BCCs with low potential for well-being. Passive engagement or watching (B), withdrawn behaviour (C) and sleeping (N) make up almost 34% of all the codes.

Mood and engagement (ME) scores were also coded every five minutes, alongside the BCCs. The most common ME score is +1, making up 62% of all the ME codes during all observations. The ME code of +1 represents a neutral mood and engagement score. Participants scored in this code would have been showing no particular signs of ill or well-being, and would have been engaged in activity but distractible, or watching on. Consequently, a score of +1 does not always represent a positive experience. The ME scores portraying a positive experience combine to make up 13% of the over-all scores, compared to 24% of the scores representing a negative experience through ill-being or disengagement. The most extreme ME scores of -5 and +5 are least used; there were no minus 5 scores, and plus 5 made up 0.1% of all the codes. Extreme ill or well-being was rarely observed.

Analysing the BCCs and ME scores in isolation did not give a full picture of experience and engagement during the observations. It was pertinent to the study to know the ME scores attached to the BCCs in each time frame. The next section presents results from the combined BCC and ME scores. Table 9 summarises the number, and percentage, of time frames, ME scores coded within each BCC. ME score meanings can be seen in the Table 9 footnote below.

Table 9: number, and percentage, of time frames, Mood and Engagement (ME) scores coded within each Behaviour Category Code (BCC) over the entire observation period						
BCC/ME	**- 5**	**-3**	**-1**	**+1**	**+3**	**+5**
	n (%)	**n (%)**	**n (%)**	**n (%)**	**n (%)**	**n (%)**
A: interaction with live person or animal	0 (0)	10 (4)	59 (24)	128 (51)	53 (21)	1 (0.4)
B: Passive engagement/watching	0 (0)	0 (0)	0 (0)	260 (100)	0 (0)	0 (0)
C: Withdrawn, no engagement	0 (0)	0 (0)	70 (100)	0 (0)	0 (0)	0 (0)
D: Self-care	0 (0)	0 (0)	5 (16)	26 (84)	0 (0)	0 (0)
F: Food related activity	0 (0)	0 (0)	100 (19)	290 (56)	124 (24)	0 (0)
G: Reminiscence	0 (0)	1 (25)	1 (25)	1 (25)	2 (50)	0 (0)
I: Intellectual	0 (0)	0 (0)	2 (29)	5 (71)	0 (0)	0 (0)
K: Walking, standing, moving independently	0 (0)	2 (4)	18 (33)	30 (56)	4 (7)	0 (0)
L: Leisure activity	0 (0)	0 (0)	0 (0)	68 (75)	23 (25)	0 (0)
O: Attachment to or engagement with an object	0 (0)	2 (2)	19 (23)	57 (69)	5 (6)	0 (0)
P: Physical assistances	0 (0)	14 (8)	27 (15)	132 (73)	7 (4)	0 (0)
T: Direct, intentional engagement of the senses	0 (0)	0 (0)	3 (12)	21 (81)	2 (8)	0 (0)
U: Un-responded to	0 (0)	6 (11)	50 (89)	0 (0)	0 (0)	0 (0)
V: Vocational, work related activity	0 (0)	0 (0)	1 (3)	25 (78)	5 (16)	1 (3)
W: Repetitive self-stimulation	0 (0)	0 (0)	6 (55)	5 (45)	0 (0)	0 (0)
Y: Interaction with self or imagined person/hallucination	0 (0)	0 (0)	12 (48)	13(52)	0 (0)	0 (0)

Table 9 footnote, ME scores key:

+5: extreme signs of well-being, focused and concentrating on behaviour or activity.

+3: moderate or considerable signs of well-being, focused and concentrating on behaviour or activity.

+1: neutral – no particular signs of well/ill-being, partially engaged but possibly distractible.

-1: moderate signs of ill-being, disengaged from task of activity.

-3: considerable signs of ill-being

-5: extreme or severe signs of ill-being, anger, distress, discomfort or unhappiness.

Some of the results in Table 9 are noticeably clustered compared to the general dispersed pattern of BCCs and MEs; they are primarily explained by the DCM rules of coding. Codes N for sleeping, and X for using the toilet, do not have ME scores attached to them. These rows in the table have been removed. Code B can only be scored as neutral (+1) as it describes passive engagement and no particular signs of well or ill-being. C, representing being withdrawn, and U, being un-responded to or ignored, can only be coded alongside a minus ME score due to the nature of the activity at that time. Other than those explained by the DCM rules, only leisure activities (L) were coded solely with positive ME scores. All other codes had a distribution of positive and negative experiences associated with the various behaviours or activities.

The most common activities or behaviours, aside from food related activity, as shown in Table 8, were interaction (A), passive engagement or watching (B), and physical assistance (P). Where interaction may be viewed as positive occurrence, 28% of timeframes with interaction

corresponded to minus ME scores. This is compared to just over 22% with positive scores. In 4% of the times of interaction, participants were exhibiting more considerable signs of ill-being, coded at -3. Interaction was one of just two BCCs in which an ME score of +5 was observed, the other being when participants were engaged in a vocational or work related activity (V). Physical assistance describes a variety of activities from personal care, to assistance to mobilise, or giving medication. These activities made up almost 9% of the observation time. While receiving physical assistance participants were showing signs of ill-being for 23% of the time. Positive mood and engagement totalled 4% of the time physical assistance was observed. Neutral coding made up the other 73% of the time.

The overall picture is important to describe a collective experience. For the purpose of the research it is useful to further explore more specific time frames. Descriptions of the DCM data were produced for the observation period 45 minutes before the meal, and the time while the meal was physically in front of participants.

5.2.2 45 minutes before the meal

Figure 9 visually displays the distribution for the percentage of time BCCs were coded within the data specifically during the 45 minutes before the meal. The pattern and distribution of the coding during this time mostly mirrors that of the overall data. Interaction (A), passive engagement or watching (B), food related activity (F), physical assistance (P) and sleeping or dozing (N), were the most common activities observed during this time.
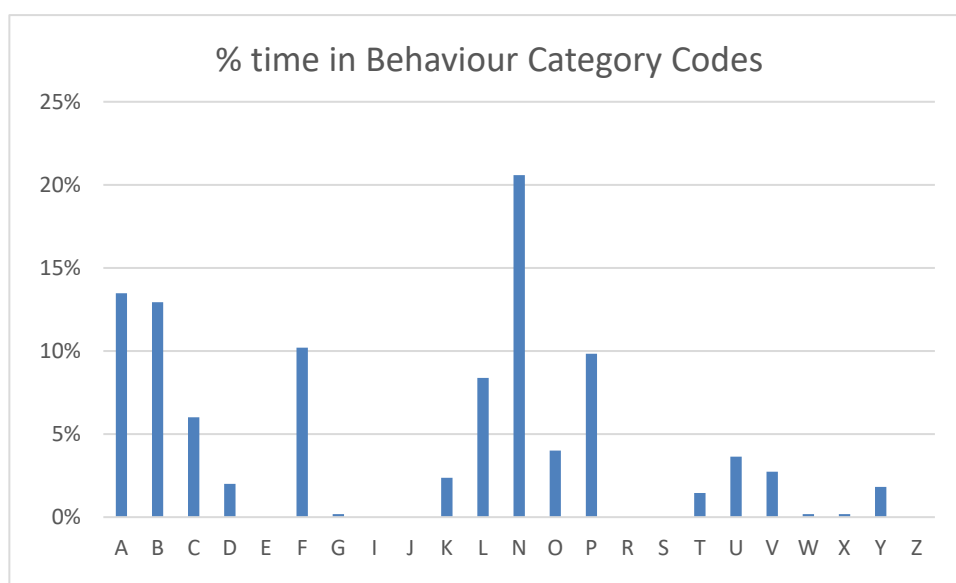
Figure 9:   Distribution of total percentage of time in each BCC for all participants for the 45 minutes before the meals.

The most commonly coded behaviour was sleeping or dozing (N), representing just over 20% of the time period. Passive engagement and watching (B) was the third most common behaviour coded, making up almost 13% of the time. These, combined with the percentage of time coded as withdrawn (C), showed that almost 30% of the time leading up to the meal was spent disengaged, withdrawn or sleeping. Being ignored, or un-responded to (U), was coded more in the period leading up the mealtime than in the rest of the observation period. On 20 occasions participants were expressing a need for attention or assistance but did not receive a response.

Interaction with staff, visitors or other patients (A) made up 13.5% of the time leading up to the meal. The prominence of physical assistance (P) in the 45 minutes before the meal can be attributed mainly to the timing of the medication round. This was often just before or during the meal. Physical assistance before the meal also included repositioning participants in preparation of the meal arriving.

In contrast to the overall data, leisure activities were also coded in the 45 minutes before the meal. The specific time frames coded as leisure activities were clustered to a small proportion of the participant sample. Out of the 46 time frames coded as leisure (L), 38 were observed across six participants. Leisure activities included looking at the newspaper, looking at photos and colouring, and were primarily instigated by visitors.

The ME scores also showed a very similar distribution within the 45 minutes before the meal as in the data for the overall observation period. Figure 10 shows the distribution of ME scores during this observation period.
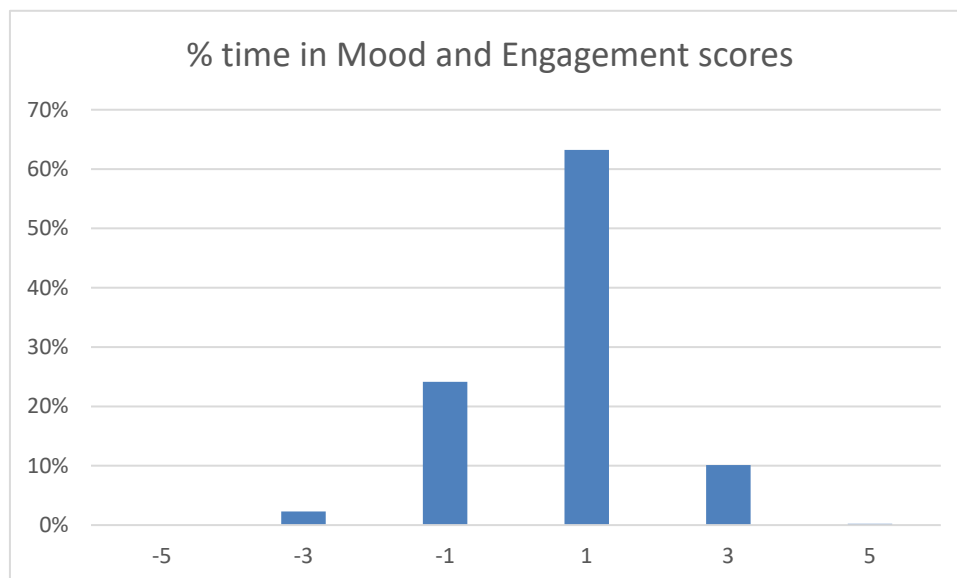
Figure 10:   Distribution of total percentage of time in each ME score for all
participants for the 45 minutes before the meal

Neutral presentation of mood and engagement (+1) significantly supersedes all other codes,
amounting to approximately 63% of all time frames. There were more minus ME scores than
positive, with -1 and -3 combining to make just over 26% of all the codes. The majority of these
were -1 (24%), which is interpreted as small signs of ill-being, including distress, discomfort,
unhappiness and boredom or lack of engagement. Over one quarter of the time leading up the
meal, participants were showing signs of ill-being. Clear signs of considerable positive mood and
focused engagement (+3) were observed for just 10% of the time. The most extreme positive ME
score (+5) was only observed in one 5 minute time frame, for one participant, in the entire 45
minutes. There were no observations of extreme ill-being (-5).

The BCCs and MEs as separate entities only provide limited explanation of the observations for
the period of time leading up to the meal. Both were combined to enhance understanding of how
the activities related to well-being in the lead up to the meal. Table 10 details the number of time
frames and percentage of ME scores applied to each BCC in the 45 minutes before the meal. ME
score meanings can be seen in Table 10 footnote below.

Table 10: Number of time frames and percentage of time Mood and Engagement (ME) scores were coded within each Behaviour Category Code (BCC) in the 45 minute time period before the meal						
BCC/ME	-5	-3	-1	+1	+3	+5

	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
A: interaction with live person or animal	0 (0)	3 (4)	11 (15)	36 (49)	23 (31)	1 (1)
B: Passive engagement/watching	0 (0)	0 (0)	0 (0)	71 (100)	0 (0)	0 (0)
C: Withdrawn, no engagement	0 (0)	0 (0)	33 (100)	0 (0)	0 (0)	0 (0)
D: Self-care	0 (0)	0 (0)	2 (18)	9 (82)	0 (0)	0 (0)
F: Food related activity	0 (0)	0 (0)	14 (25)	38 (68)	4 (7)	0 (0)
G: Reminiscence	0 (0)	0 (0)	0 (0)	1 (100)	0 (0)	0 (0)
K: Walking, standing, moving independently	0 (0)	0 (0)	3 (23)	9 (69)	1 (8)	0 (0)
L: Leisure activity	0 (0)	0 (0)	0 (0)	33 (72)	13 (28)	0 (0)
O: Attachment to or engagement with an object	0 (0)	0 (0)	9 (41)	13 (59)	0 (0)	0 (0)
P: Physical assistances	0 (0)	5 (9)	6 (11)	41 (76)	2 (4)	0 (0)
T: Direct, intentional engagement of the senses	0 (0)	0 (0)	1 (13)	7(88)	0 (0)	0 (0)
U: Un-responded to	0 (0)	2 (10)	18 (90)	0 (0)	0 (0)	0 (0)
V: Vocational, work related activity	0 (0)	0 (0)	1(7)	13 (87)	1 (7)	0 (0)
W: Repetitive self-stimulation	0 (0)	0 (0)	1 (100)	0 (0)	0 (0)	0 (0)
Y: Interaction with self or imagined person/hallucination	0 (0)	0 (0)	5 (50)	5 (50)	0 (0)	0 (0)

Table 10 footnote, ME scores key:

+5: extreme signs of well-being, focused and concentrating on behaviour or activity.

+3: moderate or considerable signs of well-being, focused and concentrating on behaviour or activity.

+1: neutral – no particular signs of well/ill-being, partially engaged but possibly distractible.

-1: moderate signs of ill-being, disengaged from task of activity.

-3: considerable signs of ill-being

-5: extreme or severe signs of ill-being, anger, distress, discomfort or unhappiness.

The most commonly coded activities or behaviours with high potential for well-being were: interaction (A), food related activities (F), physical assistance (P), and leisure activities (L). Interaction and leisure activities during this time also have the highest association to positive ME scores. In 28% of the time frames coded as leisure (L) the participants were in a +3 category, showing considerate signs of well-being and engagement. In the lead up the meal there were no periods of time where people were engaged in leisure activity but showing signs of ill-being.

When participants were engaged in interaction (A), they were displaying positive mood and engagement for 24% of the time. Interactions could also be negative. For 19% of the time engaged in interaction participants were showing signs of ill-being through their body language or the topic of conversation. In 4% of these interactions participants were showing considerable signs of distress or unhappiness, coded as -3.

Despite the high potential for well-being and engagement in the food related and physical assistance categories, 25% of food related activity and 19% of physical assistance were also times of ill-being. When receiving physical assistance with care only two time frames were coded as +3.

5.2.3   During the mealtime

The same descriptive statistics were produced specifically for the mealtime: while the meal was physically placed in front of the participants. The length of time food was in front of a person varied between individuals. Table 11 shows the percentage of time each BCC and ME was coded during this period. As expected, eating was the prominent activity during the mealtime, taking up almost 72% of the time.

Table 11: total percentage of time spent in each Behaviour Category Code (BCC) and Mood and Engagement (ME) score in the time the meal was available to participants

Behaviour Category Code (BCC) and description	Total % time spent in BCC
A: Interaction with live person or animal	5.2
B: Passive engagement/watching	4.6
C: Withdrawn, no engagement	1.2
D: Self-care	1.2
E: Expressive or creative activity	0
F: Food related activity	71.8
G: Reminiscence	0
I: Intellectual	0
J: Exercise or physical sport other than walking	0
K: Walking, standing, moving independently	1
L: Leisure	0.4
N: Sleeping/dozing	6.6
O: Attachment or engagement with an object	1
P: Physical assistance	3.5
R: Religious activity	0
S: Sexual activity	0
T: Direct, intentional engagement of the senses	0.4
U: Un-responded to	1.7
V: Vocational, work related activity	0.4
W: Repetitive self-stimulation	0
X: Use of the toilet, out of view	0
Y: Interacting with self or imagined person/hallucination	0.8

Mood and Engagement (ME)	Total % time spent in ME
+ 5: extreme signs of well-being, focused and concentrating on behaviour or activity	0
+ 3: moderate or considerable signs of well-being, focused and concentration on behaviour or activity	24
+ 1: neutral – no particular signs of well/ill-being, partially engaged but possibly distractible	52.2
-1: moderate signs of ill-being, disengaged from task or activity	23.1
- 3: considerable signs of ill-being	0.7
- 5: extreme or severe signs of ill-being, anger, distress, discomfort or unhappiness	0

Activities and behaviours other than food related activity mostly represented under 3% of the time each. Reminiscence (G), intellectual activities (I), exercises other than walking (J), religious (R) or sexual activities (S), repetitive self-stimulation (W), and going to the toilet (X) were not observed at all during the time the meal was in front of the participants. The more prominent codes observed were those describing interaction (A), passive engagement (B), sleeping (N) and physical assistance (P), each representing more than 3% of the time. The BCCs observed in the

mealtime period show that for almost 30% of the time participants were not engaging in food related activity.

Codes representing sleeping (N), passive engagement or watching (B), and withdrawn behaviour (C) combined to make up just over 12% of the mealtime. When A was coded this presents a time when conversation was taking place instead of eating during the majority or whole of the five-minute time frame. This is in line with the DCM rules which state that when interaction and another activity occur together, the other activity is coded (University of Bradford 2005). The mood within the conversation is then used to influence the ME score. For almost 4% of the mealtime people were receiving physical assistance for care tasks. This did not include physical assistance with eating as this would have been coded as F.

Over half the ME scores applied to all BCCs during the mealtime period were +1, a neutral, partially engaged, presentation. Positive and negative mood and engagement levels represented by -1 or +3 were almost equally observed for most of the other half of the time. More considerable levels of ill-being were seen for less than 1% of the time and were observed in just two out of the 49 participants. Extreme levels of well-being or ill-being were not observed during the mealtime period.

Table 12: Number, and percentage, of time frames ME scores were coded within each BCC during the meal						
BCC/ME	**-5**	**-3**	**-1**	**+1**	**+3**	**+5**
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
A: interaction with live person or animal	0 (0)	0 (0)	8 (32)	15 (60)	2 (8)	0 (0)
B: Passive engagement/watching	0 (0)	0 (0)	0 (0)	22 (100)	0 (0)	0 (0)
C: Withdrawn, no engagement	0 (0)	0 (0)	6 (100)	0 (0)	0 (0)	0 (0)
D: Self-care	0 (0)	0 (0)	2 (33)	4 (67)	0 (0)	0 (0)
F: Food related activity	0 (0)	0 (0)	70 (20)	171 (49)	106 (31)	0 (0)
K: Walking, standing, moving independently	0 (0)	2 (40)	1 (20)	2 (40)	0 (0)	0 (0)
L: Leisure activity	0 (0)	0 (0)	0 (0)	2 (100)	0 (0)	0 (0)

O: Attachment to or engagement with an object	0 (0)	0 (0)	2 (40)	3 (60)	0 (0)	0 (0)
P: Physical assistances	0 (0)	1 (6)	4 (25)	11 (69)	0 (0)	0 (0)
T: Direct, intentional engagement of the senses	0 (0)	0 (0)	0 (0)	2 (100)	0 (0)	0 (0)
U: Un-responded to	0 (0)	0 (0)	8 (100)	0 (0)	0 (0)	0 (0)
V: Vocational, work related activity	0 (0)	0 (0)	0 (0)	2 (100)	0 (0)	0 (0)
Y: Interaction with self or imagined person/hallucination	0 (0)	0 (0)	3 (75)	1 (25)	0 (0)	0 (0)

It is useful to see which BCCs were associated with signs of ill-being or well-being to understand how the mealtime experience is being influenced by contextual factors. Table 12 shows the ME scores in relation to the BCCs they were coded with. ME score meanings can be seen in Table 12 footnote below.

Table 12 footnote, ME scores key:

+5: extreme signs of well-being, focused and concentrating on behaviour or activity.

+3: moderate or considerable signs of well-being, focused and concentrating on behaviour or activity.

+1: neutral – no particular signs of well/ill-being, partially engaged but possibly distractible.

-1: moderate signs of ill-being, disengaged from task of activity.

-3: considerable signs of ill-being

-5: extreme or severe signs of ill-being, anger, distress, discomfort or unhappiness.

Almost 72% of the time represented food related activity (F), but the distribution of ME scores alongside the BCC revealed more detail about the experience of the mealtime. Within the times food related activity was observed, 20% were coded an ME score of -1; for 20% of the time participants were either showing signs of ill-being or were disengaged from eating. More often the food related activity was associated with a positive experience, shown in the +3 ME score. For 49% of the time engaged in food related activity participants were scored +1, showing no particular signs of ill or well-being and intermittently engaged in eating and drinking.

The combination of BCCs and ME scores can be helpful to ascertain what may be linked to promoting or reducing well-being at mealtimes. The only activities which were observed with -3 were receiving physical assistance and walking around during the mealtime. These combined ME and BCCs were only observed in two participants. Food related activity and interaction were the only two BCCs which included +3 ME scores. Other activities and behaviours which have high potential for well-being but included some occurrences of minus ME scores were: interaction (A), self-care (D), walking (K), attachment to an object (O), physical assistance (P), and participants interacting with themselves or an imagined other (Y).

5.2.4   Conclusion

The Dementia Care Mapping (DCM) data gives an overall picture of how participants were engaging in and experiencing mealtimes. Food related activity is clearly a prominent feature of mealtimes for people with dementia in the hospital wards observed. The main finding from the DCM data was that people with dementia are only fully engaged or focused on the meal, and having a positive experience, for about one quarter of the time. The exploration of other activities showed that a large proportion of time, not eating, is taken up with participants being partially disengaged or withdrawn from their surroundings, or sleeping. There was a balanced distribution of signs of ill-being and well-being during the whole observation period, but it was apparent that more time frames were spent disengaged or negatively experiencing the meal than having a positive experience.

The DCM data gives a detailed description of what was happening in the lead up to and during mealtimes. The numerical data is limited in allowing for interpretation of these results. The qualitative field notes provide a more in-depth description of mealtimes in the acute hospital setting for people with dementia. Analysis of the field notes provides a greater understanding of what may be influencing the mealtime experience described through the DCM coding. Further analysis, cross-referencing and merging the qualitative and quantitative data further increases knowledge and understanding of what is influencing mealtimes.

5.3   Qualitative field notes

The over-arching themes identified in the qualitative field notes were: mealtimes as a meaningful activity, independence and choice, and the impact of visitors. Sub-themes were identified within these: meal anticipation, distractions, food selection, communication, positioning, levels of assistance, knowing the person, and time. Many of these linked to more than one over-arching

theme but could be applied in different ways. All the themes influenced engagement in and experience of the mealtimes, evidenced through the Dementia Care Mapping codes.

5.3.1 The mealtime – a meaningful activity versus a task

Various sub-themes combined to inform the over-arching theme of mealtimes as a meaningful activity: meal anticipation, distractions and food selection. Each theme provided a different insight into the meaning of mealtimes, beyond just eating and drinking. Throughout the observations, barriers to meaningful mealtimes were identified. The mealtime was mainly observed to have little or no anticipation as a meaningful activity, rather it was observed as a milestone of time within the hospital day. It was observed as a task which staff completed, along-side medication rounds, taking people to the toilet, assisting with personal care and documentation.

Some individual participants had the ability to continue with their normal mealtime patterns. They were observed to conduct familiar mealtime activities such as washing their hands before the meal, waiting for others around to start eating before they commenced, making comments such as "*Bon appetite*" (Field note, participant P1), and trying to clear up afterwards. Staff were noted to create barriers to these attempts of normalisation and participation in the mealtime as a meaningful activity, as illustrated in one example:

> *"13:37 [Participant] takes empty plate and bowl out to nurse station.*
>
> *13:38 Offering to help nurses tidying up but they decline her help.*
>
> *13:40 Walks back into bay and washes her hands."* (Field note, participant P6)

Participants with more severe cognitive impairments were reliant on others to create a familiar meaningful mealtime environment. Setting up the mealtime through sensory and social cues, in an unfamiliar environment, was seldom observed.

5.3.1.1 Meal anticipation

Meal anticipation was identified as a sub-theme in relation to meaningful activity. In some instances, dependent on the staff on duty, efforts were made to anticipate the meal arrival. Patients were given hand wipes, or their tables were cleared and cleaned in preparation for the meal. The meal was often talked about as an impending event. This was rarely seen to be more than to encourage a patient at risk of falling to sit down, or to distract the person from a more distressing topic. The preparation and discussion about the meal could occur up to one hour before the food arrived.

"11:27 Doctors leave. Calls out "can I go home now nurse". HCA responds that it is nearly lunch time…

… 12:30 HCA puts dinner tray in front of her and tells her what it is...One hour since told it was nearly lunch time" (Field note, participant B14)

"16:43 HCA gives wet wipes to clean hands with. Participant asks the time and HCA tells her. [Participant] goes back to sleep.

17:11 Nurse places tray on table." (Field note, participant B11)

A recurrent description used within the field notes was that of food, or the tray, being placed in front of a participant unexpectedly. This was often after a significant period of time with no engagement or interaction. It was rare that the food arriving was linked to any anticipatory activity to suggest the meal was due. One example observed was when a participant was sleeping, disengaged and not anticipating the meal. Hand wipes had been provided as part of the lead up to the meal, half an hour before the food arrived. By this time the participant had been asleep for another 20 minutes. There were often limited field notes taken during the time leading up to the meal as limited activity was happening.

The lack of engagement before, and anticipation of, the meal, was often a precursor to confusion, not initiating eating, or subsequent ill-being and disengagement from the eating process. Signs of ill-being displayed before the mealtime were also detrimental to anticipating a positive, meaningful, mealtime experience. Participants were observed evidently in pain, frustrated, upset or confused in the lead up to the meal. The apparent priorities of the hospital system, such as risk of falls and the priority of other tasks, during this time left episodes of ill-being unresolved as the meal was delivered.

"16:58 Shouts "come in where the bloody hell are you". Saying the chair is hard. Researcher give him his call bell.

17:04 Nurse comes in. Talking to her. She encourages him to stay sitting until after tea time.

17:06 Saying "why do I have to go through this", grimacing.

17:12 Groaning, puts hands on his head. Staring ahead…

…17:23 Saying his bottom aches from being on the chair too long.

17:25 HCA brings tray of food over, takes his dressing gown which is across his front to free his hands and arms for use. Puts plate on table in front of him, puts pudding down and tells him what it all is." (Field note, participant P12)

Participants were mostly left in the same place and position throughout the morning, and into the mealtime period. There was little or no preparation of the meal arrival observed through changing position. Some patients would position themselves in preparation for the meal for example, move from the bed to the chair, or return from walking around the ward to sit on the edge of the bed. This was rare and applied only to patients who appeared to have the cognitive ability to recognise the time and anticipate the arrival of the meal on the ward. In some cases staff offered to assist people into their chairs. Often, if people were lying in bed then that is where the meal would be placed in front of them. Neglecting to reposition them prior to the food delivery often led to an inappropriate position for eating. When participants were assisted to a better position on the bed, food regularly arrived before this task was completed. As a result, the food would to start to cool down before the participant was ready to eat it.

The cases where staff had assisted participants into a good eating position in anticipation of the meal often resulted in more focused engagement in the meal.

> *"12:33 HCA wakes him and asks where he would like his lunch. Participant says he will sit up – HCA tells him what the food is. HCA sits the back of the bed up and puts table over the bed for him. HCA removes everything off the table except the food and drink. In a good position for eating and good table height.*
> *12:35 Picks up spoon and fork and eating independently."* (Field note, participant B32)

5.3.1.2 Distractions

It was a common observation that the meal was disrupted, with little environmental or sensory cues to redirect participants to re-initiate the eating process. Distractions from the eating process were consequences of the reduced attention in dementia, the division of staff's attention, and the priorities of the hospital system.

5.3.1.2.1 The hospital system

Medication rounds and physical assessments were a distraction from meals as a meaningful and protected activity. The importance of ward routine and completing tasks at a particular time appeared to be of greater priority to the nurses than keeping the mealtime a protected activity. Examples included nursing giving out medication and taking physical observations:

> *"12:46 Stops eating while nurse gives medication*
> *12:47 Eating again – independently and initiated it himself"*
> (Field note, participant B15)

> *"17:56 Eating pudding independently.*
>
> *17:58 Nurse takes physical observations e.g. BP, Sats – stops eating to allow her to do*
>
> *this."* (Field note, participant P8)

The disturbance of the medication round was often momentary and was not observed to prolong the distraction from the eating process. Other distractions, both for staff and patients, had a greater influence on mealtime experiences and engagement in eating.

5.3.1.2.2 Staff distractions

Staff were often observed telling patients to wait as they were attending to other tasks and other patients. At the mealtime nurses and health care assistants were having to assist more than one patient at a time to eat. As a result participants were given a small amount before the nurse or health care assistant moved on to the next person. Participants were observed to stop eating between the times the staff were assisting them, as illustrated well in one field note:

> *"13:03 HCA gone to assist with another patient so participant not eating.*
>
> *13:06 HCA assisting to eat.*
>
> *13:07 HCA distracted by paper work"* (Field note, participant B9)

With this pattern the mealtimes were not one protected or meaningful event. They were often disjointed with staff coming and going, leaving participants appearing confused. Care staff were often distracted by what appeared to be greater priorities: assisting patients with the most demanding needs, such as physically assisting to eat, and documentation. Graded levels of support, such as verbal or physical prompting and supervision were seldom observed. Even the important task of physically assisting someone to eat them could be put off by other tasks considered more important at that time.

> *"17:11 Nurse places tray on table – then distracted by another patient being admitted to*
>
> *the ward.*
>
> *17:14 Still asleep – food next to her on the tray, nurse busy with new patient and HCA*
>
> *assisting another patient to eat."* (Field note, participant B11)

Even outside of the set mealtime staff were unable to always meet patient's nutritional needs and preferences due to distractions with other patients and tasks. The importance of routine and structure in the wards became increasingly evident throughout the observations. One example illustrates this:

> *"11:14 [Participant] walking around asking for a biscuit and drink. HCA says "dinner's*
>
> *coming soon", participant replies "but I want something now" – frowning, seems to be*

getting more annoyed. HCA says "I'm just busy with another patient.

11:16 HCA brings biscuit in a packet – says 'you'll have to wait for lunch after that, I can't

keep running around'" (Field note, participant B3)

5.3.1.2.3   Patient distractions

People with dementia were also observed to be distracted from engaging in the eating process regardless of interaction or care provided by staff. Patients being distracted from the eating process were observed to coincide with the lack of a meaningful environment, or the meal being set aside as a protected activity. When the mealtime started and finished was dependent on each individual. Patients within the same bay could have their food delivered and taken away with as much as a ten minute time difference from each other. As well as taking away the social aspect of eating with others in the bay, this also meant care and medical activities continued within the bay while others continued to eat. Participants were observed to be clearly distracted from their meals by these activities:

> *"12:32 Offers fork and encourages him to do it himself. Able to lift fork to mouth independently – HCA leaves to assist another patient. He chews repeatedly and pushes table away. Brings cup of drink to mouth and has a drink. Distracted by other activities on the ward and stops eating and drinking."*
> (Field note, participant B5)

> *"17:39 Not eating pudding – watching what's going on around the bay"* (Field note, participant P12)

Distractions from other patients or items on the table were particularly noted during observations. In rare instances tables were cleared and wiped before the food was delivered. On the whole this did not happen so people were observed to be distracted by items on the table.

> *"17:39 Getting distracted by other things on the table – trying to open the cake wrapper, distracted from dinner. Stands up and walks off with her talcum powder."* (Field note, participant B12)

> *"17:15 Distracted by glasses case on the table – stops eating…*
> *…17:36 Pushes pudding aside after a few mouthfuls. Sits looking at a piece of paper with writing on from his table – distracted by paper."* (Field note, participant P9)

Within the hospital ward environment, many distractions were observed. There was a clear lack of environmental, sensory or social cues directing attention to the meal as a meaningful activity.

This appeared detrimental to engagement in the eating process and the mealtime experience portrayed by people with dementia.

5.3.1.3   Food selection – a part of the mealtime process

A lack of meaning to the meal process of the hospital was apparent in the process of food selection and menu choices. Independence in making choices was reduced for people with dementia in the hospital setting. Where participants were unable to express their wishes clearly, food was selected for them, often without further attempt at clarification.

> *"12:35 Nurse offers 3 different options of fruit juice – participant doesn't seem to understand and asks for chocolate. Nurse chooses apple juice for her."* (Field note, participant B11)

The timing of food selection appeared to impact on participant mealtimes. In all but one ward observed, menu choices were made for later in the day or the next day. This would involve another meal being eaten before that particular choice was relevant. Multiple occasions were observed where participants could not remember what food they had ordered, or even remember whether they had ordered at all. This impacted participant well-being, as illustrated by two participants:

> *"11:47 Asking what's for lunch – talks with ward hostess – he says he can't remember what he ordered. Ward hostess checked and told him, he says he is looking forward to it."* (Field note, participant B16)

> *"12:18 Sitting next to nurse. Crying saying 'I don't know what I ordered', 'I'm not going to get lunch'. HCA reassures her she will get a meal."* (Field note, participant B12)

Food choice timings and processes were not observed to be an important part of the mealtime as an activity on the wards. Rather, it was seen to be another task to be completed within a time frame to fit the hospital routine.

> *"12:13 Eyes closed, shaking her head and frowning, waving hand if pushing something away.*
>
> *12:15 Student nurse approaches with menu choices for tomorrow – participant waves her hand and coughs saying "no". Student nurse says she'll come back later.*
>
> *12:19 Student nurse filling out menu choices for her at the table, asks if she is OK, participant says "no" Student nurse continues writing."* (Field note, participant P3)

Enabling independence and autonomy at mealtimes was observed to be attended to less often than other pressures on staff.

5.3.2 Patient autonomy – enabling or disabling independence and choice

Staff behaviours, attitudes and clinical practice were observed to undermine participant's abilities to express autonomy in choices, and independence in the eating process. The patterns emerging from the field notes were grouped into sub-themes: positioning, assistance, communication and food selection. Combined they created the over-arching theme of "patient autonomy – enabling or disabling independence and choice". The sub-themes overlap with those observed in relation to meals as a meaningful activity. In this section they are addressed from the perspective of enabling or disabling independence and choice.

5.3.2.1 Appropriate positioning

Positive engagement in the eating process was observed when participants were positioned well, enabling physical access to food and drink. For people who were unable, either physically or cognitively, to position themselves for best access to the meal, the staff were essential in enabling access and engagement. For participants who were able, getting themselves and their table into an optimum position to engage with the meal independently was observed.

> *"12:27 Transfers himself from bed to chair. Table is at end of bed – jug and cup of water and sweets on the table.*
> *12:33 Leans over to pull the table closer.*
> *12:36 HCA puts tray down and says 'here you go'".* (Field note, participant B16)

The location or position of the table in relation to the participant impacted independent engagement in the eating process. It was not uncommon to see participants in bed sat up but with the table too high. This was often due to the use of bedside rails. As a result, the eating process was impaired. The ability to engage in the mealtime independently, while having a positive experience, was reduced. Due to physical boundaries or lack of cognitive ability to change the situation, the participants lacked autonomy or independence to manage the position of themselves and their tables.

In some instances, the reason for reduced engagement in the eating process was more obviously due to the practice of staff. Often after an interaction, or due to staff distractions, tables and food were left out of reach of participants. Some could still eat but with difficulty, influencing the mealtime experience.

> *"12:37 Using fork to eat independently. Table not close so leaning forward to reach and get food to mouth.*
> *12:43 Wiping mouth then continues leaning forwards to eat. Gets distracted wiping food*

off lap as dropping it in the gap between the table and him." (Field note, participant B31)

It was evident throughout the observations that participants who were physically frail or cognitively impaired were often left in positions not conducive to optimal engagement or independence in the eating process. Physical or cognitive frailty prevented participants being able to adjust their own position to enable better access to the food.

> *"12:38 Ward hostess puts tray of food in front of him on the table, takes cutlery out of napkin, pours drink from beaker back into normal cup. Table is too high over the bed and participant not positioned well as slipped down the bed and not fully sitting upright. Ward hostess wakes him up but says nothing about the food.*
> *12:40 Looking at meal frowning.*
> *12:45 Sleeping – HCA feeding another patient."*
> (Field note, participant B18)

The power to enable independence in these situations fell to the staff assisting the mealtimes. Strains on staff time, to feed multiple patients or attend to other tasks, impacted the staff ability to enable independence. Participants were left with less opportunity for independence and a greater dependency on staff to assist for positive engagement in the eating process.

5.3.2.2   Assistance

Assistance with eating and drinking was frequently observed. The assistance offered had potential to either promote or deny autonomy and independence. Levels of assistance varied from verbal encouragement to physical prompting or staff feeding participants. In some instances staff were observed to be attempting to promote independence before resorting to feeding participants. The most common observations noted in the field notes were staff cutting up food and handing cutlery to participants. This encouraged initiation of the activity of bringing their own food to their mouth and enabled sustained engagement with fewer disruptions of stopping to wait for further assistance.

> *"12:53 Nurse assisted with mealtime by taking cutlery out of napkin. Tries to cut up food then asks for help as broken arm is in sling. Talks and laughs with the nurse while she cuts up the food.*
> *12:55 Spooning food on own – no longer needing assistance from nurse.*
> *12:56 Eating independently with one arm and a fork."* (Field note, participant B3)

Some grading of assistance levels was seen during the observation period. When it was observed positive effects followed with participants eating and drinking in a way that they still had autonomy and control over the situation. The staff in these instances were enabling autonomy

without resorting to over-assistance, feeding a participant or taking away the abilities they still held.

> *"12:45 HCA cutting up food – puts fork in participants hand to have a go, doesn't feed*
> *herself. HCA uses hand on hand to guide the fork to her mouth. HCA talks about the food.*
> *12:51 HCA verbally encouraging and physically guiding how to get food onto fork.*
> *12:53 Sits with food in mouth – HCA verbally encourages to chew the food.*
> *12:54 HCA puts cup in hand and tells her it is Ribena, she drinks it herself bringing the cup*
> *to her mouth."* (Field note, participant B1)

The staff on the wards at mealtimes appeared attentive to removing physical barriers which were reducing independence. Drinks of juice at mealtimes came in cartons and a tiny straw. These were difficult for participants with physical frailty to use, and sometimes caused confusion. Snacks such as biscuits and cakes were all in plastic wrappers which many people struggled to open independently. Tea-time meals such as sandwiches and salads were often delivered in a plastic container or covered with cling film, which staff would open or uncover for participants to enable them to start their mealtime.

> *"12:43 Independently eating but very wobbly - struggling to get food onto fork.*
> *12:45 Struggling to get food on fork- small mouthfuls, weak upper limb getting fork up to*
> *mouth but managing without assistance…*
> *…13:03 Struggling to open pudding – HCA comes to assist."* (Field note, participant B10)

In contrast, assistance from staff could also serve to reduce participant's autonomy over their eating and drinking at mealtimes. Incidents of over assistance were observed when evidence suggested the participant could be independent, or require less assistance, with a graded approach. When participants were not eating or using cutlery independently, staff were often quick to resort to feeding the participant without further verbal or physical prompting.

> *"12:42 Nurse comes over and puts a piece of broccoli to her lips, she flinches saying it's*
> *hot. Nurse puts lasagne on fork and hands the fork to participant. She lifts it to her own*
> *mouth.*
> *12:43 Holding food on fork looking around. Takes a small mouthful and puts the fork*
> *down.*
> *12:49 Nurse comes back and starts feeding her, standing over the table in front of her."*
> (Field note, participant B19)

In the participant group observed, cognitive impairment was a primary reason for the assistance needed; staff readily resorted to physical assistance. Redirection to the food or adapted

communication techniques may have improved rather than reduced independence and autonomy at the mealtime.

Assistance at mealtimes is not just about physical assistance for people with dementia. Taking away physical barriers and feeding patients is an important role when needed, however over assistance can take away autonomy, choice and independence. Over time this can de-skill a person. Rather than over assistance, grading the level of assistance was observed as a helpful way of enabling independence.

At other times ill-being was not being noted by staff and so participants were subject to over assistance or verbal prompting without their needs being listened to. This was neither conducive to a positive mealtime, nor acted as effective assistance to encourage eating and drinking.

> *17:31 HCA assists him to reposition on the chair. Encourages him verbally to eat. He states 'I don't want anything to eat'.*
>
> *17:37 HCA starts feeding him yoghurt, he grimaces but eats it.*
>
> *17:39 Frowning saying 'I don't want anymore', HCA says 'it's almost finished' puts another spoonful in – participant is grimacing while eating."* (Field note, participant B18)

The task centred nature of mealtimes, and the observed need to rush the meals resulted in limited recognition of actual assistance needed. Communication techniques to grade assistance levels or attempt to understand what the person with dementia was expressing were limited during the observations.

5.3.2.3   Communication

Adapting communication was seen as a positive way of assisting people with dementia. Examples of this seen in the observations included, staff pointing to food, describing or talking about the food, and in one instance using a picture cue card. Effective alternative communication, not simply relying on understanding and processing of verbal interactions, was influential in maintaining independence. Breaking down options and instructions to simple one word instructions or questions was observed. This promoted understanding and processing for the participants and was effective in promoting independence and enabling autonomy in the eating process.

In one instance a participant had been ignoring their food and the main meal had been taken away with little encouragement to promote independence. A different staff member offered a variation in communication – offering yes or no options. The participant was able to understand, make an informed choice and ate independently. Other observations to promote autonomy and independence were non-verbal communication techniques. Non-verbal communication was

observed to direct participant's attention to food, such as tapping and pointing, if verbal prompting was not effective. One example demonstrates this:

> *"18:19 Visitor asks if she is finished and she nods. Visitor places pudding in front of her – taps table to encourage her to open her eye and shows her the spoon."* (Field note, participant B4)

> *"11:53 Nurse encourages to drink water – points at water – participant drinks a few sips...*
> *…12:54 Nurse points out pudding to her – takes off the lid and points to spoon*." (Field note, participant B11)

Verbal encouragement and prompts to initiate or continue eating were the most commonly observed communication from staff to participants at the mealtime. When verbal prompts to eat were noted in the observation field notes, it was not often followed by participants carrying out the instruction. Verbal prompts often came from across the room from a staff member also busy with another task or walking past. If recognised or acknowledged, they would often prompt a temporary continuation of eating followed shortly by the participant stopping eating again. The most effective verbal communication and prompting to eat coincided with focused, prolonged attention to a particular participant.

> *"13:18 Daughter making positive sounds and encouraging him to keep eating. Warns him what and when the food is coming.*
> *13:24 Eating well with daughter feeding him, slow but taking the food and smiling at encouraging words and sounds.*
> *13:32 Daughter verbally encouraging to eat more – he smiles and makes positive sounds when the food is in his mouth.*
> *13:35 Shaking head when daughter lifts food to mouth. Responds well to positive verbal encouragement."* (Field note, participant P7)

Another common observation was food being placed in front of participants without any communication to prompt eating or to suggest the initiation of the mealtime. For more cognitively able participants this was not a problem and did not disrupt the initiation of the eating process. The visual cue of food being placed in front of them appeared to be enough. For other participants cognitive or physical impairment prevented them to notice or act on this cue. The lack of verbal communication resulted in a lack of initiation of eat the meal. It was noted that in people with dementia the lack of initiation of a meal did not necessarily equate to lack of ability to eat independently. Their independence was impeded through the lack of communication to encourage initiation of the eating process. Some participants had enough of an indication of the

mealtime to start their food, but for various reasons stopped eating. An absence of communication to prompt continuation, or an assumption that the meal was finished, lead to food being taken away.

> *"13:38 Ward hostess offers a cup of tea, participant doesn't respond. HCA makes tea.*
> *Participant starts to try and drink from water jug. Ward hostess takes it away from her and*
> *puts down tea – no verbal communication.*
> *13:40 Taking sips of water from glass – watching activities around the bay – not drinking*
> *tea."* (Field note, participant B19)

> *"13:03 HCA gone to assist with another patient so participant not eating.*
> *13:06 HCA assisting to eat.*
> *13:07 HCA distracted by paper work.*
> *13:08 HCA takes tray – no verbal checking if the participant is finished or has had enough."*
> (Field note, participant B9)

Effective communication during the mealtime was observed to promote maximum independence and engagement in the eating process. This was also observed in the processes before the mealtime, making choices about what food would be served at the next meal. In order to promote autonomy and choice in the food selection process effective communication of the options was considered essential.

5.3.2.4 Food selection – an autonomous choice?

It was observed that the way menus were presented and communicated to participants was not always conducive to optimum understanding of what was being offered. Lack of attempts from staff to change the way the menu was communicated to participant lessened the ability to make informed choices. This was particularly evident when a verbal list was read out to participants to choose from. The list could include up to seven options for the participant with dementia to process, understand, retain and make an informed choice from. Confusion at this stage often resulted in choices being made for participants rather than reiteration and attempts to communicate more clearly.

> *"12:36 HCA gives verbal list of food choices for lunch – she replies an incoherent answer*
> *and looks around frowning. HCA says "would you like lasagne", the only one from the list*
> *she repeats. Patient asks "what?" HCA says OK and walks away.*
> *12:40 HCA puts tray of lasagne down, tells her what it is but patient is looking elsewhere.*
> *HCA lifts plate into her eye line which attracts her attention – then places cutlery on the*
> *tray and walks away."* (Field note, participant B19)

On the other, hand when staff took time to assist and ensure clarification and understanding of all the options, participants could make their own choices.

> *"11:27 Nurse goes through menu choices – asks things one at a time, is able to say what she likes or doesn't like."* (Field note, participant P2)

Attempts to present the list visually as well as verbally were useful to some participants. Hospital Site A had their menus on a TV screen, which was sometimes shown to the participants as a way of seeing the list of food. To make an informed choice from this still required a higher level of cognitive function than seen in many of the participants observed. Despite attempts to show the list it was still evident that the ability to choose food was significantly disrupted in many cases.

> *"12:52 HCA offering menu choices. Shows him the options on the screen and reads out the list – he looks blankly then says 'yes please that all looks delicious' not making an actual choice – HCA points to the word bolognaise and askes "pasta bolognaise?" he says "thank you'. Unsure how much he understood of the choice. HCA continues to offer choices for pudding – reads out the list to him and he asks for bananas which is not on the list, HCA says OK and leaves."* (Field note, participant B26)

The nature of the hospital ward meant staff could be easily distracted from the task of gathering menu choices, disrupting the flow of communication and confusing a person with dementia. Focused attention on the one participant while communicating and assisting to make a choice was seen to be important.

> *"11:55 Catering staff offering menu for this evening – lists 7 items. Participant is unsure what to choose – trying to ask a question but 2 staff start talking in front of her, she asks is this for tomorrow but neither reply and they continue to talk.*
> *11:57 Catering staff repeats first item on the list – participant agrees to this. Offers dessert of ice-cream – participant asks "what?" and seems confused – staff enter ice-cream as choice into the system"* (Field note, participant B11)

At hospital Site B the menu choices were presented differently – with a tick list on paper. Although participants had more time to read and process the options, the lack of support offered to interpret and understand the options prevented independence in appropriate choices.

> *"12:56 Visitors chatting while he is eating. Drinking soup independently. Talking about why he doesn't have roast potatoes or vegetables with his Yorkshire pudding and beef, he states he doesn't know.*
> *12:59 Visitor looks at the menu and shows him how he didn't tick to have potatoes or*

vegetables. He stated he had thought ticking "roast beef" would mean the whole dinner – nobody had helped him." (Field note, participant P16)

Observations where staff assisted in explaining the menu and took time to help a person often appeared more successful in the participant choosing food they wanted.

Observations at hospital Site B staff revealed staff assisting participants to order food by taking the menu away from sight and reading the options as a list. This made the food choice system much like staff reading off the screen at Site A, and removed the autonomy the participant could have when taking time to read and process the menus. This often led to misunderstanding or confusion. Staff then resorted to offering just one option rather than allowing every opportunity for the participant to understand and process all the options and make an informed choice of meal. Again this lead to food choices being made for the participant.

A task-focused approach to taking the menu was seen to detract from a person-centred approach. Choices were made for participants if they could not make their own decision at the required time for staff.

> *"12:15 Student nurse approaches with menu choices for tomorrow – participant waves her hand and coughs saying "no". Student nurse says she'll come back later.*
> *12:17 Eyes closed, murmuring but more settled.*
> *12:19 Student nurse filling out menu choices for her at the table (4 minutes late), asks if she is OK, participant says "no" Student nurse continues writing."* (Field note, participant P3)

Menu choices were usually made the day before the relevant meal. The outcome of the specific food selection activities seen by the researcher was therefore not observed. There was evidence during some mealtimes observed that food selection had been an issue prior to the commencement of the observation. It was observed that lack of autonomy in making food choices could lead to confusion at the relevant mealtime.

> *"13:03 Struggling to open pudding – HCA comes to assist. Participant asks for custard – cannot remember ordering pudding or why she would not have asked for custard. HCA asks domestic staff for custard. None available so was offered alternative of trifle."* (Field note, participant B10)

It is evident, then, that the timing and way in which food selection was made, in the hospitals observed, were not always conducive to enabling autonomy of choice and independence for people with dementia. This was mainly the case for people with more severe dementia who had reduced cognitive ability to make choices independently. Observations were also made where

people were able to make their own choices and engage in the eating process with less dependence on staff. These were seen to be instigated through staff making further attempts to include them in the food selection process, or because of higher cognitive functioning and understanding.

> *"11:36 Volunteer approaches to offer choice for evening meal – gives the screen to participant and allows her to read and decide. Verbally prompts with reading some out and how to use the screen."* (Field note, participant B13)

For the people who did not have the cognitive function to express their own choices, staff knowing participants as individuals, acknowledging their preferences of food choices, lead to a more positive experience for the participants.

> *"13:51 Ward hostess offers him a glass of milk and some biscuits – says she knows what he likes.*
> *13:55 Eating biscuits and dipping in milk.*
> *13:58 Eating biscuits and dipping them in milk."*
> (Field note, participant B16)

It was observed that having food available outside the specific mealtime allowed further engagement in the eating process.

> *"11:19 Helps herself to sweets from the table in front of her…*
> *…12:12 Takes a sweet from the table and eats it.*
> *12:14 Eats another sweet"* (Field note, participant P2)

> *"12:52 Visitors arrive – sister and niece. Have brought cartons of juice and some grapes. Niece puts the drinks in cabinet by bed. Verbally encourages him to eat grapes…*
> *…13:17 Picking at grapes while talking."* (Field note, participant P16)

The importance of other people in enabling autonomy and independence of choice was observed to be an important factor in influencing participant experience and their engagement in the eating process. Staff in the hospital setting are a huge part of enabling autonomy, but the impact of visitors appeared to play a significant role at mealtimes.

5.3.3 Visitor impact

In the presence of visitors at mealtimes, participants were often observed to be having a more positive experience and were more engaged and focused on eating. There were only two occasions where visitor presence was seen to have a negative impact. In one instance the visitor was feeding the participant while video calling a relative. The reaction of the participant was two-

fold. On the one hand, they were distracted from their food in socially engaging with the person on the screen; the participant also showed signs of embarrassment and pushed food away when the visitor attempted to feed her. The other occasion was a case of the visitor lacking understanding in managing dysphagia. Nursing intervention was required to take over feeding the participant.

On the whole, visitor impact at mealtimes was observed to be a positive influence in improving experience and encouraging engagement in the eating process. This appeared to be for a variety of reasons: the visitor knowing the participant personally as an individual, the visitor knowing effective communication techniques to encourage engagement in eating, and visitors having the time to give participants the undivided attention required to continue prompting while eating and drinking.

5.3.3.1 Knowing the person

The value of knowing the person with dementia and their preferences was evident during the observations when visitors were present. Family and friends could speak for people who cannot express their own needs and wishes because they knew what was familiar and preferred. They had the opportunity in both hospitals to bring in food and drink for patients, which added to the options available from the hospital.

> *"16:31 Wife gives him some squash – he drinks sips while saying how hungry he is, gets more cross as he asks for food. Wife asks HCA if there is anything he can eat – he can only have non-dairy and has to be soft – HCA says there are no options on the ward as they can only offer biscuits or a yoghurt. HCA agrees to heat up microwave pudding wife has brought in her bag.*
> *16:37 Wife leaves the pudding on participant's lap with a spoon – he starts eating independently."* (Field note, participant B29)

In addition, visitors were noted to assist with food selection choices when participants became confused or did not appear to understand the options. This meant participants received a meal that they were familiar with or family and friends knew they liked.

Visiting family, friends and carers knowing the individual participants resulted in effective communication when encouraging participants to eat and drink. The visitors were observed to be familiar with techniques that worked well in encouraging eating. They had been used in the participant's home setting, and could be replicated by visitors in the hospital. It became clear that

a knowledge of the person as an individual was beneficial in knowing what kind of encouragement they would respond best to.

> *"12:54 Visitor starts by encouraging verbally, then hand over hand guiding fork to mouth. [Participant] independently breaks and eats bread."* (Field note, participant B4)

5.3.3.2 Time

Visitors at mealtimes also had the time to give undivided attention to the participants without distractions of other tasks or priorities. Staff often had other patients to assist, or other tasks to attend to, but visitors were there solely there for the one person they were visiting. As a result, continual prompts and redirecting participants to their food could occur. Prompts could be followed up if not adhered to, whereas staff often prompted but then were called away to another activity.

5.3.4 Conclusion

Three over-all themes emerged to add depth to the understanding of what influences engagement and experience at mealtimes for people with dementia. Firstly, the meals did not appear to be a meaningful, anticipated or protected time. Evidence of this was revealed through observations of distractions from the meal both for participants and staff. The food selection process was often disrupted, or choices made for people, reducing the meaning of their meal even further. The lack of recognition of the meal as a meaningful activity appeared to lead to disengagement. When participants had environmental and social cues to anticipate and recognise the meal, engagement in the meal was more focused.

A second over-arching theme identified that both physical and cognitive barriers could be overcome through ensuring patient autonomy and enabling independence in the eating process. Participants were often inappropriately positioned physically, not allowing for access to the food. Communication was often limited to verbal attempts to encourage eating and drinking, or in some cases was completely neglected. In cases where adapted communication was attempted people were seen to make independent choices and engage in the eating process at the mealtime.

The impact of visitors was evident in improving mealtime experiences and promoting engagement in the eating process. Person-centred care approaches were able to be applied by visitors, without the restrictions imposed by the hospital system experienced by staff. The system restrictions included other tasks taking priorities, or not having enough time to give each patient the full

attention they need to complete the eating process. Person-centred approaches, seen by visitors, included, giving the time required to meet an individual's cognitive and physical needs, knowing food preferences, and knowing appropriate and effective communication techniques to manage individual difficulties in engaging in the eating process.

5.4   Merging quantitative codes and qualitative field notes

The field notes added a richness and depth to the quantitative observations. In-depth qualitative description of the mealtimes developed the findings from being able to describe what was happening, to understanding meanings and relationships between the activities in the ward environment and experience and engagement at mealtimes. The quantitative coding and qualitative field notes were used in parallel to give evidence to the interpretation of each individually.

The most commonly observed and significant Dementia Care Mapping (DCM) codes were cross-referenced with the qualitative field notes. These were interactions (A), physical assistance (P), passive engagement (B) and food related activity (F). The code for being un-responded to (U) was included in the further analysis of interactions, as during these times participants were seeking out interaction but not having their needs met. The code for withdrawn and disengaged behaviour (C) was included in the further analysis of times of passive engagement (B), as these categories were often observed to occur together. This gave more depth in understanding what was happening around the times specific coded behaviours occurred.

5.4.1   A - Interactions

Table 13 lists the observed activities from the field notes corresponding to the times when interactions (A) were coded. The positive interactions, represented by A+1, A+3 or A+5, are shown in the left column. Negative interactions, represented by A-1 or A-3 are in the right column. There were no instances of A-5 observed.

The most noticeable, and significant, difference between the two columns is the presence of visitors, a common theme emerging throughout the quantitative and qualitative data. Visitors were generally observed to be a positive addition to the experience of mealtimes. In the interactions observed, visitors often offered the attention, reassurance and listening ear that staff did not appear to be able to give. In some instances the positive interactions, and improved well-being, even resulted from visitors of other patients, not related to the participants.

On the whole, the descriptions in each column appear to be of similar situations but the actions and reactions of staff and participants directly contrast each other. For example, participants showed signs of ill-being through expressing worrying thoughts, but the interaction was prevented from being negative when staff took time to reassure and listen to participant needs. When participants were ignored, or appeared to feel ignored, it had an impact on their well-being and experience within the observation period.

Table 13: Summary of field note descriptions at the times A was coded in the DCM tool	
A +	**A -**
+1 - Visitors present and interacting. - Visitors prompting to eat or drink snacks or meal. - Chatting to cleaner/domestic staff. - Combined leisure activity, such as reading the paper, with intermittent conversation. - Receiving attention and assistance from other patients. **+1** - Receiving reassurance about worries or concerns, being listened to. - Having questions answered e.g. about what is for lunch, when they are going home. - Staff talking about non-care related subjects during care or just generally. - Staff talking about family and personal things specifically distracting from worries or concerns. - Staff prompting to eat or drink meals or snacks. - Staff giving direction and assistance with making food selection choices from menu.	**-1** - Participants expressing worried thoughts to staff or other patients or to the room e.g. about discharge plans, eating the food, where to sleep, bank and house details, disorientated to time and place, needing to go home, waiting for results. - Expressing sadness about deceased loved ones. **-1** - Expressing pain verbally or through body language. - Getting cross due to hunger. - Frustration at not being understood. - Expressing displeasure at the food quality. - Expressing boredom. - Participant frowning or showing displeasure at being ignored by staff. - Calling out for assistance or attention but staff busy with other tasks or patients. - Getting impatient waiting for staff to fulfil a promise e.g. coming over to talk, or getting a cup of tea.

Table 13: Summary of field note descriptions at the times A was coded in the DCM tool	
A +	**A -**
+3	**-3**
- Visitors present and interacting.	- Participant crying or cross due to: confusion,
- Participants having the opportunity to help	remembering sad events, not being listened to,
other patients.	being told to sit down, and being stopped from
- Laughing or talking with others while eating	leaving the hospital.
and drinking.	- Participant expressing pain.
- Partially engaged in conversation with others	
while engaged in leisure activity.	
	- Unmet needs – staff focused on the task
	rather than listening to the participant.
- Receiving reassurance about worries or	- Staff getting cross with participant for
concerns.	continuing to call out/cry.
- Mirroring staff positive expressions and tone.	
- Staff talking about non-care related/personal	
subjects while conducting care.	
- Staff validating and showing understanding	
even if participant is incoherent.	
+5	
One occasion only – participant talking very	
excitedly and squealing with excitement.	

There were also occasions where participants were seeking interaction, either through verbal or physical expressions, but were not responded to. These were coded as 'U' – un-responded to. On five of these occasions participant's signs of ill-being reached a level to be considered a -3 ME score. At these times participants were showing considerable signs of distress, anxiety or pain such as crying, considerably grimacing and groaning, or verbalising their negative feelings. Staff who were in the area ignored these signs, not paying attention as they were busy with another task or patient, or continuing their own agenda of the interaction.

> *"11:44 Dr. came over to talk – participant cries and asks her to go away and leave her*
> *alone saying her husband has just died.*
> *11:46 Sitting crying, blowing nose and muttering to herself. Staff carrying on with tasks*

around her e.g. cleaning, writing notes." (Field note, participant B13)

"11:45 Coughing – cries "no it hurts" – wipes her mouth.

11:47 Coughs – says "oh come on" and bangs the table with her fist.

11:51 Nurse looks over into bowl, participant crying and coughing saying "I'm dying aren't

I"- nurse smiled at her then responded to a call from another patient. (PD15 Ignored)"

(Field note, participant P3)

On the other occasions of U being coded the participant expressions of ill-being were less severe. These were occasions where staff or volunteers were present in the room but not responding to expressed needs. Examples of participant behaviours and activities included:

- calling out and waving at staff walking past with no response,
- directing questions at staff doing notes or other tasks and getting no response,
- calling for help with no response,
- trying to stand or move, and asking for help, with nobody coming to attend to them,
- general expressions of ill-being such as whimpering, groaning, grimacing, flinching and frowning with no response from any one.

Through combining the DCM codes and field notes, it is clear that the number and quality of interactions had an impact on participant experience of, and engagement in, the mealtimes. Interactions were commonly seen throughout the observation periods. The evidence presented in this chapter about interactions shows the importance of meaningful, person-centred, assistance and communication during the meals and in the surrounding time period. There was evidence in observations presented in the A- column of Table 13, which showed that staff had the potential to be absorbed with their busyness and tasks at the expense of relational, person-centred care through meaningful interactions at mealtimes.

5.4.2   P - Physical assistance

A significant element of the nursing role in the hospital is that of physically assisting with all aspects of care. This includes assisting with personal care such as washing and dressing, taking people to the toilet, administering medications, and taking physical observations such as blood pressure, to name a few specific tasks. These occasions in the DCM observations were coded as P, making up almost 9% of the overall observation period. As with the interactions, the P codes were cross-referenced to the qualitative field notes to understand what was influencing experience and engagement at the mealtimes. Table14 presents a summary of the observations described in the

field notes at the times P was coded. The table is split between positive and negative experiences of physical assistance.

Interaction appeared to be significant in influencing participant's experiences of receiving physical assistance. When coded as P+1 (neutral presentation without particular signs of ill or well-being) the care task took place with limited interaction or with conversation primarily to do with the task. There were times when there was the potential for participants to have a negative experience, but effective communication and interaction from staff reassured participants. On the other hand, participants with a negative experience of physical assistance, represented through the P-1 code, were often ignored, the task not explained, or their expressions of discomfort not acknowledged.

The times when expressions of considerable well-being became evident, and participants were scored positive ME scores. These were often linked with positive interactions and communication. The interactions went above and beyond normal interaction, talking about the task at hand, to social, jovial conversation including laughter. In some instances ME scores changed from negative in one time frame to positive in the next as a result of positive interaction, comfort or reassurance. Participants were observed to have considerable negative experiences of physical assistance when staff did not interact at all. Participant's well-being was significantly reduced at times when staff provided care with no introduction, explanation or instruction to the participant. This included one occasion when an injection was given without warning, and a time when staff began to reposition a participant on the bed without explanation.

Table 14: Summary of field note description at the times P was coded in DCM tool	
P+	**P-**
+1 - Positive interactions including social chat, while receiving physical assistance. - Positive interactions including reassurance and comfort provided by staff at time of physical assistance. - Physical assistance with limited interaction between staff and participant. - Delivery and collection of food and drink with	**-1** - Participant expressing worried thoughts or concerns, while receiving assistance, e.g. worries about getting home, getting to another place, paranoia about medication or food, - Confusion with multiple choices or instructions. - Expression of annoyance or pain from injections.

Table 14: Summary of field note description at the times P was coded in DCM tool	
P+	**P-**
limited interactions. - Discussions about discharge and medical planning with reassurance from staff or visitors. - Normal activities of care with no signs of ill-being or well-being: medication administration, assisting to mobilise, changing pads, assisting on/off the commode, observations e.g. blood pressure or weight, repositioning on the bed, or changing a cannula. - Participants expressing discomfort verbally or through body language, made more comfortable through physical assistance with care. - Physical assistance received at the time it was asked for.	- Expressing pain generally. - Discomfort from assistance e.g. cold cream on skin, pain on rolling, - One staff member starts assisting then goes away and another one takes over. - Staff do not explain procedure or circumstances – lack of communication. - Participant questions ignored. - Expression of pain unnoticed/ignored.
+3 - Positive interactions, including laughing and joking, while receiving physical assistance. - Positive interactions including social chat and reminiscing about participant's past, while receiving physical assistance. - Staff talking about the sensory elements of the physical assistance, e.g. smell of the soap, feel of the clothes.	**-3** - Observations taken and expression of distress not considered. - Staff conducting physical assistance without explanation or introduction, including giving an injection. - Pain and distress during care.

It is clear that receiving physical assistance impacted the experience of care for participants during the observation period. It is unclear, looking solely at the times of physical assistance, whether these positive and negative experiences of care influenced engagement and experiences at mealtimes specifically. The time the meal was available to the participants, and the 45 minutes

before this, were scrutinized to examine the relationship between P codes and food related activity.

As is evident from Table 12 (refer back to section 5.2.3) only sixteen time frames were coded as P during the time the meal was available to participants. Generally these fell directly before or after the participant ate their meal, not influencing the meal experience or engagement. Of the sixteen time frames, five corresponded to a negative ME score. There were only two occasions where this disrupted the participant's engagement in eating. On both occasions the participants swiftly restarted the eating process with positive encouragements, or medication for pain relief. On one occasion, a positive experience of physical assistance disrupted the eating process. Again, this was for a short period, and the engagement in food related activity surrounding all of these circumstances remained positive.

Meal anticipation was an overall, significant theme which emerged from the field notes. It was pertinent, then, to see how the physical assistance given in the 45 minutes prior to the meal influenced engagement in the eating process. Table 10 (in section 5.2.2) shows that eleven time frames in the 45 minutes leading up to the meal were observed as participants receiving physical assistance, which corresponded to a negative ME score. In just three cases P-1 or P-3 preceded F-1 in the mealtime. In only one instance was it evident that disengagement from eating was a direct result of the negative experience of physical assistance. The participant had been highly distressed during their time using a nebuliser and coughing. When staff then encouraged her to eat she declined, as illustrated in the field notes:

> *"12:32 Nurse gives nebuliser. She is crying and coughing, they comfort her saying "that's it well done". Crying and screaming with the nebuliser on, coughing.*
> *12:35 Nurse leaves her with nebuliser but returns as she is too distressed, rubs her back and comforts her while she coughs up…*
> *… 12:47 Coughing, grimacing but less distressed – spitting in to the bowl, whimpering and wiping her mouth….*
> *…13:16 HCA wakes her saying lunch is here. Participant saying her mouth "isn't right" and points to the bowl and tissues. HCA offers to put the food in front of her and see how she gets on. Participant declines main course…*
> *…13:23 Looking at food on the table, soup and yoghurt and ice-cream, shakes her head at it.*
> *13:26 Waves hand as if waving the food away."* (Field note, participant P3)

Physical assistance around the mealtime clearly influenced participant's experiences on the whole. Staff interactions during these times appeared to be the most significant factor in influences participant experience. There were very few occasions where physical assistance in the lead up to the meal negatively impacted engagement in the eating process.

5.4.3 B, C and N - disengagement

In many instances the lead up to the meal was a time of disengagement or withdrawal, often relating to negative ME scores. In the 45 minutes leading up to the mealtime almost 30% of the time was spent disengaged from any meaningful activity or interaction (see details in section 5.2.2). In the overall observation period, before during and after the meal, a total 34% of the time was observed to be spent passively engaged (B), withdrawn or completely disengaged (C), sleeping or dozing (N). The time frames coded B, C and N, within 45 minutes before the meal, and during the meal, were cross-referenced to the matching time in the field notes, in order to explore the relationship to food related activities.

The DCM coding supports the importance of mealtime anticipation, which emerged from the field notes. Disengagement, withdrawn behaviour and sleeping often preceded mealtimes where people had a negative experience or did not fully participate. The reason for this varied between actions of staff, and participant factors evidently beyond the control of the staff. Actions and attitudes of staff, which appeared to enhance the negative impact of disengagement leading up to the meal included:

- placing food in front of the participant while withdrawn or watching around the ward, with no explanation or direction to the food – meal not initiated,
- placing food in front of the participant while still asleep and leaving it there with no attempt to wake them,
- not acknowledging signs of distress, discomfort or pain while delivering the meal,
- starting to initiate through prompting or assistance, but being distracted by other tasks or patients,
- attempting to feed the participant while they are too sleepy still – leading to coughing, flinching or cross reactions,
- failing to reposition participant into an appropriate eating position.

In some cases the staff made every effort to support the participant to engage in the mealtime. There were factors that made this very difficult to overcome, leading to negative experience or lack of engagement in the mealtime:

- the participant being medically too unwell to eat or drink
- evidence of dysphagia
- participant being too sleepy to eat or falling asleep while eating.

Not all occurrences of disengagement or sleeping before the meal lead to negative experience or lack of participation. In the cases where mealtimes were still positive there were many contributing factors. These can be seen in more detail when the food related activity coding and field notes were compared.

5.4.4   F - food related activity

The combined BCC and ME results for food related activities (F) presented in Table 9 (section 5.2.1) are visually displayed in Figure 11.
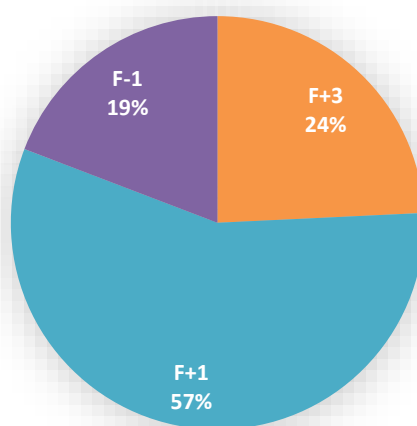
Figure 11:   Visual display of the distribution of ME scores within the BCC F for the overall observation period.

57% of food related activity corresponded to a +1 ME score, 24% corresponded to +3 and 19% corresponded to -1. This suggests that for almost one quarter of the time behaviour and activity was related to food, the participants were having a positive experience and were focused and engaged well in the eating process. Over half the time participants were in neutral ME score, suggesting they were showing no particular signs of well or ill-being and were intermittently engaged in eating or drinking, but distractible. The rest of the time (19%) participants were either disengaged from the eating process or were showing signs of ill-being during the meal.

The distribution of ME scores for F codes in the time period where the food was in front of the participants follows a similar pattern to other results from the rest of the DCM coding. Almost half the scores were neutral at +1 meaning even with food in front of people they were distractible, struggling or slow and were not showing particular signs of a positive or negative experience. 31%

of the time participants were showing moderate signs of well-being and were focused and engaged in eating during the mealtime specifically. For 20% of the time participants displayed signs of ill-being during the mealtimes, or were disengaged from eating despite the opportunity in front of them. No F-3s were coded, suggesting no participant showed any more significant signs of ill-being than warranted an F-1 code.

DCM codes provided a description of how people were presenting through behaviour and signs of ill or well-being during the observation periods. They also gave a quantitative measure of how much people were engaged and participating in the mealtimes and surrounding time period. Qualitative field notes taken in parallel to the DCM observations were used to add richness and detail to the DCM coding. They were essential for providing essential details that DCM could not. In order to address the research aims the researcher had to ask what was happening around the most extreme positive and negative ME scored time frames during food related activities: F-1 and F+3. Each participant's DCM data was studied in detail to examine whether and when they had an F-1 or F+3. The field notes at these times were cross-referenced in order to begin to understand what may be influencing the BCCs and MEs for those time frames.

Table 15 shows the list of occurrences recorded in the field notes at the time of the F-1 and F+3 codes. This adds a more detailed description of what was happening during the mealtimes to influence engagement in eating.

Table 15: Summary of field note descriptions when F-1 or F+3 were coded in the DCM tool	
F-1	F+3

- No communication/explanation – putting food down and walking away. - Staff being distracted by other patients and tasks - Participant distracted by other items around them - Staff focused on task of offering food/drink (menus and feeding) not acknowledging signs of ill-being - Ill-being during the meal - "grimacing while eating" - Pain/discomfort/distress. - Declining food for unexplained reason –limited skill to deal with this or it doesn't fit with hospital routine so food is taken away - Having to eat at that time because cannot keep food warm so refusing - Recognising how to use objects – not assisted - Uncomfortable/inappropriate eating position on the bed. - Choices being made for participants - Sleeping/dozing before and during meal - Ill-being leading up to mealtime. - Interruptions – medication, menu choices for other meals, noisy confusing environment. - Position of table – food not accessible. - Accessibility of food outside of meal when participant wants it	- Physical assistance/prompting - cutlery placed into hands, - cutting food up - undoing wrappers - Picture cue card used to communicate - Yes/no questions offered - Verbal prompting/instruction - Telling participant what the food or drink is - Physically pointing to food/drink to encourage eating - Social – positive interaction, laughing, acknowledging others having the meal/waiting for others to get theirs before starting. - Appropriate position - pulling tray or table closer/higher - moving self to sit in a chair - Staff talking positively about the food and discussing sensory input while eating - Knowing patient's preferences - Uninterrupted assistance. - Presented in a recognisable way - plate with sandwich cut into triangles rather than in a packet. - Positive comments by participants about taste and sight of food - Visitor encouraging or providing social stimulation and assistance. - Able to express own choices, ask for condiments or preferred cutlery. - Able to take initiative to prepare for the meal – aware of time.

The participants who scored F+3 more were generally showing signs of having a higher cognitive functioning ability. There were examples of people being able to prepare for the meal by recognising the time and moving to a more appropriate seating position or go and wash their hands before the meal arrived. The higher functioning participants showed more signs of being able to communicate their preferences. They also showed more positive signs from social interaction during the meal as opposed to participants with more F-1 scores who were more likely to be distracted from eating by social interactions around them. The occasions where F+3 was

scored, despite reduced cognitive function, was through communication and assistance that was appropriate and directed at a particular patient's needs.

The presence of visitors had a positive impact on well-being and engagement in all but two observed. They often appeared to use communication techniques and strategies to improve intake which stemmed from a knowledge of the participant, their personality and their preferences. Staff, volunteers or visitors placing cutlery into participant's hands was a commonly noted observation and often triggered initiation of the meal. The opposite was noticed when examining the F-1 coded times. Food could be placed and left in front of people with no communication indicating it was time to start the meal or giving details of the food itself.

Pain, discomfort and distress were evident during the mealtime for some participants, represented in the DCM coding through F-1 ME score. It was not uncommon to see this presentation of ill-being being ignored, unrecognised or not addressed in a skilled manner by staff. Staff also appeared to lack a pool of resources to manage people who were refusing or not initiating food for unclear reasons.

Poor positioning of the table and the participant was often related to F-1 scores as participants were unable to reach the food or were in a poor seating position to manage getting food to their mouth, reducing engagement in eating and diminishing experience of the mealtime.

Hospital routines and the divided responsibilities and priorities of staff also appeared to have an impact on providing opportunity to engage in the mealtime. The task-focused nature of the work lead to participant needs and expressions not always being acknowledged. An example of this which influenced a negative ME score was needing to collect menu choices for the next meal as the kitchen staff needed it. At times patients were asking questions for other topics or were showing signs of ill-being but the task at hand took priority at the expense of the well-being of the participant.

5.5   Conclusion

The results presented throughout this chapter suggest that an improved mealtime, with F+3 as the prominent code and F-1 would not exist, would involve changing care practices. Some practices need to be reduced, where others would benefit from being continued or developed. To strengthen the interpretation of the observation findings, the staff involved in care on the same wards were interviewed as a second phase of the research project.

Chapter 6 Methods used in phase 2 – semi-structured interviews

The findings from the observations were used to frame the semi-structured interviews and analysis of the next phase of the research project. Between the two phases a Public and Patient Involvement (PPI) representative from the NIHR CLAHRC Wessex was consulted about moving on to the next stage of the research. Their input was considered when designing the interview phase, including the interview schedule and participants.

The data and analysis so far has aimed to include the perspective of the people with dementia under the care of the acute hospital staff. The second aim of the research project set out to understand the perspective of the hospital staff who care for people with dementia. The PPI representative suggested including nutrition focused health professionals, such as dietitians, in addition to the ward based staff. This was taken into consideration.

This chapter presents the methods used to conduct phase 2 of the research project.

6.1 Data Collection – semi-structured interviews

Semi-structured, qualitative interviews were conducted with hospital staff working on the same wards that the observations took place. Flick (1998 p.87) describes the goal of semi-structured interviews as, "to reveal existing knowledge in a way that can be expressed in the form of answers and so become accessible to interpretation". Qualitative interviews were conducted with the view that knowledge is contextual; the research was seeking to construct the understanding of eating and drinking difficulties for people with dementia in hospital through the meanings and interpretations provided by the interviewees (Mason 2018).The interviewees were asked to recall both the external reality of mealtimes on the wards, and their internal experiences and feelings about how the mealtimes are, and could be, managed (Mason 2018). The interview data was then used to reconstruct a collective, subjective, viewpoint from the staff of how people with dementia experience and engage in mealtimes in the hospital setting (Flick 1998).

It was important to use interviews as well as observations in order for the researcher to have a non-judgemental understanding of the lived experiences of staff working with people with dementia in hospital wards. Researcher subjectivity of the observation data was reduced by combining the observation and interview data for discussion and interpretation of the overall research project findings (Finlay & Ballinger 2006). As a health care professional in a hospital setting the researcher was particularly at risk of bias in interpreting the observation findings.

Listening to the stories and views of a variety of other health care professionals added value to the objective understanding of mealtimes for people with dementia in the hospital setting (Seidman 2013).

Qualitative interviews were used above quantitative survey or interview methods. The selected method was in line with the aim of exploring individual staff perspectives and experiences of caring for people with dementia at mealtimes in the hospital setting. In semi or unstructured, qualitative, interviews the interviewer can be recognised as a tool in the data collection process. They can use social and intellectual skills, sensitivity, flexibility and understanding, to encourage rich and meaningful data (Seidman 2013). Qualitative interviews produce more in-depth, rich, data as the interviewer has flexibility to probe and use follow-up questions. In the research interviews, allowing interviewees to "ramble" or go "off topic" was not discouraged as it gave the interviewer insight into the thoughts and opinions of the interviewee which may not have been expected by the interviewer (Bryman 2016, p.470).

6.1.1 Setting up the semi-structured interviews

The aims of the interviews were:

1) Understand staff perceptions of factors influencing experience and engagement at mealtimes for people with dementia in the acute hospital setting.
2) Identify interventions for improving mealtimes for people with dementia. These included, interventions currently practiced, and those staff might recommend.
3) Explore the roles of individual health professions and their potential in contributing to mealtime care for people with dementia.

The topic list informing the interview guide for the semi-structured interviews is outlined in Table 16. The topics in the list were informed by: the research question of what influences experience and engagement at mealtimes, the key themes identified in the observational findings, and the aim to inform potential further research into the specific roles of individual health care professions in improving mealtimes for people with dementia in the hospital setting.

Considerations for setting up the interviews included:

- *An interview guide* – the interviews were thematic and topic centred, based on the observation results and suggestions from the PPI representative. The interviews were not designed to be a rigid sequence of questions as in a structured interview, but rather to give the opportunity for a fluid and flexible conversation where unexpected themes may

arise (Mason 2018).

- *Structure* - Flick (1998) suggests starting the interview in a more unstructured way and increasing the structuring as the interview develops. The opening questions of the interviews used "retrospective inspection" where the interviewee was asked to recall situations or experiences (Flick 1998, p.77). This enabled the interview to be based on topics the interviewees introduced, allowing for more meaning for the interviewee. Specific topics were introduced when the interviewee was interpreted by the interviewer as having reached the extent to which they were introducing new topics.

  Main topics, as seen in the interview topic guide (Table 16), were introduced either by using broad opening questions, or using threads of conversation derived from the interviewees' previous responses. Prompts or more specific questions, were used a follow-up questions to the topics raised by interviews, as suggested by Mason (2018). The "funnel structure" of broad to narrow and specific questions was applied within each topic as it arose as well as in the interview as a whole (Flick 1998). Closing questions followed after the in-depth conversations, generally drawing on the content of the interview and asking interviewees to give any further comments or recommendations, and asking about their profession specifically.

- *Practical* – the main practical issue in setting up the interviews in the acute hospital setting was to find a quiet space and appropriate time (Bryman 2016).

Table 16: Interview topic guide and question justification	
Question/topic	**Justification**
Introduction – tell me about yourself professionally, experience to date.	Opening with a broad question (Flick 1998)
Tell me about your experience of mealtimes on the ward. - Specific examples of person with dementia having eating difficulties? - what evidence have you seen to suggest there are difficulties? - Reasons? Regular? Other contributing factors?	A broad question to allow for in-depth answer from which to take direction for the next question or topic. Uses the M3 model of mealtimes (Keller et al. 2014), considering meal experience. Meets the research aim of exploring staff experiences and understanding of mealtimes for people with dementia.
Menus and food processes - Choice process? - Accessibility?	Funnelling the questions to more specific topics (Flick 1998).

Table 16: Interview topic guide and question justification	
Question/topic	**Justification**
	Suggested by PPI representative. Topic taken from key theme of the observation findings. Uses the M3 model of mealtimes (Keller et al. 2014) considering meal access and meal quality. Using follow-up and probing questions to gain more insight and depth.
Impact of visitors - Do you have any examples from your practice where you've seen this happen?	Funnelling the questions to more specific topics (Flick 1998). Suggested by PPI representative. Topic taken from key theme of the observation findings. Uses the M3 model of mealtimes (Keller et al. 2014) considering the influence of social interaction and meal environment and quality and experiences. Using follow-up and probing questions to gain more insight and depth.
Importance of the time leading up to the meal - Do you have any examples from your practice where you've seen this happen?	Funnelling the questions to more specific topics (Flick 1998). Topic taken from key theme of the observation findings. Using follow-up and probing questions to gain more insight and depth.
Hospital environment impact on mealtimes? - Do you have any examples from your practice where you've seen this happen? - Potential for distractions	Funnelling the questions to more specific topics (Flick 1998). Topic taken from key theme of the observation findings. Uses M3 model of mealtimes (Keller et al. 2014) considering environmental influence on quality and experience of meals. Using follow up and probing questions to gain more insight and depth.
Social interaction - Is it something you see much of at mealtimes? - Impact?	Funnelling the questions to more specific topics (Flick 1998).

Table 16: Interview topic guide and question justification	
Question/topic	**Justification**
	Topic taken from key theme of the observation findings Uses the M3 model of mealtimes (Keller et al. 2014) considering the influence of social interaction on quality and experiences. Using follow-up and probing questions to gain more insight and depth.
Current interventions - Are you aware of any policies/practices in place? *(start with closed question)* - Any ideas or recommendations for improvement? - Further potential for specific profession?	To meet research aim in exploring current interventions. To provide data to compare to researcher observations and reduce subjectivity of what is happening on the wards (Finlay & Ballinger 2006)

The topic guide was used flexibly throughout the interviews depending on where the interviewee directed the questions. During the interviews the interviewer used a variety of questions to introduce, follow-up or probe with regard to the topics highlighted in Table 16. Bryman (2012) outlines nine interview question types, as introduced by Kvale (1996). These types, listed below, were all used in the interviews. Rather than having them detailed in a structured interview schedule, the interviewer decided on how to use the types within the interviews in response to interviewee responses.

1) Introducing questions
2) Follow-up questions: getting the interviewee to elaborate
3) Probing questions: following up with direct questioning
4) Specifying questions
5) Direct questions
6) Indirect questions
7) Structuring questions
8) Silence
9) Interpreting questions

Bryman (2012): Types of interview questions

6.2   Recruitment

A poster (Appendix K) was displayed on wards and in staff areas advertising the opportunity for engagement in the research interviews. Meetings were also held with ward managers and therapy teams to inform them of the research interviews. Staff volunteered their interest to participate in the interviews through contacting the researcher via email, phone or face-to-face while the researcher was present in the relevant departments. Staff who showed interested in participating were given a Participant Information Sheet (Appendix L). If they still wished to participate they were asked to sign a Consent Form (Appendix M). Participants were provided a gift voucher as an expression of thanks for interview participation.

6.2.1   Sampling

Purposive sampling was used to create a meaningful range of participants from different professions in order to best answer the research question (Creswell 2014; Mason 2018). The sample was created to provide a wide range of perspectives from different professionals working with people with dementia in the hospital setting. The typical exposure to staff from a patient perspective would be primarily nursing staff, health care assistants and members of the therapy team. Due to the nature of the research question, and recommendations from the PPI representative, it was also considered important to include Dietitians and Speech and Language Therapists. The theoretical and methodological underpinning of the research gave scope to include more Occupational Therapists that would typically be available to patients on the wards. The aim of exploring current and future potential interventions, with the focus of how Occupational Therapy in the hospital could be developed, also gave justification for this.

Experts in the field of qualitative interviewing suggest conducting 12-60 interviews, taking 30 as an average. There is a wide range here dependent on the depth and detail of the data provided. The sample size for the study was decided, in principle, as 12-16 interviews as the data will be heavily supplemented by the observation findings. Despite this guide, the transcripts were still reviewed throughout the data collection period and the principle of data saturation was maintained within the resources available.

6.3   Data analysis

Interviews were transcribed in full, verbatim. The data was organised and analysed within the computer software NVivo 11 (QSR 2016). A framework matrix was created within the software in order to complete framework analysis.

6.3.1 Framework analysis

Framework analysis is a type of thematic analysis used by qualitative researchers (Ritchie et al. 2014). As a type of thematic analysis, framework analysis involves thorough and rigorous examination of the data, in order to identify patterns and themes which inform the research question (Smith and Firth 2011). Framework analysis allows for a systematic approach to thematic analysis where the researcher analyses the qualitative data within structured topic guidelines (Smith and Firth 2011). As the observation findings informed the topics for the semi-structured interviews, it was considered fitting that the themes from phase 1 of the research were used to create an initial framework in which to structure the thematic analysis.

6.3.2 Framework analysis in practice

The five stages outlined by Ritchie et al. (2014) were used in the data analysis:

1. Familiarisation

The researcher read through the interview transcripts and listened to the audio recordings at the same time. Annotations summarising key points from each interview transcript were made during this time. This enabled the researcher to be fully immersed in the data and become familiar with it. A list of emerging themes, found inductively, was created. A second researcher then went through a random selection of six interview transcripts, taking notes of emerging themes and concepts inductively. The themes identified in this initial stage of familiarisation were added to the themes developed in phase 1 of the research project (Ritchie et al. 2014).

2. Constructing an initial thematic framework.

The themes from the observation findings were used to frame the interviews. These included visitors, distractions and the environment, meal anticipation, food selection and menus, positioning, assistance, communication and social interaction. These were created as Nodes in the NVivo 11 software (QSR 2016) and added to the framework by way of building on observational data findings. Additional themes were added to the framework based on the themes emerging from the initial familiarisation stage. A theoretical framework was then added to aid in organising and interpreting the findings. The selected model was the Making the Most of Mealtimes (M3) model (Keller et al. 2014). This was considered the most appropriate theoretical model to use at this point as it links to food intake and considers engagement as an outcome. This fits the research question better than other models which were considered, for example Murphy et al. (2017) model of person-centred nutritional care, or Bisogni et al. (2007). The model also includes meal experience, which is relevant to the overall research aims.

3. Indexing and sorting

The NVivo 11 software (QSR 2016) was used to code and sort the data into the identified theme headings.

4. Data summary and display

The distinguishing feature of the framework method of analysis is the matrix in which the analysis is displayed (Gale et al. 2013). A framework matrix was created in the NVivo 11 software (QSR 2016). All the themes including the key themes from phase 1, and those identified through familiarisation, were included across the top of the framework matrix. The vertical axis of the table was made up of the individual interview participants. It was then possible to summarise, within each cell of the table, what each participant had contributed about the particular topics. This helped to understand the over-all ideas, which were emerging from the data, and highlight important areas for discussion and application.

The completed framework matrix was printed and sorted into the categories of the Making the most of Mealtimes (M3) model (Keller et al. 2014) (Figure 3 – refer to Chapter 1.4.2) in order to frame the presentation of the findings.

6.3.1 Reflections on using semi-structured interviews

Reflective notes were written by the researcher after each interview. Guidance from Mason (2018), Bryman (2012), and Kvale (1996), on a variety of interviewer skills were used when preparing for and reflecting on qualitative interviews. Mason (2018) suggests a high degree of intellectual and social skills are required when conducting interviews. Reflections on using semi-structured interviews are outlined below, using some of the skills as headings.

6.3.1.1 Intellectual skills – assessing relevance of responses

The open and qualitative nature of the interviews was beneficial in meeting the aims of the study and allowing participants to express their views. Although an interview guide was used, the opening question of "Tell me your experiences of mealtimes on the wards with people with dementia" and a few probing questions to expand, often led to comprehensive answers encompassing many of the planned topics. The interviewer could take threads of topics from the answers and use the words of the interviewee to guide the conversation (Mason 2018). This generally led to many of the desired topics being covered without the interviewer needing to introduce them separately. For example, one interviewee introduced topics of food choices, environment, family and visitors without the interviewer raising them. Another interviewee

introduced menus straight away as their main point. Later they brought up the topics of family and visitor involvement, the environment and social interaction.

6.3.1.2 Intellectual skills: Making decisions about depth and breadth

The interview schedule and topics generally allowed participants to bring up their views, and scope to move onto the next topic if they had finished. At times interviewees led from one topic to another without a break for the researcher to probe further. In these instances, the researcher took notes and returned to the topic at an appropriate time in the interview, allowing the interviewee to go into more depth on a certain topic without interruption.

In one interview the participant stated they only had five minutes to participate, so there was not time to discuss all the planned topics. On reflection, the interviewer had to consider how and why the conversation was guided as it was. On reviewing the interview audio and transcript the interviewer chose breadth as opposed to depth, trying to cover all the topics. It may have been more beneficial to allow the interviewee to go into more depth but the interviewer felt rushed in the situation. Still, intellectual skills were applied in reflective listening and using what the interviewee said to guide the conversation into the next topic, but perhaps too leading. An example of this is selected from the interview with participant IB7:

> *"IB7: it's not like the home surroundings, sometimes we try and play a little bit of music or something like that, you know --- or put a radio or a television on to try and calm them down a bit and bring something that they might do at home…*
> *INTERVIEWER: So, it is very different… to their home. But bringing a degree of normality… can sometimes help.*
> *… along those lines of familiarity and things, have you see visitors have an impact on mealtimes?"*

6.3.1.3 Intellectual skills: Being non-judgemental and considering intrusion of own biases

Using the reflective notes from previous interviews, the researcher made an effort to concentrate on not using terms like "good" or "yes" as if adding their own value to the responses. This was a noted habit within the first few interviews, but the researcher acknowledged the added benefit the use of silence could be.

6.3.1.4 Social skills: listening and talking, achieving the balance

The researcher felt they used reflective listening throughout the interviews. Examples of this were repeating and summarising. At times, especially initially, the researcher noted using the word

"yes" too much, sounding as if they were about to interrupt. This is displayed in the reflective notes taken after listening back to each interview:

> *"don't rush people when they're answering. Saying 'yeh' a lot which sounds like I'm interrupting or wanting to say something" (Reflective note, IB3)*

> *"saying 'yeh' again. Need to allow silence rather that sound like I'm trying to cut in. Could also just be confirming I'm listening to what they are saying" (Reflective note, IB9)*

The researcher has training and experience in listening skills through working as an Occupational Therapist. The interview transcripts show that on the whole there was a good balance between talking and listening. When the interviewee had finished talking about one topic and the conversation didn't naturally lead to the next topic or question, the interviewer attempted to change the subject without being too abrupt (Mason 2018)

Chapter 7   Findings from phase 2

Introduction

A total of 16 members were interviewed. All interview participants were staff who worked directly on the wards where the observations took place. None of the participants were part of the Dementia Specialist Teams in the hospital as these teams assisted with recruitment. Table 17 displays the characteristics of the interview participants across the two hospital sites.

Table 17: Characteristics of interview participants

Characteristic	Overall	Hospital	
		1	2
Participants	16	9	7
Gender			
Male	2	1	1
Female	14	8	6
Role			
Qualified Nurse	3	2	1
Student Nurse	1	0	1
Health Care Assistant	3	2	1
Ward Hostess	1	1	0
Dietitian	2	2	0
Physiotherapist	1	1	0
Occupational Therapist	4	1	3
Rehab Assistant	1	0	1

This chapter presents the findings from a complete analysis of the interview data. When familiarising with the interview data, additional themes were identified which were added to those carried over from the observation findings. Additional themes included: protected mealtimes, normality and familiarity, time, staffing, use or loss of day rooms, other settings comparisons, prompts and encouragement, profession specific roles, and volunteers. The number of themes and concepts emerging from both sets of data became so vast and complex that it was considered valuable to use a model to frame the presentation of the findings. The Making the Most of Mealtimes (M3) model (Keller et al. 2014) (Figure 3) was used as a framework when analysing and drawing more themes from the data. The results write up in this chapter reflects this. The umbrella terms provided by the M3 model (Meal Access, Meal Quality, and Meal Experience) are used to categorise the identified themes. Some themes are repeated in different categories to demonstrate how the observation themes, and topics discussed by interviewees, influence the different sections of the model in different ways.

Table 18 adapts the M3 model to outline the structure of the findings presented below. The central focus of the M3 model is food intake. The main focus of the research presented in this thesis is engagement in the eating process. In Table 18 engagement replaces "food intake". The three elements of mealtimes (Meal Access, Meal Experience, Meal Quality) influence engagement. Within the third column, the themes emerging from the interviews as topics discussed are listed as influencers to each element of mealtimes. In the model, which is developed from research in residential homes, the "Home" and "Government" are outer circles, ultimately influencing mealtimes and food intake. These have been described in the findings as System Drivers. System drivers is added as a fourth row, and heading, in which the themes are categorised.

Table 18: Summary of framework analysis based on the Making the Most of Mealtimes (M3) model (Keller et al. 2014)		
Central concept	**Category heading**	**Themes**

Engagement in the eating process	Meal Access	Assistance
		Prompts and Encouragement
		Volunteers
		Visitors
		Normality and Familiarity
		Day rooms
		Social interaction
		Staffing
		Meal anticipation
		Positioning
		Food selection
		Communication
		Time
	Meal Experience	Communication
		Meal anticipation
		Environment
		Social interactions
		Normality and Familiarity
		Staffing and Time
	Meal Quality	Interdisciplinary working
		Food selection
		Time and staffing
	System Drivers	Profession specific roles
		Comparison to other settings
		Protected mealtimes

The pull between person-centred care approaches, and the systems described by participants is displayed within these headings. The final section of the chapter highlights in more depth the impact of system drivers in detracting from person-centred care in meeting individual's physical and cognitive needs at mealtimes.

7.1   Meal Access

Meal access is interpreted as those factors which enable or disable a person's ability to initiate engagement, and continue, in the eating process. The M3 model describes meal access in physical terms, that is, as a person's ability or need for support in eating, the ability to chew and swallow, taste and smell, the availability of food, and whether food textures meet the needs of the person (Keller et al. 2014). However, the findings from the interviews revealed a much richer description of the complexities of meal access for people with dementia. Participants described cognitive barriers to meal access in the hospital setting in addition to the physical barriers identified in the M3 Model. The themes identified for meal access are described below.

7.1.1   Assistance with meal access

Participants described assistance as a way of improving food intake and engagement in the eating process. Many indicated that assistance would generally only be given to people highlighted to the team as requiring help as system restraints (such as staffing and time) meant support had to be targeted. Participants described different ways of assisting people with dementia at mealtimes. They acknowledged that adapting levels of assistance to meet the individual needs of the person would be an ideal, person-centred way of providing mealtime care. Different levels of assistance were described and included preparing patients for the meal (e.g. handing them cutlery), preparing the meal (e.g. cutting food up) and physically assisting them to eat. Participants described how patients were assisted through either simple techniques of assistance, such as verbal encouragement, or were physically assisted to eat. Many expressed there is often little attempt to encourage and try other techniques in between these two extremes:

> *"If people have shown that they need help eating [staff] will sit there and try and help them eat. They'll spoon feed them. Cut it up for them and help them feed. But it's the patients who aren't identified as being (pause)--- needing assistance--- quite often people don't think outside the box and it's very much: this, this, they can eat. Therefore they can eat. So, the fact they haven't eaten means they're not hungry therefore we'll take it away from them."* (Participant IB4 - Physiotherapist)

> *"Is it just that they need some prompting? But that's just being missed and they're being fed because that's--- that's the jump that it goes to, I guess."* (Participant IB5 - Occupational Therapist)

It was identified that a person with dementia may have different needs for assistance than other patients with just physical needs. Cognitively preparing people for the meal, and prompting to initiate their meal, could be as helpful as sitting by them physically assisting them. The participants described regular prompting and encouraging during mealtimes as an effective way of reminding a person of the mealtime and therefore promoting access to engaging in the meal.

7.1.2   Prompts and encouragement to access meals

Participants described food and drink being available throughout the day, on tables, on snack trollies, and at mealtimes. Despite this, continual verbal and physical prompts and encouragements to eat and drink were considered as an essential addition for meeting an individual's need for cognitive access to the food. This prompting has the potential to enable a person to initiate, concentrate and maintain attention throughout the meal, or be encouraged to re-initiate the eating process. Two participants stated:

> *"…whether it's the fact that they need helping with their meals or just encouraging or reminding. A lot of the time they do just need reminding that it's there. It's not that they can't do it by their self they just need a bit of encouragement to do it."* (Participant IB6 - Health Care Assistant)

> *"Prompting's a big thing. Because if they haven't got someone prompting… are they gonna drink? Are they gonna eat? Or are they just gonna forget? And then it's cold and then they don't want it so..."* (Participant IP2 - Rehab Assistant)

Prompting and encouragement was suggested to be one of the most effective ways to promote cognitive access to meals. However, they described how cognitive access to food, enabled through simply prompting or encouraging, is too often neglected in the hospital setting. This was attributed to a lack of staff training, lack of time and lack of staff resources. Participants' resignation to the system was evident, even something they considered important to improving engagement at mealtimes. The lack of staff numbers was attributed to still not having the power to enforce it. One participant described it as being "*just one of those things*" (Health Care Assistant – IP3).

Participants identified people with dementia may be left to initiate and continue eating alone. Food is often left in front of people, physically accessible, but that whilst it is physically accessible, it may be left uneaten, and then cleared away. Alternative solutions were suggested by

participants. These included the use of assistive technology to prompt, and presenting food from the finger food menu which could be left longer than a normal hot meal. Participants also highlighted the value of other people on the wards to overcome the system driven factors of limited staff time and resources, to prompt and encourage people with dementia. These could include visitors and volunteers.

7.1.3   Volunteers and visitors supporting meal access

Opinion among participants was that volunteers could valuably encourage engagement at mealtimes, although, few described any experience of them on the wards. A barrier to availability of volunteers was suggested to be the system by which they were requested. Participants who knew about the availability of volunteers, such as the Dietitians who trained them, expressed uncertainty about whether ward staff were aware of their availability.

Some participants described their experience of volunteers and visitors being helpful in enabling them to meet the expectations of their own roles, as exemplified by the following statements:

> *"one thing is we sometimes get mealtime companions who are like volunteers and they come up and that relieves us a little bit. So, we can spend a bit more time with individuals, you know, encouraging."* (Participant IB9 - Health Care Assistant)

> *"Sometimes if--- I'm a nurse to one to ten patients so, if there's five feeds, I'm not going to have--- I won't be able to do all of them at the same time even with my HCA. So, sometimes there will need to be extra support around those times."* (Participant IP5 - Nurse)

Volunteers and family visitors were a suggestion made by participants as a way of relieving pressure on staff, and enabling access to food for people with the greatest needs:

> *"if there isn't family around more staffing would help for feeding or more volunteers. That can help with feeding as well."* Nurse – IP5

Visitors at mealtimes were viewed by interview participants in two ways. They were considered a potential distraction from the meal, but on the whole a way of encouraging engagement in the meal. Various positive examples in practice were highlighted where family visitors came and assisted to feed patients. One participant relayed an example:

> *"we've got someone at the moment who's got dementia who takes--- can take up to an*
> *hour sometimes to eat and staff on the ward, unfortunately, just don't have the abilities to*
> *spend that length of time. So, her husband comes in at all mealtimes and feeds her."*
>
> (Participant IP6 - Occupational Therapist)

7.1.4 Normality and familiarity to promote eating

Normality and familiarity of the people around, food and drink preference, routines and the environment were all identified as essential in promoting cognitive access to food and drink. Without normality and familiarity a risk of disengagement from the mealtimes was acknowledged, leaving food left uneaten, and reduced mood and appetite. Knowing the person's preferences and individual routines was identified as promoting access to and encouraging engagement in mealtimes. Normality and familiarity of the environment was reported to create cognitive cues for the mealtime as a distinct activity.

There was a clear distinction between this person-centred approach and the restrictions of the hospital environment limiting patients' normal routines. Restrictions within the hospital environment were highlighted as a potential barrier to people with dementia engaging in mealtimes. Participants talked about the normality of autonomy at home, people being able to get up and access food and drink when it was normal for them. In hospital people are constrained to the set times for food and drink delivery. The timing of food choices and giving enough time to eat were viewed as significant. The importance of timing with regard to normality of people's routines was raised as important in making mealtimes meaningful and recognisable as an occupation for people with dementia.

The hospital environment was described as being different to usual eating environments. Participants explained that the unfamiliar hospital environment could be a cognitive barrier to initiating eating and drinking at mealtimes due to the lack of environmental cues. It was described as a busy place, with many tasks continuing throughout the mealtimes, such as medication rounds and patients being taken to the toilet. Participants also had positive examples of how creating familiar and meaningful mealtime environments had promoted access to the food through social and environmental stimulation. One participant gave a specific example:

> *"her husband happened to be a gentleman on another ward and they used to bring him*
> *down and they had meals opposite each other and they would sit together and eat meals*
> *together because you don't often sit by a bedside at home and eat a meal."* (Participant
> IP6 - Occupational therapist)

Visitors were described as a greater help than volunteers for individuals with dementia in having a "familiar face" around, a concept which was widely expressed throughout the interviews. The addition of familiarity to the meal was presented by participants as important. It sets up the mealtime as a meaningful occupation, promoting a relaxed atmosphere, for patients who may be confused about their surroundings and the time of day. Participants expanded on this:

> *"I have to say that most of the time you hear that the patient's eaten better when they've got someone that's familiar to them or knows them better and knows what assistance they need and maybe has a little bit of a sort of--- a personal interest in the patient's intake rather than someone that's come in as a volunteer or (pause) the health care assistant"* (Participant IB2 - Dietitian)

> *"if their family comes in they might even help them with their meal, you know, and they're more likely to eat something from their relative rather than one of us. Like I say, someone they don't--- they've only met on the day. If, you know, their daughter usually comes in and feeds them while they're at home it's normal for them."* (Participant IB6 - Health Care Assistant)

Family visitors were also considered important in their personal knowledge of the patient's mealtime preferences even if they were not physically present at the meal. Their ability to describe usual levels of assistance, usual food routines and their food preferences was reported to be invaluable to the staff in the hospital. The use of this knowledge meant staff would be able to make mealtimes as normal, familiar and person-centred as the hospital environment allowed. In turn, this would encourage people with dementia to recognise the activity, and take the normal cues of the mealtime as prompts to initiate and continue the eating process.

The lack of space and resources to create a familiar, meaningful mealtime environment within the hospital was an issue raised throughout the interviews. Encouraging cognitive access to food through recognition of a mealtime environment was identified as the opposite of reality in the hospital setting. An example of this was illustrated well by one participant:

> *"you know, nobody eats, lives in a chair, sleeps in a chair, sits in a chair, eats in a chair. Go to the toilet in a chair. There's not like--- why would you? Like must kill your appetite. Must kill it."* (Participant IB8 – Nurse, ward manager)

7.1.5 Day rooms and social interaction influencing meal access

In discussing the importance of the mealtime environment in allowing access to food, half of the participants raised the use of day rooms. Participants described day rooms as positive in encouraging engagement in eating, through cultivating a normal eating environment. They reminisced about using day rooms in the past, or in other wards and settings.

The predominant feelings expressed about day rooms were those of loss and resignation to them not being an option in the acute hospital setting. Barriers to being able to facilitate meals in a day room included, limited space for a day room, and limitation of staff numbers to supervise the meal away from the beds. Participants also expressed it simply not being an option in the acute hospital ward, without explanation. This was illustrated by participants from different professions:

> *"If there was a separate place where people could go to eat if they were able to be--- able to mobilise there or be transported then that would definitely improve mealtimes. But limitations unfortunately. We don't have that space."* (Participant IB5 - Occupational Therapist)

> *"most people are just sat by their bedside. It is a shame that the day rooms aren't here now because most people, if they're at home, would go and sit at a table and eat. They haven't got that option really here.*" (Participant IP3 - Health Care Assistant)

> *"I've been on placements in like community hospitals and we used to always get everyone into the day room for dinner and things and sit in groups… Obviously, it's a bit different in the main--- big hospital than community hospital. But, yeah, it did work there."* (Participant IP4 - Student Nurse)

Using day rooms was described as positive in the potential to create a social mealtime environment. Social interaction during meals was recognised as a way of promoting engagement by participants. Many identified that seeing other people eat may be another way of overcoming some of the cognitive barriers people with dementia face during mealtimes when in an acute hospital ward. It was suggested that sitting alone would not provide the visual prompt of others eating, whereas social eating may encourage and prompt food intake. The main restraints in allowing for social mealtimes in the hospital setting were highlighted as, space to encourage social interaction, time and staffing levels.

Participants described patients eating alone by their hospital bed as isolated. Some suggested this could impact mood and reduce appetite. Eating together in a social setting had been seen to improve appetite. One Occupational Therapist particularly illustrated a time they had seen the benefit of social eating:

> *"we had like a tea party or something…that social environment was so positive and people who hadn't eaten like a few days were eating lots of cake and drinking tea"* (Participant IP1 - Occupational Therapist)

Enabling social interaction was viewed as something difficult to facilitate in the hospital setting. Mealtimes in hospital were described as a "*tick box task*" (Participant IP1 - Occupational Therapist). Creating a social and recognisable mealtime environment was considered useful in allowing anticipation of the meal.

7.1.1   Meal anticipation promotes access

Participants acknowledged that helping people prepare for the meal would be a valuable way of allowing physical and cognitive access to the meal. They identified that "*plonking*" (Health Care Assistant – IP3) the food in front of people with no prior warning was not conducive to stimulating eating and drinking. Preparing people for the meal was identified by participants as a way of enabling recognition of the mealtime:

> *"IB3: … somebody goes around washes the hands maybe and then, you know, maybe there's a countdown to lunch time or something. I don't know (laughter). …It could be a good idea.*
> *INT: A visual kind of display of when the meal's gonna be coming.*
> *1B3: Yeah. Yeah, because otherwise…they're just like plonked in front of them and they don't know what time it is, you know."* Nurse - IB3

Suggestions were made to improve anticipation of the meal. These included washing patient's hands, taking them to the toilet, and ensuring patients were in a good position, prior to the food being delivered.

7.1.2   Physical positioning to access meals

Participants highlighted sitting up, and out of bed, as a normal part of eating. It was considered an important physical and cognitive consideration for initiation and continuation of the eating process. Nurses and Health Care Assistants agreed that the positioning of people at mealtimes

was important for encouraging access to food and intake.

The main restriction from providing this was system lead. Participants described restrictions with staff levels and time allowed to prepare people physically for the meal. There was no mention from the nurses or health care assistants of how other health professionals may be able to assist with this, rather they assumed the responsibility themselves. Therapy staff who were interviewed described mealtime care as a nursing role, as part of the caring remit. They did, however, state that their mobility assessments could be completed in the mornings by way of helping people transfer into their chairs for lunch. Being in a good position for the meal was generally considered important in the anticipatory stage of the eating process. Anticipation also included making food choices.

7.1.3   Accessing food selection

The food selection process was primarily described in two ways. Access to making autonomous and informed choices through presentation of menus was considered important. Also, people making their own choices, and knowing what this choice was at the mealtime, was identified as influencing positive engagement at mealtimes.

Timing of food choices was raised as a potential impact on whether people will engage in eating when the food arrives. Some participants described a time in the past when people would choose meals from a trolley, at the time the meal was being served. This was recognised as an appropriate and ideal way for people with dementia making their food choices. The present system of making menu choices on the wards was described differently. Choices were considered to be made too far before the meal would be eaten. It was suggested that people with dementia may forget what they have ordered, or want something different by the time the food arrives. Two Health Care Assistants illustrated this, stating:

> *"So, sometimes they don't recall what they've ordered or by that point it's not what they fancy to eat. Or they'll have got something else stuck in their heads. So, it might be that there was fish pie and shepherd's pie and they've picked one but have remembered the other one."* (Participant IB9 - Health Care Assistant)

> *"I'd probably forget what I'd ordered a day in advance as well. So, as far as the dementia patients go it's not just them that forgets what they've ordered. Often you'll take a meal to somebody and they say: "I didn't order that"."* (Participant IP3 - Health Care Assistant)

Presentation of menus was considered influential in creating cognitive barriers to accessing food choices. It was widely acknowledged that people with dementia were not always being enabled to make autonomous decisions over their choice of food. Participants from both hospitals described too much choice, and options being offered in a long list. It was suggested that people might be making a choice because it is the last thing they heard. The long list of choices read to people could be overwhelming for someone with dementia who may struggle to process or remember what is being offered:

> "They've read out fifteen things and go: 'and which one would you like?' And they just look at them like: 'what are you going on about?' So, I think, it's good that there is the range for people to eat but, I do think that when you're reading a list to someone, especially with cognitive impairment, it's--- it's too much for them to take on board." (Participant IP6 - Occupational Therapist)

> "I don't know if sometimes [the ward host] gives them too many [choices] or just like relays a list of things and then by the time he's got through them all, they may have forgotten what they were or they don't--- they can't like picture what they are" (Participant IB3 – Nurse)

Participants from Hospital B explained that they found the menu system complicated. The different sections and complexity of the paper menu meant people with dementia, if left unsupported, might not be able to select the combination of foods to make a meal they would want. One participant described how a patient ended up with cheese on toast with green beans for a meal, which they did not eat.

Due to the difficulties and time required to support people with dementia to make autonomous and appropriate meal choices, participants admitted that at times the decision is made for people with dementia. Food that was not ordered by the person with dementia may still be left untouched. One participant illustrated the potential problems with choices being made for people:

> "But we did have someone who--- the family came in and: 'oh--- oh, they're not really eating and drinking'. And they were like: 'well, that's because you keep giving them curry. They don't eat curry' and you're like: 'oh, OK' … and they were like: 'I don't know who's doing these menu choices but it's not my mum'." (Participant IP6 - Occupational Therapist)

The food that is presented to a person at mealtimes was considered very important in influencing whether they will eat it. Enabling autonomous and meaningful meal choices allows cognitive access to the food, as it is conducive to people recognising it, liking it and engaging in the eating process. The food selection process was considered a restricting factor for access to engaging in the eating process, imposed by the hospital systems.

Finger food menus were described as a strategy to overcome the hospital restrictions of systems and set times. The finger food option allows access to food throughout the day, not purely subject to the hospital set mealtimes. As the finger food options were cold, there was less pressure on time as the food could be left with the patient for longer periods. Although the finger food menu enabled wider physical access to food, the concern was raised that the menu contained different food to the main menu. Not being able to use cutlery, or being slow to eat, were acknowledged to be poor reasons to take away the normal food choices that other patients had. Rather than changing the food being offered, participants agreed that the way the menu choices were presented could have a greater impact on enabling autonomy and engagement.

7.1.4 Communication enables access to food

From making menu choices, to supporting people with dementia to eat and drink, communication was a common theme emerging from the interviews. The way people with dementia are approached and communicated with was deemed essential in enabling access to engage in the meal.

It was acknowledged that people with dementia may not be able to understand and process information, but also may struggle to communicate what they want to say. Alternative communication techniques to promote access to food were suggested participants, such as: pictures, demonstrating actions, or prompts in order to reinforce a verbal message. Participants also discussed alternative ways of telling people where and what their food is as one participant described:

> *"You know, maybe people that just go and put their plate there and it's not really good enough for someone with dementia that's just: there you go, there's your lunch. You need to tell them: your knife and fork's here. Do you need anything else?"* (Participant IB6 - Occupational Therapist)

> *"often we'll use like the clock face. You know: 'this is at twelve o'clock, that's at six o'clock'. Just so they can maybe recognise what's--- what they've got on that day."* (Participant IP3 - Health Care Assistant)

Taking time to communicate was recognised throughout the interviews as an important part of communication.

7.1.5 Time and staffing impacts access to meals

A recurrent theme throughout the interviews was the importance of time in giving the person-centred care and communication needed. The value of giving time was recognised as a significant enabling factor, suggesting it "*could make all the difference*" (Physiotherapist – IB4). Lack of time was described as a pivotal factor in not being able to provide care that may enable access to food as exemplified by one participant:

> *"I find that sometimes there's just not enough time because they take a lot longer…to assist them with their dinner. So, I always find that--- that there--- sometimes there's not enough time and staff to sit there and encourage them and… sometimes they're very confused and it's quite hard to spend the time to engage with them to try to get them to eat as much as they can. It's very difficult at times."* (Participant IP4 - Student nurse)

Participants widely acknowledged that people with dementia often need more time to eat. They expressed that if staff had more time available, they may be able to provide more personalised and enabling care to improve physical and cognitive access to mealtimes. The limitation of staffing levels was described as reducing positive influences on mealtimes. Participants reported that due to the staff to patient ratio, people needing close supervision or feeding often ended up being rushed due to other pressures on staff time.

Other demands on staff time added pressure, reducing staff ability to assist at mealtimes. Participants described the mealtimes as busy, with limited time to spend with people who need the extra time. Other demands included taking people to the toilet and having to reposition people on the bed so they were in a better position to eat. These were recognised as tasks which could be done in preparation for the meal, but again staff reported lack of time to do this due to the demands of other tasks.

7.1.6 Conclusion

Promoting both physical and cognitive access to meals in the acute hospital setting was presented by the participants as a complex issue. A plethora of factors were identified as enabling or disabling people to access mealtimes and engage in the eating process. The lack of staff numbers

and time were highlighted throughout the themes as system lead, inhibiting, factors to promoting physical and cognitive access. Positive social interactions, appropriate people, appropriate communication, and an appropriate eating environment were all considered by staff to impact access to food and engagement in the eating process. The M3 model (Figure 3) (Keller et al. 2014) shows that access to food is just one part of enabling engagement at mealtimes. The participants revealed, in line with the model, that experience of mealtimes is also important.

7.2   Meal Experience

Within the M3 model, meal experience includes factors such as social interactions, ambience, meal pace, appetite and desire to eat. Topics identified by interview participants relating to meal experience are presented below. Some themes overlap with themes described in the category of meal access, but are described in the meal experience category as influencing meals in a different way.

7.2.1   Effective communication influences meal experience

Participants identified meal experience being positively or negatively influenced through communication in the presentation of the food being offered. The way in which staff communicate was described to impact the person's perception of the food or drink being offered. Participants expressed that people with dementia may not understand the reasons for needing food supplements or different textures; some participants recognised the need to promote the positive aspect of the food through their own approach:

> *"things like Fortisips, or any other type of supplement, encouraging that as well. So, you know, not opening the bottle and turning your nose up at it … you know, encouraging those kind of drinks and being creative with how they can be administered."* (Participant IB1 – Dietitian)

It was reported that the task-orientated nature of some care leads to lack of time given to communicate effectively with patients with dementia. When staff had not used appropriate communication techniques, people with dementia could potentially have a worse experience of the mealtime, limiting their food intake. This was described as pertinent during the food selection process. Lack of ability for people with dementia to communicate their choices was suggested to contribute to decisions being made which did not promote the optimum mealtime experience. For example, they may get something which tastes plain because they're not able to communicate their preferred choice, as described by one participant:

"if they're not sort of saying one way or other, or if they're not initiating what they would like, then they generally just order something quite plain like a jacket potato or something." (Participant IB5 - Occupational Therapist)

7.2.2   An unpleasant eating environment

The environment of the wards involved in the research project presented in this thesis was described by participants as unpleasant, smelly, busy, noisy, unfamiliar, isolating and distracting, making it unpleasant for eating. It was suggested that the hospital environment lacks the right ambience conducive to eating. The environment impacts the experience of mealtimes, and desire to eat. Two Health Care Assistants illustrated this through their descriptions of supporting patients within the ward environment:

"INT: So, the people with dementia particularly, is there anything that you've noticed?

1B3:   I think, it can be difficult (pause) to get them to eat and drink. I don't know if it's to do with the noise or, you know, a lot going on at the same time. But, yeah, it--- it can be a struggle." (Participant IB3 - Health Care Assistant)

"people don't tend to even like to eat in hospital, do they? …people use the commode next to their bed so, it's your toilet space as well as your bed space…And then you've gotta see other patients in there with you, so you're looking at Doris across the room (laughter) which you might not wanna look at while you're eating… Maybe there's a lady using the commode next to you… there's just curtains around so, it's hard." (Participant IB6 - Health Care Assistant)

A less busy and distracting environment was suggested as a way of allowing people to "*enjoy their meals*" (interview transcript, IB1). A recommendation for improving the meal environment was to take patients away from their bedside in what were described as busy and noisy bays. This alternative environment was reported by participants as potentially providing a more relaxing, social, less confusing and less clinical environment, conducive to enjoyment of the mealtime.

Protecting the meal through reducing environmental distractions and un-pleasantries was highlighted as potential to improving meal experience and improving engagement. Some participants discussed the policy of protected mealtimes, how this could be used to reduce some of the environmental distractions during the meals. It was suggested that protected mealtimes could reduce the disruptions and busyness of having too many people around. Non-urgent health

professionals, such as therapy staff and doctors, who could complete their assessments at other times, are discouraged from being on the wards at mealtimes. Concerns were raised that, even without these non-urgent health professionals, the hospital bays are still too busy at mealtimes. Often nurses are completing medication rounds. Visitors were generally viewed as a positive influence but participants commented that they added to the number of people at mealtimes and could be a distraction to other patients.

Despite the busy environment, participants identified a "*hospital silence*" (Participant IB5 – Occupational Therapist). They highlighted how the hospital set up can be isolating as it does not promote social interaction, even though there are a lot of people around. Isolation was described as reducing the desire to eat, whereas eating with other people could improve the mealtime experience and increase food intake.

7.2.3 Social interaction improves meal experience

Social interaction at mealtimes was viewed as an important factor in improving the mealtime experience and therefore engagement in the meal. The potential isolation of patients at mealtimes was widely recognised. It was expressed that patients only received interaction at mealtimes when they had been specifically assigned to staff as needing assistance. Social interaction was not just something participants expressed would be nice for the meal environment, but also something they had identified as patients wanting. It was suggested that, even if a day room is not possible in the hospital setting, patients could be moved to a place where they could more easily socialise at mealtimes.

The topic of volunteers and visitors at mealtimes were also discussed with regard to improving the mealtime experience through social interactions. Having visitors or volunteers present was generally seen as a positive addition to the meal experience. One participant disclosed how they had seen the volunteer socialising with patients at mealtimes as encouraging a positive social environment. People would appear to be enjoying the meal, and engaging better, when the volunteer was present. Having a social environment was also identified as a way of introducing normality to the meal as a pleasant and meaningful activity.

Visitors who are familiar with the person with dementia were described as adding to the normality and positive experience of mealtimes by bringing in food and telling staff about the preferences of the person. Participants were in consensus that knowing the likes and dislikes of a patient could make all the difference to the experience and engagement at mealtimes. This was previously discussed as a strategy to break down cognitive barriers and improve recognition of

the meal. More than this, having familiar food, which the person with dementia likes, can make a clear difference to the enjoyment of the food. With this positive experience of eating, participants have seen an improvement in engagement in eating and drinking. One participant provided an illustration:

> *"so, she comes in and she brings her mum smoked salmon (laughter) and like salami and the things that she loves. … so much better and you can see like that they're actually enjoying that mealtime rather than just sitting there with a plate going cold, not interested in eating."* (Participant IP1 - Occupational Therapist)

Aside from creating a pleasant social environment and ensuring food is enjoyed, a familiar person present while eating was suggested to be a way of reducing distress or confusion at mealtimes, as illustrated by participants:

> *"I've had many occasions where patients are so upset and they don't wanna drink coz they're just--- they're too worried about where they are, who you are. They don't even know you. They don't even know the person that's telling them to do drink (laughing) so, it's like--- it's--- it's hard."* Health Care Assistant – IB6

Other care settings, such as community hospitals and residential homes, were recognised as having a more positive eating environment and allowing more positive experiences of mealtimes. Participants attributed this to the restaurant and dining room style environments in which the people in these alternative care settings ate their meals. Some participants suggested that the hospital setting is unable to provide these situations and so meals are experienced more negatively and people with dementia engage less. They explain this is due to the extra pressures of staff numbers and limited time which exist in the hospital setting.

7.2.4   Rushing meals reduces experience

The M3 model (Keller et al. 2014) highlights meal pace as impacting the meal experience. The theme of 'rushing' was prominent throughout the discussions about staff and time. It was clear that staff recognise the value of giving people with dementia adequate time to promote independence and a comfortable meal pace. Participants expressed that they felt pressured to rush meals because of the limitations placed on them. Two participants expressed their feelings and experiences of task centred, rushed and busy mealtimes:

> *"Like making sure that person's got that food and: so, they've got their cutlery? Yes, OK, move on. Next one, you know, and it--- it does feel like that sometimes and, to be fair, like staff are busy and they're rushed and they don't always have a lot of time to sit and*

support, you know, as much as they probably would like to." (Participant IP1 - Occupational Therapist)

"especially here because it's very busy. I find that sometimes there's just not enough time because they take a lot longer to…assist them with their dinner. So, I always find… sometimes there's not enough time and staff to sit there and encourage them… Sometimes there's several patients that all need assistance and sometimes there's only one of you." (Participant IP4 - Student Nurse)

It was felt also that time was limited between kitchen staff delivering meals and collecting the empty trays. This was described as putting pressure on staff to rush the mealtime, which was viewed as detrimental to meal experience.

7.3   Meal Quality

Along with enabling physical and cognitive access to meals, and enhancing mealtime experiences, in the M3 model (Keller et al. 2014) recognises meal quality as influencing engagement and food intake. The model includes sensory appeal, nutrient density, variety and preference, presentation, and food safety, as factors influencing the meal quality. The quality of food and drink was raised by interview participants. Various themes emerged as topics discussed around what may influence meal quality. These matched the M3 model (Keller et al. 2014), and raised other issues pertinent to the hospital setting in particular. The themes discussed in the interviews included, interdisciplinary working and quality of the food.

7.3.1   Interdisciplinary working

The issue of interdisciplinary working was raised by the interview participants but is not mentioned in the M3 model. Different health professionals working together was considered important in ensuring the quality of meals. The dietitians in particular had nutrient quality as a prime focus in their role at mealtimes:

"Our role's more kind of training and advising. You know, working out the patient's needs and how much they need to eat--- be eating." (Participant IB1 – Dietitian)

"we try other things. Dietitians with build-up and… Finger Food. Things like that." (Participant IB8 – Nurse, ward manager)

Interdisciplinary communication was valued by all professionals in supporting their own roles in providing meal quality. Nurse participants particularly acknowledged the value of being able to

refer to dietitians and speech and language therapists for support with meals. They acknowledged how these professions added quality and value to meals, sharing their expertise through training and advice. The ward hostess and Health Care Assistants expressed that they were the people at the face of mealtimes, offering required assistance to patients, but they take their guidance from dietetic and nursing staff. The dietitians highlighted the importance of having feedback from ward hostesses and nursing staff. All staff recognised the importance of working together as a multi-disciplinary team, illustrated well by one participant:

> "it's not just our task, it's everybody's responsibility to make sure that patients are getting
> their right diet and nutrition." (Participant IP3 - Health Care Assistant)

The ward hostesses and Health Care Assistants were particularly involved in food selection. The choice of food was considered to have an impact on the quality of the meal. One dietitian interviewed was of the opinion that even if people could not communicate their preference, the most important thing is that they get something of nutritional value.

7.3.2 Quality of the food

It was clear from the interviews that adequate nutrition was not the only factor in having a quality meal. The quality of what, and how, food and drink was presented was considered important, as highlighted by one Occupational Therapist:

> "if they're giving them water and it's warm water in this heat quite a lot of our elderly
> patients aren't drinking it coz it's warm water but you will drink warm squash. So, actually,
> if you just put a bit of lemon juice with it, a bit of orange juice with it, actually you can
> drink that if it's warm. You can't warm water because it's gross (laughter)." (Participant
> IP6 - Occupational Therapist)

The participants generally described a wide, good selection of food options. The wide selection of food was not viewed as a positive by all participants, and comparisons were made to other care settings. It was suggested that a preferable way of having good quality meals, which would improve food intake, would be to have less variety but more personal choice.

The timing of when menu choices were made, also impacted the quality of the meal to an individual patient. People may even be eating a meal that has been chosen by somebody else because of the changeover of patients in the beds. This was raised by the ward manager interviewed:

> *"people have ordered food from the previous person and then they've gone home and a*
> *new person's come in and they get that meal and it's not as personal."* (Participant IB8 -
> Nurse, ward manager)

The timings of the hospital systems, such as a limit on when to order food, were blamed for such occurrences of not being able to provide individualised care in improving meal quality or experience.

7.4   System drivers

Within all the themes discussed so far, the way the hospital system works has been recognised as impacting engagement in mealtimes through influence of meal access, meal experience and meal quality. Examples have been discussed of how staff recognise person-centred approaches as best practice, but feel restricted by the hospital system to provide it. Numbers of staff, available staff time, timings of the hospital routines, and food selection processes, all heavily depend on the way the hospital works to be able to have positive or negative influences on engagement in the eating process.

The routines, systems and priorities of different health professions, and the kitchen staff, influenced mealtimes in the hospital setting. Different internal groups and systems did not always appear to work together with the routines and priorities of the wards. Staff complained of kitchen staff coming to collect trays before meals were finished, and having to rush to complete personal care tasks in time for the meal to arrive. This could lead to a negative experience of personal care in the lead up to the meal arriving. Where positive and person-centred solutions to improving mealtimes were recommended, it was often the rules and restrictions of the hospital system that were described as barriers to implementing these approaches.

Key themes emerged from the interview data regarding how the system impacts mealtimes: profession specific roles, protected mealtimes, and comparisons to other care settings. All these discussions were followed by expression of resignation to the system, and the powerlessness to change.

7.4.1   Profession specific roles

Participants shared their views of their own roles in mealtimes and nutritional care. Participants rarely described the responsibility for mealtime care falling within their own professional roles. There was evident confusion about who took responsibility for nutritional and mealtime care. As a result, it was evident that care at mealtimes was the priority of nobody in particular.

Nurses were described by some therapy staff as being responsible for mealtime care within their "caring remit" (Interview transcript IB5, OT). The nurses who were interviewed had different views of this, claiming to have other priorities at mealtimes. Even within the nursing role there was confusion about what was expected at mealtimes. The ward manager described a ban on medication rounds at mealtimes to free up nursing staff to assist with the meals, although did not consider themselves as part of this responsibility. A nurse from another ward claimed to not be involved in assisting at mealtimes as the medication round was her priority. Nurses generally assigned the responsibility of nutritional care to dietitians and speech and language therapists, raising referrals for people who needed specific input.

Dietitians reported that the main responsibility for mealtimes lay with the ward staff. They described their own roles as being advisory, for training, and only for people with specific issues such as weight loss. There was discussion of how dietitians could be of value on the wards at mealtimes, by way of assessing and supporting the ward staff. This was not viewed as feasible within the staff resources, as the dietitians cover so many different wards. The dietitians who were interviewed expressed how valuable the Health Care Assistants and Ward Hostesses are to their role in giving them feedback after advice or suggestions had been followed through. They viewed the Health Care Assistants and Ward Hostesses as the people with the main responsibility for mealtime care.

The Ward Hostesses at Hospital site A were reported to be highly valued by other staff. The participants described valuing their contributions towards helping patients order their menu choices. One Health Care Assistant described how their job was harder at weekends when the Ward Hostess was not on shift as their responsibilities then became the job of the Health Care Assistants. It was suggested the value of the Ward Hostesses stemmed from their sole focus being food and drink provision. Participants reported that within the Ward Hostess' role they are able to focus on getting to know the patient and their preferences, deliver food and drink, and assist at mealtimes where needed. Ward Hostesses were described as not having the tasks and responsibilities expected of the Health Care Assistants and nurses to distract them from their meal focus. The Health Care Assistants described it as difficult to maintain focus on the mealtimes as they had other pressures on their time. These included taking people to the toilet, assisting other patients to eat, and answering the ward doorbell.

Health Care Assistants were the only profession to claim responsibility for providing mealtime care. They described themselves as the "closest to the patients" and the "eyes and ears" for the nurses (Interview transcript, IB6). They described their role as being involved in delivering meals, assisting people who need feeding, and are expected to be available to generally encourage and

prompt intake. They were also described, along with the Ward Hostesses, as the most likely group to be facilitating the preparation and anticipation of mealtimes. Despite this hands-on role the Health Care Assistants claimed not to have ultimate responsibility for nutritional care; one stated that it is everyone's responsibility and it should not be left to them as a profession. They also highlighted that they simply work under the instruction of the nurses, dietitians and speech and language therapists in the mealtime care they deliver.

The main staff group not included in other professions' descriptions of mealtime care were the therapy staff – Physiotherapists and Occupational Therapists. As a whole they expressed they do not get involved with nutritional or mealtime specific care, but described potential for their skills to provide input. A physiotherapist participant explained part of their assessment is around mobility, dexterity, strength, and grip, all of which could be applied in mealtime assessments.

Occupational Therapist participants described their primary focus in the hospital setting as planning safe and timely discharges, but the mealtime was identified as an occupation which was important. There was a consensus among the Occupational Therapist participants that within their resources, there was insufficient time to extend their role to improving mealtime care. Some even expressed feelings of being judged or questioned if they tried to include this area in their assessments. Still, the potential value of the skills Occupational Therapists could offer at mealtimes were discussed. Occupational Therapist participants suggested their skills could be valuable in assessing, and improving the mealtime. They referred to their roles in other settings where they had been instrumental in getting people sat up at tables or in a day room, used breakfast and lunch groups to assess function at mealtimes, and advising family members about access to eating and drinking at home. The main reason they could not do this in the older person's medical wards was that their lunch breaks coincide with the ward mealtimes. The therapy team lunch breaks were described as purposely assigned at the set lunch-time of the ward to honour protected mealtimes, and allow patients the space they need for eating and drinking.

7.4.2 Protected mealtimes: a system driven policy

Protected mealtimes was raised by participants as a policy intended to improve mealtimes for patients on the wards. The protected meals were described as a time when non-urgent health professionals would leave the ward, and staff focus on delivering and assisting with food and drink. There was confusion between participants as to the application of protected mealtimes, and who they were intended for.

There was a lack of clarity between participants whether the policy should, or does, exclude visitors from being on the wards at mealtimes. Visitors were considered to be helpful in supporting mealtimes for people with dementia, but participants also reported the potential for increased noise and distractions created by extra people on the wards. There was no clear answer whether the policy discusses visitors. Participants expressed being unable to discuss issues and questions from visitors during the mealtimes as they themselves should be honouring the protected mealtime.

Some confusion about protected mealtimes arose because of the expectations on staff at mealtimes. They described it as a time when distractions and other tasks should be reduced, but a time that still seemed to be busy and full of interruptions. There was a general consensus among participants that it is difficult to maintain a truly protected mealtime in the acute hospital setting.

7.4.3   Comparisons with other settings

Participants who had worked in other hospital wards or care settings compared their experiences of mealtimes. Even within the acute hospital different wards had different attitudes towards mealtimes.

Within the older person's medical wards the Occupational Therapy role focused primarily on discharge planning, including functional assessments such as washing and dressing, equipment assessments and mental capacity to make decisions. Occupational Therapy participants described this role expectation as a limiting factor to their input at mealtimes, whereas in the stroke wards they were expected to facilitate breakfast and lunch clubs, assessing functional ability at mealtimes. The meals in stroke wards and in care homes were treated as more of a meaningful occupation; in older person's medical wards it was viewed as a "*tick box task*" (Interview transcript, IP1). These other care settings were also described as having the resources to make mealtime meaningful.

Having a dining area was viewed as a key difference between the older person's medical wards and other settings. A Student Nurse described her experience of a placement in a community hospital as different to the acute hospital. She stated that in the less acute setting staff had more time to focus on getting people up at tables to eat and create an appropriate mealtime environment. Laying the tables and moving people to the day room for meals was viewed as an important part of care.

The participants had various views on the reason for differences between acute older person's hospital wards and the other settings described. It was suggested that rehabilitation was a focus

in the stroke wards, mental health teams, community hospital and community teams. Consequently, rehabilitation as a function of mealtimes and the eating process was viewed with importance. The other key difference described was time. It was felt that the limited time and resources for therapy staff meant that their focus could not stretch to mealtime assessments and interventions. The ward staff participants described the acute nature of the patients, with their medical needs, meant mealtime care could not be as much of a priority as they may like. It was felt among the participants, that although improving mealtimes would be ideal, they were limited in what they could do to change the current ways of working.

7.4.4   Powerlessness to change

Overall there was a general expression of powerlessness, lack of control and resignation to a lack of positive change regarding improving the mealtime process. These feelings were articulated by a variety of professions and grades of staff, across both the hospitals, including those in more senior positions:

> *"…unfortunately there isn't anything we can do about that"* (Participant IB8 – Nurse, ward manager)

> *"I don't' know a way round that"* (Participant IB9 - Health Care Assistant)

> *"It's just one of those things isn't it"* (Participant IP3 - Health Care Assistant)

> *"In an ideal world…"* (Participant IP6 - Occupational Therapist)

Participants were also asked to describe current policies, procedures or interventions, driven by the hospital, which they considered may improve nutritional care. These included: protected mealtimes, red trays to identify patients needing assistance, build-up drinks and modified food textures, and the finger food menus. Participants also described routines within the day such as well-being rounds where people were offered drinks and snacks between meals, and the use of food and fluid charts to record intake. Some participants discussed the use of adaptive cutlery and coloured crockery to increase access to food, but there was confusion about how to get these and if they were even available to the wards. The policies and interventions currently used were seen as positive, but there was a general feeling that more could be done to improve mealtimes, the access to food and the experiences of people with dementia.

7.5   Conclusion

The themes identified in the interview data have all been presented as influencing meal access, meal experience and meal quality for people with dementia in hospital. The use of semi-structured interviews was successful in enhancing the observation data. New concepts were developed through the interpretation of the findings framed by the M3 model. These concepts included system drivers specific to the hospital setting, the powerlessness staff feel to change these, and the concept of cognitive access to food and meals. Within the accounts given by staff participants in the qualitative interviews, it became evident there is a pull between being able to provide person centred dementia care at mealtimes, and the system drivers creating a system centred care approach. The observation data supports the identification of tension between the system centred care approach, and the desire of staff to provide person-centred care at mealtimes. The interview findings support the observation findings in presented elements of care that inhibit or improve engagement in, and experience of, mealtimes in the acute hospital setting.

Chapter 8   Discussion and implications of all findings

8.1   Introduction

Exploring factors influencing engagement and experience at mealtimes for people with dementia in the acute hospital setting is a complex issue. Interrelating factors differ depending on each individual person. As such the research project required research methods which reflected the complexity of the issue. A combination of quantitative and qualitative methods, conducted with a combination of participant groups, added strength to addressing this complex phenomenon. The limitations of the methods used are considered in section 8.2 of this chapter.

This discussion chapter draws together the findings from all phases of data collection, and the published literature. Application of the findings to improve hospital mealtimes for people with dementia is discussed.

Overall, the findings support and enhance the existing knowledge and understanding of engagement in mealtimes presented through the literature review in Chapter 2. Previously published literature displayed three key influencing factors to the eating process for people with dementia: person factors, environmental factors, and organisational factors. The findings from the research project reflect these three factors in highlighting the importance of person-centred care (considering person factors) and the influence of system driven restrictions (organisational factors). Environmental factors contribute to these approaches, with positive or negative influences on engagement at mealtimes. The merging of quantitative and qualitative data in this research project showed that positive engagement and experiences at mealtimes were often directly related to person-centred, relational care, during meaningful mealtimes. A relational knowledge of participants' personal needs and preferences appeared to equip staff to provide the appropriate approach to mealtime care, meaningful to each individual. The impact of visiting family or friends appeared to influence mealtimes positively through introducing personal knowledge of an individual. On occasions where participants were observed to show signs of ill-being, or were disengaged from the eating process, mealtime processes appeared to be driven by the structure and priorities of a system driven care approach.

There was evidence throughout the findings of tensions between the desire to provide person-centred care, and the restraints of the hospital system. People with dementia display unique difficulties at mealtimes. The addition of system factors to a person already confused by a hospital admission appeared to be detrimental to providing positive mealtime care. The findings support

the work of Parke and Chappell (2010); people with dementia do not fit into the one-size fits all, system driven, approach of hospitals.

This research adds to our current understanding of influencers on the eating process in people with dementia in the acute hospital setting. The findings give rise to the novel concept of cognitive access to meals, which has not been discussed previously in the literature. Cognitive access here refers to breaking down cognitive barriers to enable a person to initiate and continue the cognitive processes required to engage in the eating process. Elements of the current hospital care and environment impact the ability of people with dementia to manage the cognitive load that a complex occupation, such as mealtimes, presents. For a person to cognitively access the eating process, the meal must be presented as a recognisable and meaningful occupation. The findings highlight areas of improving cognitive access through providing social mealtime environments, effective communication, and combining multi-sensory considerations.

The current understanding of eating and drinking for people with dementia is developed in the research findings through a novel, occupational perspective to the knowledge base. On the whole, meals were not times of meaningful occupation, anticipated, or cognitively accessible to people with dementia. Rather, they appeared to be isolating occasions where people remained at their bed side or in bed, sometimes in inappropriate eating positions. Rather than focusing on meals as a meaningful occupation, staff were easily distracted by other tasks such as medication provision or administration tasks. People with dementia were seen to experience institution driven occupational injustice because of this system-centred care approached (Durocher et al. 2013). Occupation was enabled through person-centred actions of staff, and in making meal times a meaningful occupation.

The research findings revealed limitations to promoting the meaningful nature of mealtimes and enabling physical and cognitive access to the occupation for people with dementia. The overall findings are applied to the Person-Environment-Occupation fit model (Law et al. 1996), presented at the end of this chapter. The Person-Environment-Occupation model draws together the findings, and previously published literature. It presents mealtimes for people with dementia in the acute hospital setting from an occupational perspective. The model is dynamic, rather than static or linear. It can be used as a visual resource to show how different aspects of the hospital system and environment, and the meaningful mealtime occupation, can be adapted to improve meals for people with dementia. In the model, the system drivers are considered to be part of the hospital environment. The model shows how the system-driven environment, when detracting from meaningful mealtimes and person-centred approaches, reduces occupational performance, in this instance engagement in the eating process.

The following chapter discusses enabling meaningful mealtimes through person-centred, relational care. Person-centred care and system-centred care are introduced as individual concepts, then the tension between the two is discussed. Both are presented as concepts that originate outside the study of mealtimes, but are applied to mealtimes supported by the findings of this research project. Cognitive access is then discussed as a new theory, which can be applied when meals are encouraged as a meaningful occupation.

8.2   Person-centred care

The concept of patient-centred care is not a new concept to the health service. For decades health professionals have been trained and encouraged to provide care which is centred on a patient's needs and preferences (Tolson et al. 1999; McCormack 2004). Common themes of patient-centred care are: informing and involving patients in decisions, respecting patient preferences, treating patients with dignity, allowing access to care, and ensuring continuity of care (Robb and Seddon 2006). Placing the person at the centre of care goes beyond meeting a patient's immediate needs to approaching them as a person. There has been an increased drive to provide physical care for people with dementia in a person-centred way, to deliver the best outcomes. Kitwood (1997) introduces personhood as: "a standing bestowed upon one human being by others in the context of a relationship and social being. It implies recognition, respect and trust" (Kitwood 1997. p.8). Person-centred care requires the health system to go beyond just involving people in decisions, or respecting their preferences, but includes the need to understand and enter into a relationship with the person. To understand the provision of person-centred care further, the concept of the person must first be defined (McCormack 2004).

From an institutional perspective, a person is simply a singular of people; people who can be conformed to a system led by rules and boundaries, which serve the objectives of the organisation (Higgs et al. 1992; McCormack 2004). The meaning of a person exceeds this narrow definition. Dewing (2008) draws on the work of past discussions (Quintin 1973; Kitwood 1997) and summarises what being a person means:

- Having distinctiveness and autonomy.
- Combining spiritual, social and psychological elements of being.
- Being dynamic, ever developing, not just one state or status.
- Being relational – having the capacity for communication and feeling, influenced by interpersonal relationships.
- Having the ability to feel, perceive and experience.

- Having a fundamental need for love, inclusion, attachment, comfort, identity and occupation.

To provide care for people with dementia in a person-centred manner all these aspects of a person must be considered, and every effort made to meet basic human needs. As Dewing (2008 p.7) illustrates: *"…despite many losses in function and capacity, persons with dementia do not lose their essential non-cognitive attributes of humanity"*.

The research presented system based priorities and organisational barriers, which inhibit this person-centred approach to dementia care. Limited staff time and resources lead to ward staff attending to other priorities such as medication rounds, taking physical observations, or administration tasks. Nolan et al. (2004) go as far as to say that true person-centred care, that is maintaining a person's autonomy and personhood, is not possible within the system-led context of the hospital environment. The concept of relationship-centred, or relational care, emerges through the realisation of the complexity of providing true person-centred care in the hospital setting (Nolan et al. 2004). To respect personhood relationship is central, the person does not exist without relationship (Kitwood 1997; Dewing 2008).

The Fundamentals of Care Framework for nursing care, presented by Kitson (2018) (Figure 12) has the nurse-patient relationship as central to providing good care. Within that relationship, trust is developed, helping the person being cared for to engage fully in their care. The nurse gets to know the person under their care and so anticipates needs, focusing their attention on the area of care most needed. Integration of a person's relational, physical and psychosocial needs are considered fundamental to providing good nursing care (Kitson 2018).
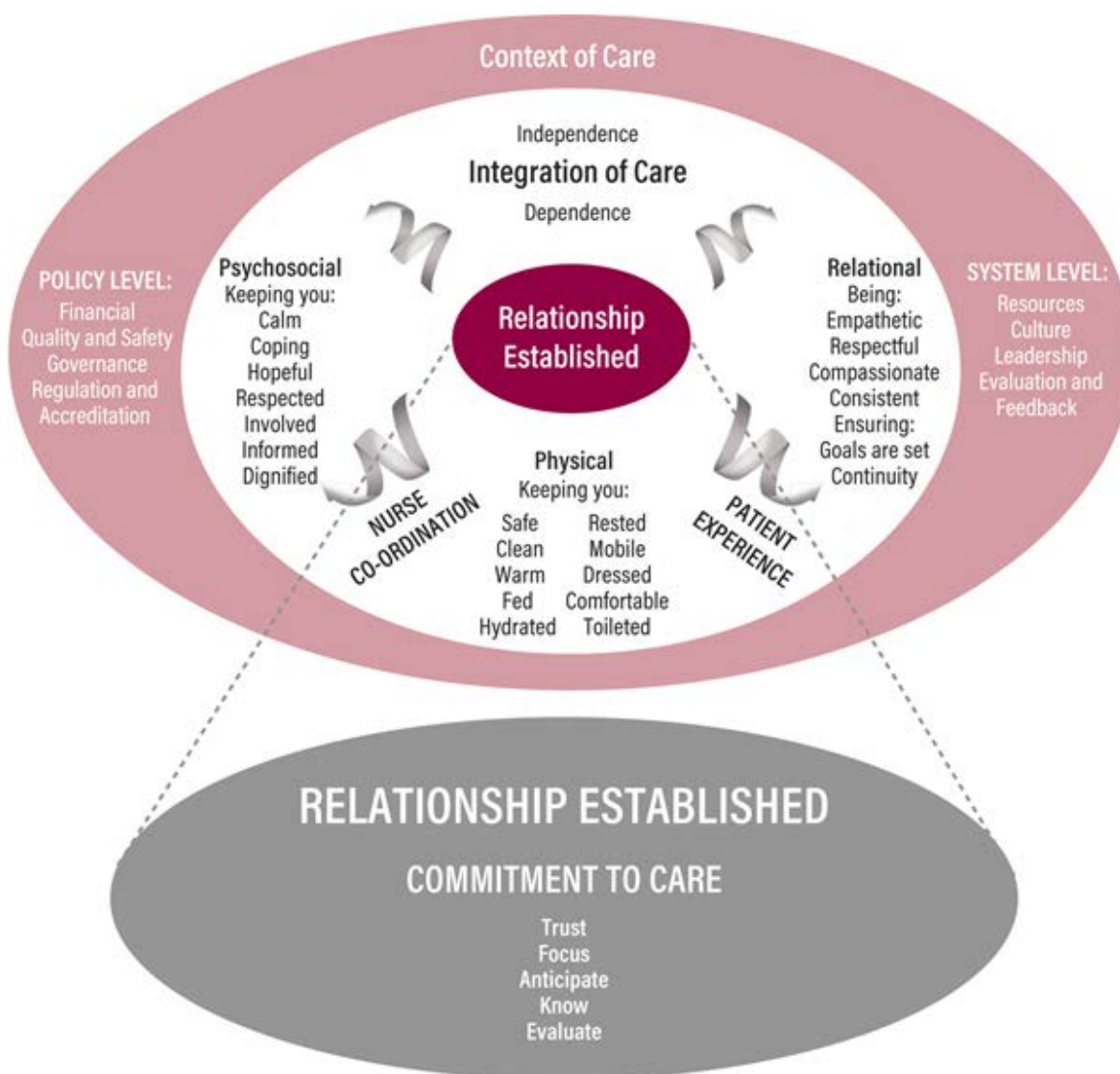
Figure 12: The Fundamentals of Care Framework

The limitations in providing truly person-centred care has been attributed partly to the failure to capture interdependencies and relationships between all subjects involved in the care (Adams and Gardiner 2005). The application of these principles, displayed in the Fundamentals of Care Framework, was clearly seen in the research findings through the value of visitors with their personal knowledge and relationship to participants.

Adams and Gardiner (2005) introduce the concepts of dementia care triads, which involve the person with dementia, their family or carers, and the ward staff in providing care. The Australian Commission on Safety and Quality in Health Care (2011) endorse this idea in stating a person-centred approach to care also requires consideration of the staff feeling cared for. This increases staff members' capacity to care effectively. Within the interviews, nursing staff participants expressed feelings of powerlessness and not being cared for themselves. The burden of the

expectations of the systems impacts their ability to provide positive mealtime care to people with dementia (Hammar et al. 2016). The pressures to complete tasks within a certain time, and the priority of other tasks appeared to be factors influencing the staff ability to provide person-centred care. Staff suggested that being able to work in relationship with participants and their families could positively influence engagement in the meal.

There is a risk within the care system that two out of the three subjects in the dementia care triad could form an alliance and exclude the other. This is a particular risk for people with dementia as their cognitive impairment may reduce their own input into the care triad (Adams and Gardiner 2005). The research findings highlighted the importance of effective communication and liaison with family and visitors who knew the patient well to ensure good relational care. This reduces the risk of exclusion of the person with dementia from decisions.

For care to be truly person-centred, an interdependent, relational approach needs to be taken to ensure all subjects experience security, belonging, continuity and consistency, achievement, and significance (Nolan et al. 2004). This includes all subjects in the dementia care triad: the person, the family or carers, and the staff involved in supporting care (Nolan et al. 2004; Adams and Gardiner 2005). The research findings endorse the importance of all elements of the dementia care triad being involved in mealtime care. The system-driven, task-centred nature of the hospital setting appeared to inhibit the appropriate relational approach needed to improve mealtimes for people with dementia.

8.3   System-centred care

The research findings, portraying the pull between person-centred and system-centred care approaches at mealtimes are supported by findings from other published studies, outside of the hospital setting (Hung and Chaudhury 2011; Gilmore-Bykovskyi 2015; Hammar et al. 2016; Lea et al. 2017). Rather than promoting independence and choice during the meal processes, the structure of the hospital system creates functional dependence (Holmes 2008; Ullrich et al. 2014). Poor nutritional intake in hospital can be a result of impaired function, and has been described as an iatrogenic condition (Graf 2006; Holmes 2008).

When claiming lack of engagement in mealtimes as an iatrogenic problem, it is important not to lay the blame on a group of people, but to consider further the context in which nutritional care is being provided (Dickinson et al. 2008). As observed in the research findings, hospital care has been described as having a 'one size fits all' approach (Parke and Chappell 2010) . The individual needs of people with dementia often did not fit into the care typically provided by the institutional system.

Chapter 8

Higgs et al. (1992) describe the institutional nature of older person's acute medical wards using Goffman's institutionalisation theory:

- All aspects of life (sleep, work, play) are carried out in the same place, under the same authority.
- Each aspect of life is carried out alongside others who are all subject to the same conditions.
- Daily life is tightly scheduled by a system of formal rules, which are there to fulfil the objectives of the institution.

The findings presented in this thesis give evidence that older person's acute medical wards are an institutional setting as described by Goffman (Higgs et al. 1992). All aspects of life are carried out in the same place under the authority of the ward staff. The routine and structure of the day was observed and described as being the same for everybody, despite individual patient preferences. Patients in acute hospital wards have been known to feel a camaraderie with other patients in the bay because of their identical situations (Gladman et al. 2012; Goldberg et al. 2014). The hospital system is run by bureaucratic rules and regulations which have the potential to reduce autonomy and independence (Parke et al. 2014).

The hospital routine and provision of care are ruled by a system of formalities and the need to fulfil the objectives of the hospital setting. There is a drive to fulfil system objectives, rather than individual patient objectives for care. Goffman describes institutionalisation as an intentional attempt to remove people's individuality. Higgs et al. (1992) suggest the loss of individuality in the care of the older person in hospital is in fact unintended, with the objectives of the hospital, in theory, primarily driven by the needs of the patients.

The complexity of describing a hospital setting completely as an institution described in Goffman's terms, lays in what it means to fulfil the objectives of the institution. The objective of the hospital setting is broad and ever changing but, in short, is a place that serves the community as a central point where people come to be treated for an illness, or have their long-term illnesses managed (World Health Organization 2001a). The objective of nursing staff is to meet physical needs such as washing, going to the toilet, assisting with eating, and administering medication (Goldberg et al. 2014). Historically, it has been identified that meeting the physical needs supersedes the acknowledgement of psychological or cognitive needs until these become problematic to staff (Tolson et al. 1999). Research into nursing satisfaction goes as far as claiming that putting the system-centred approach in health care above personalised care, is a reason for nursing staff leaving the profession (Kitson 2018).

In more recent years the concepts of patient safety, patient satisfaction, and patient rights have started a major shift in the overall objectives and expectations of hospital care provision (World Health Organization 2001a). Hospitals started as a bureaucratic hierarchy of professionals, and a clear power imbalance between professional and patient. Today the goal is shifting towards a health service governed by integration of professional skills and partnership with patients (World Health Organization 2001a; Kitson 2018). National drivers for health care have become increasingly driven by promoting care to meet the needs of individuals. Despite this shift, and the changing expectations of hospital care, there are still signs of institutionalisation and the fulfilment of the institution's objectives superseding person-centred care. There is recognition of the need for person-centred care, but limited evidence that this is being implemented in daily practice (Kitson 2018). This may be due to scarce health care resources and the cost implications of adapting services to meet the needs of individual preferences. The interview findings showed that staff strive to provide person-centred care, but there is an inevitable compromise due to resource allocation. Still, the system-driven culture means that objectives of staff appear to be driven by task-centred practice, and a "checklist mentality" (Kitson 2018, p.100) also applied to mealtimes (Goldberg et al. 2014).

The timings of the food and drink often fitted around the structure of the hospital system, kitchen staff coming to collect plates and nurses needing to do other tasks with a higher priority. There is much work to be done to improve mealtimes for people with dementia so that they are centred round the needs and preferences of the patient rather than the objectives of the hospital system. Golberg et al. (2014) reveal how the drive of the institution to meet the physical needs of people in their care can be to the detriment of recognising and addressing psychological and cognitive needs. The task driven care, promoted by the system and its goals, mean staff focus on their physical care tasks and avoid the more challenging needs of psychological and cognitive symptoms (Goldberg et al 2014; Ullrich et al. 2014).

This system-centred approach to care is not just an issue in the hospitals in the research presented in this thesis, but is a global phenomenon (Borbasi et al. 2006; Ullrich et al. 2014; Ottrey et al. 2017; Conchin and Carey 2008). There are clear similarities between the findings of this research and the other research projects, which describe specific restraints of the system in providing person-centred, relational care at mealtimes. Temporal factors can create constraints and interruptions of mealtime care, including the dictatorship and pressure of time and lack of resources (Borbasi et al. 2006; Dickinson et al. 2007; Goldberg et al. 2014; Ullrich et al. 2014). There is a lack of clarity around the responsibilities and expectations of mealtime care for specific professions, which can disrupt optimum mealtime care provision (Dickinson et al. 2007; Ottrey et al. 2017). These topics will be discussed in detail in the next section, along with factors identified

in the research and supported by existing literature that positively influence person-centred care: family/carer involvement, and meaningful mealtimes.

8.4   System-centred verses person centred

There is a longstanding discussion in relation to system-centred versus person-centred care, not just with regard to mealtimes for people with dementia, but in hospital care for older people in general. It is not dissimilar to the discussion from Schnell and Kayser-Jones (1999) of empathic versus task driven and mechanistic care. They emphasise the necessity of compassionate understanding of another person's experience to be able to provide good care (Schnell and Kayser-Jones 1999).

The findings from the research present mealtimes in older person's acute medical wards as a paradoxical phenomenon, in some ways a highly anticipated break in the routines of the day (Ottrey et al. 2017). They are ingrained as a temporal structure in the hospital routine, and not meaningful to the individual. They are a continuation to the flow and pressures of hospital routines. They appear to be another task to be ticked off in the long list of tasks falling into the caring remit of the ward staff. Task-centred, system-driven, mealtimes appeared to impact on engagement and experience of mealtimes for people with dementia in particular. This is in line with other published research, which highlights how task-centred care was driven by inflexible timings of hospital systems (Gilmore-Bykovski et al. 2015; Hammar et al. 2016; Lea et al. 2017).

The impact of task-centred versus person-centred care at mealtimes was explored by Gilmore-Bykovskyi et al. (2015) who found a 19 to 21% likelihood of negative eating behaviours following a task-centred caregiver action. In comparison, there was only a 2% likelihood following a person-centred caregiver action. Task-centred interactions in the study presented by Gailmore-Bykovski et al. (2015) included items such as outpacing the participant, ignoring expressed needs, not giving appropriate choice, all of which were identified in the research project presented in this thesis. On the other hand, person-centred care included giving choice, seeking the person with dementia's opinion and non-verbal communication like giving eye contact. The skills and knowledge needed to provide truly person-centred care, where the individual needs of people with dementia are met, is still underestimated, and the research findings support the concept that system priorities appear to continue to take precedence (Dewing and Dijk 2016).

A recent study by Bridges et al. (2018) included observations of quality of interaction between staff and patients. Although 78% of interactions were positive, 56% were focused on care tasks, compared to 22% which included an element of social interaction beyond the task. The study by Bridges et al. (2018) was not exclusive to mealtimes, and did not consider the impact of task-

centred care on engagement in occupation, however it gives further evidence to the task-centred culture of care which appears prevalent in hospital care for older people. The importance placed on other scheduled care tasks, such as medication administration and taking physical observations, was an evident disruption to mealtimes in the research findings presented in this thesis.

Distractions from, and disruptions to, mealtimes through tasks, such as medication administration and taking physical observations, were not uncommon in the observations in phase 1 of the research project. Mealtimes being disturbed by hospital tasks was not an unexpected observation; other studies presented similar findings (Barnes et al. 2013; Goldberg et al. 2014). The expectation of the system to complete tasks at and by certain times was an evident burden described by staff in the interviews conducted for the research presented in this thesis. Staff interview participants expressed the desire to give person-centred care through allowing time and the necessary attention required for each individual at mealtimes. However, the reality was rushed mealtimes, patients being told to wait, more than one person being physically assisted to eat at one time, and an absence of qualified nursing staff to support with mealtime care. The cross-referencing of quantitative data gave evidence to these elements of hospital mealtimes having a negative impact on engagement and experience of meals for observed participants.

In contrast, throughout the research person-centred care approaches were observed and described as positively influencing engagement and experience at mealtimes. Positive engagement and well-being were observed when: participant's individual needs were listened to, care included personal and reminiscent social interaction beyond the task at hand, participant preferences and norms were considered, the meal was made meaningful to the individual, and communication or assistance appropriate to each individual were used. Mealtimes were often enhanced by the presence of familiar visitors. These findings supported previously published literature that presented factors influencing engagement in the eating process (McGillvray and Marland 1999; Lin et al. 2010; Nell et al. 2016; Murphy et al. 2017). All report the importance of individualised approaches to care.

The unique difficulties that people with dementia experience add to well-documented difficulties with providing nutritional care for older people in hospital (Watson and Deary 1997; Borbasi et al. 2006; Geary 2014). The research findings support this in recognising the importance of familiarity and normality and appropriate methods of communication to overcome cognitive barriers, and reduce sensory disruptions from the environment. Yet, issues at mealtimes were often due to the system, not necessarily the person with dementia. Interview participants considered focusing on

the needs of the person rather than the expectations of the system as best practice for mealtimes for people with dementia.

Ottrey et al. (2017) introduce a model, seen in Figure 13, showing the tensions between system-centred and person-centred care at mealtimes in medical wards for older people. In the model, "System" relates to hospital and food service systems, systematic approaches, system expectations and performance. Teamwork, communication and problem-solving are described as actions and interactions of staff, visitors and volunteers observed by Ottrey et al (2017). These support the findings presented in this thesis. As care triad relationships and effective communication are endorsed or neglected for various reasons, care becomes more system or person-centred.
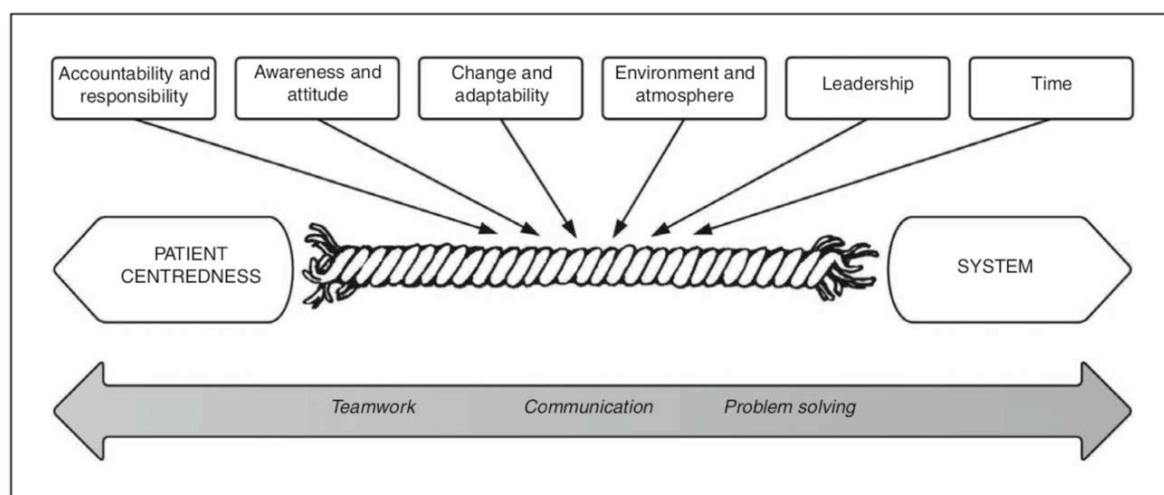
Figure 13: Mealtime complexity model illustrating tension between patient centredness and system (Ottrey et al. 2017)

Throughout the interview findings a person-centred, relational, approach to care was considered important in positively influencing mealtimes. Using person-centred, relational care to improve engagement in, and experience of, mealtimes was highlighted through two key areas: family and carer involvement, and making mealtimes meaningful to the individual. These are discussed, with the factors identified as enforcing system-centred care.

8.4.1   Family/carer involvement to influence person-centred care

The research findings and existing literature highlight the invaluable contribution of visiting friends or family to the provision of person-centred mealtime care. When a person with dementia

has experienced the confusion of a dramatic change in environment, combined with an acute illness or trauma, familiar people with an established relationship of trust are the best people to have around (Borbasi et al. 2006; Chang and Roberts 2011). Limited time and staff resources may create difficulties for ward staff to establish this necessary relationship (Hung and Chaudhury 2011). The interview participants suggested family members supporting mealtimes is beneficial as they have time to give full attention to the person and already have an established trusting relationship. This has positive outcomes for eating behaviour and intake (Murphy et al. 2017; Kitson 2018).

Providing person-centred mealtime care for people with dementia must include a family-centred care approach (Dubé et al. 2007; Bamm and Rosenbaum 2008; Lin et al. 2010). The concept of family-centred care started in the paediatric health care setting, but is being explored as a concept that can be applied to wider health care (Bamm and Rosenbaum 2008; Mackie et al. 2018). The application to adult or older person's medical care may create more complexities. Families may not be so constant, or present, in an older person's life as in a child's. There is still little research into the effectiveness of family-centred care outside of the paediatric setting (Mackie et al. 2018). The research findings evidence the potential scope for further research into using family-centred care approach to improve engagement in, and experience of, mealtimes for people with dementia in acute hospital wards for older people.

Health care professionals who were interviewed highlighted the value of family visitors, but mainly through anecdotal examples. Mackie et al. (2018) add depth to the research findings, recognising that families may differ with the type and level of involvement they are able, or want, to provide. Bamm and Rosenbaum (2008) summarise some important features of including family carers in health care. These principles can be applied to older person's medical wards based on the research findings.

1. Families are considered experts in what helps and hurts the patient.
2. Families are recognised as central to the life of the patient.
3. Families are indispensable, invaluable partners for policy makers, helping professionals, and advocates. Families bring expertise to the care.
4. Families are not called, or treated as, dependent clients. They are citizens and equals with whom health professionals collaborate.

These principles emphasise how valuable family, if present, can be in assisting health professionals to provide mealtime care which is centred round the needs, values and preferences of the person with dementia.

Eating with a person who has a previously established a trusting relationship has been identified as important in encouraging engagement in the eating process with regard to people who do not have dementia. Social interactions with family and friends have a stronger effect in facilitating meals than with strangers (Dubé et al. 2007). Cruwys et al. (2015) discuss social modelling of eating, and its influence on food intake. They conclude sharing a meal with a familiar person is likely to impact food intake positively. This could be due to pre-established norms of eating with the familiar person, and an acceptance that they have the right to set boundaries on how much is or is not eaten (Cruwys et al. 2015).

Relating the research findings to social modelling theory provides the potential for practical applications to mealtimes for people with dementia in hospital. Visitors eating the same food, at the same time, as the patient may encourage the patient to engage in the eating process. Kaisari and Higgs (2015) suggest that other confounding factors of meal companions, such as age or gender, may also impact the level of food intake with social modelling, and that familiarity may not have a significant difference. These studies were conducted with young adults. With the knowledge of the importance of familiarity with people with dementia (Lin et al. 2010) the research findings display scope for further research into the use of social modelling of food intake with family or carers in the hospital setting.

A key element of existing family-centred care programmes appears to be a constant and effective communication between the family and the health professionals involved in providing care (Bamm and Rosenbaum 2008; Mackie et al. 2018). This was clearly illustrated in examples given by staff in the research interviews. Family bringing in favourite foods, or informing staff of preferences and routines, positively influenced the ability of the person with dementia to engage in the eating process. Collaboration between visiting family or carers, and the health professionals providing mealtime support, is essential for enabling engagement in meaningful mealtimes (Adams and Gardiner 2005).

8.4.2 Adding meaning to make mealtimes person-centred

Meaningful mealtimes are reflective of person-centred care improving mealtimes for people with dementia. They add individual meaning to the meal as a recognised, familiar, occupation. Meals are meaningful in different ways to different people, as an occupation which is experienced globally in different contexts throughout their lives (Fjellström 2004; Bundgaard 2005). It is widely recognised that when a meal is meaningful to an individual it can enable a person to experience normality, which is pertinent to people with dementia in the hospital environment (Bundgaard 2005; Genoe et al. 2010). Overlooking the cultural and social elements of eating, and the normal

routines of an individual, can have detrimental consequences to engagement in eating during the meal (Fjellström 2004). Meals as a meaningful occupation is a concept well understood in the Occupational Therapy profession.

In order to understand how to make mealtimes meaningful in hospital, there must first be an understanding of meaningful occupation as a concept, which is the underpinning philosophy of Occupational Therapy as a profession. Wilcock (1998) describes occupation as a synthesis of doing, being and becoming. "Doing" is a common way of described how people engage in the activities which make up daily life. The true nature of occupation is beyond doing, it is fundamentally about the expression of self: "being" (Wilcock 1998). Occupation becomes meaningful to a person through bringing their self into it, through individuality, distinctiveness, experience, and relationship (Fjellström 2004; Dewing 2008). "Becoming" adds a sense of future to engaging in occupation; there is potential for growth and putting to use abilities not currently in use (Wilcock 1998).

Bundgaard (2005) supports this in describing the meaning of occupation as something that builds identity, holds value, depicts personal values, and has purpose or intention. Bigelius et al. (2010) develop the concept of value in meaningful occupation by describing concrete value, symbolic value and self-reward value. For an occupation to be meaningful it signifies something for a person, has immediate, visible value, and brings satisfaction and achievement to the doer (Bigelius et al. 2010). For a mealtime to be meaningful beyond the simplicity of nutritional intake through "doing" there must also be elements of "being" and "becoming". A meaningful, valuable mealtime must possess all these elements, and enable people with dementia to express their abilities and identity (Fjellström 2004).

Meals are a meaningful occupation in normal daily life (Fjellström 2004). They have been known to provide purpose, structure, connection to others, value and the opportunity to value others, and opportunity to express identity (Bundgaard 2005; Genoe et al. 2010). There is risk in a system-driven hospital setting that mealtimes are not valued as meaningful occupations, but rather are another task of "doing" to gain nutritional intake. In the findings in this research project mealtimes appeared to be treated as acts of "doing" the eating process, as part of the hospital routine.

Enabling engagement in mealtimes where "being" and "becoming" are promoted beyond "doing", allows expression of individual identity and value, and can be viewed as a matter of occupational justice (Durocher et al. 2013). Participants were observed to move from disengagement and ill-being, to focused engagement and observable enjoyment food, when they were enabled to "be" and "become" through these positive mealtimes and were not expected to fit into the 'one size

fits all' hospital system (Parke and Chappell 2010). The published literature supports the research findings in recognising the value of expression of identity and individuality. It does this through recognising individual preferences, reminiscent food related conversation, and considering personal cultural significance of food, in improving engagement in mealtimes for people with dementia (Hanssen and Kuven 2016; Lea et al. 2017). A lack of understanding of the value of meaningful mealtimes as times of "being" and "becoming" for an individual was evident in the task-centred approach to mealtime care.

The system structure of professionals within the hospitals where the research project was conducted, meant Occupational Therapists were off the wards at mealtimes, to honour protected mealtime policies. Creating meaningful mealtimes, enhancing person-centred care, has the potential to be within the remit of the Occupational Therapy role in hospitals (Timmer et al. 2015). Both nursing staff and Occupational Therapists could work together to incorporate elements of person-centred care and meaningful mealtimes into the older person's acute medical wards. Having Occupational Therapy involvement could be an improvement for mealtimes for people with dementia in hospitals.

Part of creating a meaningful mealtime includes creating a social environment. Occupational Therapists who were interviewed as part of this research project described involvement in mealtimes in other settings, such as stroke wards, through social occasions such as breakfast and lunch clubs, or an afternoon tea. The social element of the meal is not just about community or normality, but also about expressing identity and individuality, and having fundamental psychological needs met through conversations with others (Kitwood 1997; Bundgaard 2005). Isolated mealtimes at bedsides, with a lack of social interaction, have been identified as an antecedent to feeding difficulties (Chang and Roberts 2011). Eating alone negates the opportunity for social benefits of eating; meals have been known to take longer, with greater food intake when eaten in company (Warde and Yates 2017). The use of day rooms or sitting at tables has the potential to make mealtimes more recognisable and meaningful to people with dementia.

As well as making mealtimes person-centred, meaningful mealtimes can contribute to breaking down cognitive barriers to engagement and create a positive experience of mealtimes. Familiarity of objects or people, making autonomous choices, a normal social context, and stimulating the senses, can all give a mealtime meaning (Hannam 1997; Bundgaard 2005). Meaningful mealtimes may reduce the cognitive load required to process an unfamiliar situation.

8.4.3   Temporal factors of system-centred care

One factor that inhibits meaningful, person-centred mealtimes, is limited time resource. In the model of mealtime complexity (Ottrey et al. 2017) (Figure 13) introduces "time" as an element which influences the tension between person and system-centred care. The research findings supported this in that the temporal restraints on the hospital care create a system in which person-centred, relational care was considered difficult to establish or maintain. Organisational aspects of meals, routines and timings, and the level of staff resources and time, were all identified as impacting experiences and engagement in mealtimes, supported by the published literature (Dickinson et al. 2007; Heaven et al. 2013).

The impact of routines and timings goes beyond the pressure on staff resources for the duration of the mealtimes. The timings of the food delivery throughout the day is institutionally driven, with food choices being made at times that fit in with the organisational needs and routines (Murray 2006). Typically, the structure of the modern hospital institution requires food choices to be made one to two days in advance of a particular mealtime (Heaven et al. 2013), exemplified in the hospitals in which the research was conducted. This was seen to have adverse effects for some participants in the research. They would forget what they had ordered, would receive food ordered for the patient in the bed prior to them so that it did not match their preferences. They also expressed confusion when a different meal was delivered to what their most recent order was.

Lack of time available to complete mealtimes, and the need to rush, was a significant theme emerging from the interview data, clearly a relevant and central issue for staff. Mealtimes have been known to be experienced more positively, and people with dementia engage better, when more time was allowed (Chang and Roberts 2011). The use of mealtime volunteers was suggested by interview participants as an improvement in allowing more time for individual patients at mealtimes. Volunteers have the potential to be used to address the scarcity of time and staff resources, freeing staff to meet the expectations of their own roles. In a literature review of studies exploring the role of volunteers in dementia care, staff identified volunteers as extra bodies to observe and support on the ward (Hall et al. 2017). Although not specific to mealtimes, volunteers have been identified by staff as of value in relation to helping their own work load (Hall et al. 2017).

Howson et al. (2018) explored the use of volunteers in relation to mealtimes in older people's care in an NHS hospital in England, the same setting as the research presented in this thesis. In the interviews conducted by Howson et al. (2018) staff, patients, and volunteers were in consensus in identifying that the competing priorities for nursing staff time reduced engagement

in the eating process at mealtimes. The volunteers were highly valued by staff and patients on the wards, releasing nursing time for other clinical tasks (Howson et al. 2018). They were not used just to provide assistance to eat meals, but also engaged in other meal process activities such as preparation for the meal.

In order to protect staff and patients from avoidable interruptions at meals time, the protected mealtime policy was suggested as a way of improving meals in the research presented in this thesis. Protected mealtimes is a nationally recognised policy, with various versions across NHS hospital Trusts, created as a way of setting boundaries on mealtimes to make nutritional care the priority of all staff during that time period. With protected mealtimes, interruptions should only occur when clinically relevant to improving care at that time (Murray 2006). Nursing staff interviewed for the research, however, still expressed other priorities distracting them and were observed to have lack of time available to support with mealtime care. Within the hospitals where the research project was conducted, the expectation was for only nursing and nursing support staff to remain on the wards at mealtimes. The guidance for Protected Mealtimes does not clarify which professions are to be included in providing mealtime care.

8.4.4 Expectations and responsibilities of different health professions influencing system-centred care

The boundaries, expectations and responsibilities placed on the different health professions have been seen to create barriers to multidisciplinary working. Individual professionals' awareness and attitudes towards their roles at mealtimes, could impact how people with dementia experience and receive care at mealtimes (Dickinson et al. 2007; Ross et al. 2011; Ottrey et al. 2017). Communication and collaboration between family or familiar visitors, health professionals and patients has been considered as potentially invaluable in improving mealtimes for people with dementia (Dubé et al. 2007; Bamm and Rosenbaum 2008). However, if professionals are unclear of their responsibility in mealtime care provision, this relationship is not effective. Francis (2013) states that nutrition and hydration must be considered the responsibility of all staff.

Each profession involved in the care of patients in hospital have boundaries to their skills and expected responsibilities. The variety of different health professionals involved in patient care creates a system made up of extensive multi-disciplinary skills. There is potential for the system to provide a comprehensive, multi-professional approach to improving mealtimes and creating individualised mealtime care plans. The reality observed and described in the research project presented in this thesis did not depict this. Rather than seeing value in their skills on offer to improve mealtimes, Allied Health Professionals described their own contribution as staying away

from the wards at mealtimes, because of Protected Mealtime policies, as in other interview studies (Ross et al. 2011). Each profession interviewed by Ross et al. (2011) expressed competing priorities by which they justify handing over the responsibility of mealtime to somebody else.

The interview findings highlighted the confusion as to whose responsibility mealtime care is, supported by other published literature (Dickinson et al. 2007; Ross et al. 2011). Various health professionals in the research interviews assumed mealtimes are a nursing responsibility. The professional standards of practice for nursing consolidates this assumption in stating fundamentals of care must be upheld, highlighting that nutrition and hydration, and people's physical needs are to be continually assessed and responded to (Nursing and Midwifery Council 2015). Despite this, there is a lack of clarity for nursing staff over their own understanding of their role in mealtime care (Xia and McCutcheon 2006). The interview data suggested nursing staff have become detached from the meal processes, passing responsibility of any difficulties in eating and drinking to Dietitians or Speech and Language Therapists. Other studies interviewing nursing staff support this in that nurses take responsibility for ongoing nutritional assessment, but the provision of care and assistance at mealtimes is delegated to Health Care Assistants (Dickinson et al. 2007). Other Registered Nurse responsibilities such as administering medications and administrative tasks may take priority when meeting people's physical needs while patients in hospital, as previously discussed (Ottrey et al. 2017). This appears to be subsequent to another attitude towards mealtime care; it is viewed as a non-skilled task (Ross et al. 2011; Heaven et al. 2013). Mealtime facilitation for people with dementia is clearly complex with the need for skilled assessment and interventions from a variety of professions (Dickinson et al. 2007)

Nolan et al. (2004) suggest that a multi-disciplinary approach goes beyond using the skills of each profession in creating strategies and interventions for improving care. A mutual respect and clear understanding of their own roles is also essential providing care that centres around the person (Nolan et al. 2004). In order to improve mealtimes for people with dementia different professions in the multi-disciplinary team need a clear understanding of their own role. Different professions need to work in a mutually respecting relationship with others to provide multi-domain care plans, centred on the needs of individual people in their care.

The profession that admitted potential for further input in the provision of assessment or intervention at mealtimes, recognising them as complex and meaningful occasions, were Occupational Therapists. As part of their role in maximising and enabling functional capabilities (Miller and Butin 2000), the Occupational Therapists interviewed acknowledged that their skills in assessment could potentially be used in mealtime care. Occupational Therapy involvement specifically in providing mealtime care for people with dementia in the acute hospital setting is

not recognised in the current literature or published research. Although the area of food provision on discharge is sometimes addressed in the initial assessment, Occupational Therapists would not typically be informed of patients with eating difficulties (Ross et al. 2011). This differs from other functional activities such as washing and dressing routines, and kitchen assessments which were focused on functional ability and food preparation rather than engagement in the eating process during mealtimes on the wards (Eyres and Unsworth 2005; Timmer et al. 2015).

When scrutinising the Occupational Therapy skills, and role in dementia care, it is left to be questioned why they assume their role is best met by leaving the ward at mealtimes. Their unique viewpoint of understanding mealtimes as meaningful occupations places them at the forefront of improving mealtimes for people with dementia in creating meaningful mealtime environments. Occupational Therapists have a unique set of skills in the assessment and adaptation of environmental factors, assessing and modifying functional activities, and identifying specific and complex components of activities through activity analysis (Miller and Butin 2000; Froleck-Clark et al. 2007). This is recognised in guidance for other conditions or settings such as post-stroke treatment (Perry and McLaren 2003). Even the National Institute for Health and Care Excellence guidelines for Dementia acknowledge the value of Occupational Therapy in supporting functional abilities for people with dementia (NICE, 2018). Yet there still appears a lack of understanding, even within the profession, of how this can be applied to mealtimes in the acute hospital setting.

Educational institutions need to take responsibility for health professionals to graduate with a firm understanding of their role in the provision of nutritional care (Kowanko et al. 1999; Xia and McCutcheon 2006; Ullrich et al. 2014). The system structures and expectations also need to be challenged to give all staff confidence to overcome systematic barriers, to contribute their knowledge and skills to improving mealtimes for people with dementia in acute hospitals.

Comparisons were made, in the research findings, with different care settings. In these instances staff groups who dismissed their responsibility for mealtime care in the older person's wards, reported their involvement in other settings, e.g. Occupational Therapists facilitating breakfast and lunch clubs on the stroke wards. In the interview findings presented in this thesis, staff recognised a need for change in order to improve mealtimes for people with dementia.

8.4.5 Conclusion to system-centred versus person-centred care

It is recognised that there are many organisational and inter-professional issues that challenge person-centred care (McCormack 2004). Ottrey et al. (2017), in their model of mealtime complexities, present the disharmonious relationship between the system drivers and the desire to promote person-centred care at mealtimes. Person-centred care could be seen as more time

consuming (Goldberg et al. 2014) and therefore a challenge in a time pressured hospital environment. Nursing staff are known to complete other pressing tasks at mealtimes, with nutritional care sometimes taking second place. They have expressed that the pressures of the timings of the system drive them to this, and it is not their preferred way of providing the best care, but they too are constrained by the system (Ross et al. 2011). In a study by Dickenson et al. (2007) staff expressed the organisational influences on mealtimes as beyond their control. The change for improvement of meals is recognised as needing to come from the hospital objectives and systems in driving a culture shift.

> *"in order to transform mealtime care it is necessary to change the ward culture."*
> *(Dickinson et al. 2007, p273).*

In order to improve mealtimes changes need to be made to the system structures and culture (Conchin and Carey 2018). The research findings, supported by other published literature, highlight the detrimental effect of system drivers on nutritional care for people with dementia. Care at mealtimes needs to shift from being driven by the hospital systems, to being focused on individuals, with a culture of enabling and independence. The complexity of mealtime care for people with dementia needs to be acknowledged (Dickinson et al. 2007; Heaven et al. 2013).

The key issues identified in system-centred care at mealtimes lie in the institutional nature of the setting. There is a lack of change in the environment at mealtimes as all activities are happening in the same place. Additionally, all the people in the institution are subject to the same rules and routines (Higgs et al. 1992). Therefore, mealtimes may not be meaningful occasions for individuals and people lack autonomy in the mealtime processes. This does not match the drive to meet individual needs and preferences which are recognised to be indicators for best practice in provided adequate nutritional care (Department of Health 2010; Nursing and Midwifery Council 2015). Staff strive for person-centred mealtime care, but are challenged by a complex system of alternative priorities so are often left feeling powerless to change (Ross et al. 2011; Ottrey et al. 2017).

Visitors were considered to be essential in providing the care staff may feel powerless to provide. The presence of visitors could counteract some system restraints placed on staff, making meals meaningful through their presence, their knowledge of the person and their time available to support the meal. The presence of visitors, or the information they could provide about the person with dementia, was also considered useful in addressing the cognitive barriers to people with dementia accessing and engaging in mealtimes.

8.5   Cognitive access

Cognitive barriers to accessing meals include, reduced ability to initiate the meal, short term memory loss and reduced attention, disorientation, reduced ability to make decisions, reduced executive functioning skills, impaired visual and spatial perception, and not recognising the mealtime (Chang 2012; Edahiro et al. 2012; Geary 2014; Liu et al. 2016). Improving cognitive access to meals means breaking down any cognitive barriers to engagement to allow every opportunity for an individual to process, understand and respond to the cognitive stimulation around them. The research findings portrayed that reduced cognitive access resulted in occupational deprivation. People were unable to access the occupation of eating due to environmental, and organisational factors, outside their control (Durocher et al. 2013).

Efforts have been made to improve occupational performance at mealtimes through interventions and strategies to overcome the lack of physical access to food (Whear et al. 2014; Bunn et al. 2016). Geary (2014) supports the research presented in this thesis in describing reasons for lack of physical access to food in hospitals. These are described as: not being able to reach the tray of food, not having physical strength to feed themselves, or not having the food laid out and introduced to the patient, in a way which stimulates initiation of the activity of eating. Geary (2014) goes on to highlight the importance of breaking down cognitive barriers:

> *"The issue with this is that for the most part, staff are only assigned to feed the immobile, bed bound and unresponsive patient who is easy to identify as confused. But what about the little elderly woman in the next room over who is watching television calmly in her room and looks content, but does not touch her meal? The fact that she is not eating does not mean that she is not hungry or does not want to. The woman may actually have dementia and not even realise it is mealtime or that the tray is in front of her."* (Geary 2014) p.24

The literature outlining current interventions describe studies using cognition as an outcome of mealtime interventions. It does not identify interventions which aim to reduce the cognitive load of mealtimes (Whear et al. 2014; Bunn et al. 2016). Neglecting the cognitive needs of people with dementia may be interpreted as institutionalised occupational injustice, or occupational apartheid, as cognitive barriers to engagement are not addressed (Durocher et al. 2013). In order to ensure access to the meaningful occupation of mealtimes, interventions are required to reduce the cognitive load of eating.

There are two main categories of cognitive load: intrinsic cognitive load and extraneous cognitive load (Paas et al. 2003). Intrinsic cognitive load of an activity or situation refers to the demands

placed on the cognitive systems, such as use of memory, in order to make sense of the situation or complete a functional task (Paas et al. 2003). The intrinsic cognitive load increases as dementia progresses; the less intrinsic ability to process and understand, the more effort it will be to make sense of the surroundings. The research findings and published literature support this. The hospital environment was described by interview participants as a noisy, busy, environment. Published literature exploring factors influencing eating and drinking in dementia showed that crowded, noisy eating environments were detrimental to eating (Chang and Roberts 2008b; Chang et al. 2017). In the hospital environment is was apparent that more effort would be required from somebody with a decreased cognitive ability, to make sense of the surroundings and engage in the eating process.

Extraneous cognitive load refers to elements of the environment which create a need for internal cognitive structures to work, in order to understand and process the surroundings (Paas et al. 2003). If intrinsic and extrinsic cognitive loads are high, a person will have reduced ability to learn, understand and function. In addition to the meal process being complex and creating increased cognitive load, the system driven mealtime processes in the hospital add unnecessary extraneous cognitive load to the activity. Paas et al. (2003) claim that when the intrinsic cognitive load cannot be managed by an individual, the task must be simplified and every effort made to reduce the extraneous load. As cognitive load decreases through person, environment and system considerations, cognitive access to the meal may increase. The research findings highlighted times when cognitive access may be improved through social mealtimes, appropriate communication techniques as well as using various sensory cues through interactions and the environment to suggest a meaningful mealtime.

8.5.1 Social aspects of eating can improve cognitive access

A part of making a mealtime cognitively accessible is giving it meaning, in that it is recognisable as a normal meaningful occupation. A meaningful mealtime environment can be partly supported through eating with others. A social, family-style meal environment has been recognised as improving meal experience and food intake in hospitals and long term care (Nijs et al. 2006; Wright et al. 2006; Goldberg et al. 2014; Nell et al. 2016). A recognisable meal environment reduces cognitive load in that the familiarity of the situation immediately indicates the mealtime as an activity. The social element of eating with others has been known to introduce the potential mimicking of appropriate eating behaviours (Nell et al. 2016).

Cruwys et al. (2015) reviewed 69 research papers, concluding that social influences and social modelling of eating impacts food choices and intake in people without dementia. Modelling of food intake has been found to be a robust phenomenon (Kaisari and Higgs 2015). This was identified through the research findings in examples of positive engagement in eating observed and described in conjunction with positive social environments. In the research observations, even with strangers, for example other patient's visitors or other patients, participants followed social modelling of eating, which was also identified in the review by Cruwys et al. (2105). Normative theory, applied to social eating situations, suggests that people will use the intake of others to influence their own intake (Kaisari and Higgs 2015). It is suggested that seeing others act stimulates the motor programming for a person to imitate that action; when applied to eating this could mean people might imitate the eating process automatically regardless of their own hunger or desire (Kaisari and Higgs 2015). The automatic, unconscious mimicking of other's actions during eating means that people are more likely to reach for food straight after seeing someone else do it (Cruwys et al. 2015). The automatic, unconscious mimicry of actions gives evidence to the fact that the social element of eating could help reduce the cognitive barriers to eating in the isolating mealtimes identified by the interview participants in the research presented in this thesis.

Throughout the research findings it was evident that patients were always assisted to make their food choices either hours or the day before a set meal and were generally sat by the bedside alone when choices were offered. Cruwys et al. (2015) conclude that people's food intake and choices largely depend on social factors and social modelling. The implication is that normative theory and modelling could also be applied to the hospital setting, if the system allowed it, through changing the timings and methods of food choices being made. Further research is needed to determine whether food choices being made together with others, and at the time of the appropriate meal, would positively influence the person with dementia's ability to make autonomous and informed choices.

For people with dementia, reducing the cognitive load of the eating process is key in improving engagement and reducing the risk of occupational deprivation. The theory of reducing cognitive load through eating together with others who are able to establish the norms of what is to be eaten and at what pace, needs further research and clarification. The research presented in this thesis adds evidence to how social interactions and eating together influence mealtimes.

8.5.2 Enabling cognitive access through communication

Communication was a theme, which emerged throughout both the observations and interviews as a limiting factor in enabling choice and independence in the meal process. This was particularly

noticeable when supporting people to make selections of food choices. The ability to make food choices is recognised as a way of sustaining identity; having autonomy to make decisions enables retaining former roles, feeling valued, and is a normal part of life (Bundgaard 2005; Genoe et al. 2010). Communicating choices effectively was observed to be essential in enabling or disabling autonomy in the food selection process. Institutionalised occupational apartheid was again observed, as people with dementia were expected to make choices in the same way that people without dementia do (Durocher et al. 2013).

The findings suggest that the cognitive load within the hospital environment limits opportunity to express autonomy or choice over food selection decisions. There was a lack of effort to use alternative communication techniques to verbal listing, complex presentation of choices on paper, and rushed interaction. People with dementia were talked at across a noisy ward, or expected to follow rushed verbal instructions. Rushed decision making, or unclear presentation of choices, are not compatible with people with dementia due to cognitive decline in understanding, processing speed, word finding and memory, attention and executive function (Chang 2012; Stanyon et al. 2016). Within the food choice systems already in place, staff allowing more time and effort to adapt their own communication may be an opportunity for improvement in promoting food choices and consequent engagement in the eating process at mealtime.

Murphy et al. 2017 mention some cognitive elements in the description of their model of person-centred nutrition. These include the importance of regular reminders though encouragement and prompting, allowing more time, and environmental cues such as setting the table. Murphy et al. (2017) emphasise how presentation of choices and meals is important for effective nutritional care in people with dementia. Communicating food related options, and communication at mealtimes, can be more than talking but should engage all the senses.

8.5.3   Sensory stimulation and cognitive function

The research findings suggest that stimulating appetite and encouraging engagement in the eating process includes communicating the mealtime through environmental and sensory cues (Malik et al. 2008). The research findings identified that using these cues to anticipate the mealtime positively influenced mealtimes. In the normal processes of aging, sensory processing, including visual, olfactory and auditory impairment, is known to decline (Murphy 2008; Collier 2012; Dumas et al. 2016). Sensory impairment, and declining sensory processing, in older people, has been linked to functional decline and worsened quality of life (Freiherr et al. 2013; Mahoney et al. 2015). Enhancing appropriate sensory stimuli can increase sensory processing and create

cues which trigger cognitive responses to inform function, pertinent to engaging in the eating process (Laurienti et al. 2006).

The sensory environment is known to have a positive impact on occupational performance (Collier 2012). Stimulating the senses to improve engagement specifically in the mealtime has been recognised as valuable for people with dementia (Murphy et al. 2017). This was evident in the research findings through the improved difference in engagement noticed when mealtimes were anticipated as a meaningful activity. Murphy et al. (2017) support the research findings in suggesting pre-meal activities such as anticipatory conversation may improve engagement during the mealtime. Sensory stimuli, in anticipation of and during the meal, which enhance the recognisability of a meal environment, and the expectation to eat, was seen to improve engagement in the eating process. Increased stimuli of the appropriate sensory information reduces the effort to seek out sensory stimuli (Collier 2012) and therefore would reduce cognitive load to process, understand and engage in the mealtime.

Intervention studies for mealtimes exploring sensory considerations in the environment, such as lighting or noise levels, generally had outcome measures focused on reducing anxiety, rather than engagement in the meal as a meaningful occupation (Whear et al. 2014; Bunn et al. 2016). The studies that considered food or energy intake generally showed promising results, but were focusing on one aspect of sensory input, i.e. just visual. Due to the multiple component of sensory and cognitive decline in a people with dementia (Mahoney et al. 2015; Dumas et al. 2016) there is a potential place for multi-sensory intervention at mealtimes in hospital. Multi- rather than uni-sensory stimuli increases processing and response time (Laurienti et al. 2006).

Sensory processing speed is known to reduce in older people, and people with dementia (Laurienti et al. 2006; Hugenschmidt et al. 2009; Freiherr et al. 2013; Dumas et al. 2016). Allowing more time for processing of the sensory stimuli at mealtimes may reduce the cognitive barriers which inhibit the initiation of engagement in the eating process. Using enhanced or multi-sensory stimulation at meals may increase processing time, and provide cues to prompt initiation and continuation to completion of the meal. This approach should be considered in light of the adapted communication techniques identified as important in enabling independent food choices. Further research is needed to explore potential benefits of enhanced and multi-sensory, anticipatory, interventions for improving engagement in mealtimes for people with dementia in the acute hospital setting.

Understanding the effectiveness of multi-sensory interventions in older people and people with dementia is limited. Existing studies have primarily been focused on reducing behaviours and psychological symptoms of dementia, or improving mobility and balance with older people (Burns

et al. 2002; Mahoney et al. 2015; Dumas et al. 2016). There is limited work linking sensory interventions in dementia to improved function, but existing research present promising results (Collier 2012). Further research is needed to explore the use of sensory considerations to create meaningful and recognisable mealtimes in hospitals, to reduce the cognitive load required to process and initiate the activity, and improve occupational performance.

8.5.4 Conclusion

Cognitive barriers to engaging in the eating process were common in the observations and interview discussions. Social considerations, appropriate communication and multi-sensory interventions are suggested as ways in which cognitive access could be improved. Adapting communication styles, or setting up social and sensory cues in the environment, may reduce the extraneous cognitive load required to process and understand the mealtime as a meaningful occupation. The research findings suggest that a focus on anticipating the meal as a meaningful occupation may reduce cognitive barriers to engagement. Further research is required to build on the theory developed in this cognitive access section.

Reducing cognitive barriers to people with dementia engaging in the eating process in hospital is suggested through the research to be a way of improving occupational performance and reducing the risk of occupational deprivation.

8.6 Conceptual model

"…every participant in a health care encounter, interprets and constructs a subjective world, and these worlds are modified by the dialogue between them." (p.48) (Nolan and Mathews 2004)

The quote summarises the importance of mealtimes in hospitals being meaningful to individuals. Meaningful mealtimes are individualistic. Meals are conceptualised differently by different people and therefore have different meanings (Fjellström 2004). These is a dialogue between the person with dementia and the surrounding environment (Nolan and Matthews 2004).

The implications of the research presented in this thesis offer a complex picture of meals times for people with dementia in the acute hospital setting. Occupational injustice (Durocher et al. 2013) in the hospital setting has been evidenced through the research findings, with a plethora and variation of factors inhibiting the opportunity for people with dementia to engage in the eating process as an occupation. Occupational injustice is primarily observed in the hospital setting, evidenced by the research findings, as occupational deprivation and occupational apartheid

(Durocher et al. 2013). System-driven routines, attitudes and expectations, outside of the control of a people with dementia, all reduce physical and cognitive access to engagement in mealtimes.

The findings are therefore applied to the occupational based model, the Person-Environment-Occupation Fit model (Law et al. 1996), displayed in Figure 14, by way of acknowledging the complexity and inter-relational nature of the factors influencing engagement and experience at mealtimes. The model puts engagement in the eating process at the centre, describing it as occupational performance, which is the focus of the research. The model is the first model of influencing factors to engagement in the eating process in hospitals, which acknowledges the importance of mealtimes as a meaningful occupation. In its focus on occupational performance, when applying factors influencing engagement in the eating process through the research findings, and supporting published literature, the model is the first to be used to highlight the occupational injustice so prominent in the system driven culture of the acute hospital environment.

Other models centre on food intake (Keller et al. 2014) or a person-centred approach (Murphy et al. 2017). These approaches are valid and useful for practice, but miss the essence of meaning and experience of mealtimes, which an Occupational Therapy perspective adds. The Person-Environment-Fit model examines the relationship between the person and their surroundings, in particular when applied to the hospital setting it highlights tensions between older people with additional care needs and the acute hospital system and environment (Parke et al. 2014). Furthermore, the model presented by Ottrey et al. (2017) (Figure 13) illustrates this tension between system and person-centred care at mealtimes, but is not specific to people with dementia, and does not apply the tensions directly to occupational performance or engagement at mealtimes within the model.

The Person-Environment-Occupation-Fit model considers a wider view of the mealtime. When applied to practice, interventions should aim to change the whole combination of, the person, the hospital environment or systems, and the mealtime as an occupation. In line with the work of Kielhofner and Burke (1980) in their Model of Human Occupation, the Person-Environment-Occupation Fit model presents people as occupational beings, in one transactional relationship and existence with the external environment. It is also in line with the social ecological perspective. This assumes that people cannot be understood apart from their environmental context and that organisational environments must be considered as an integral part of understanding experiences and outcomes (Parke et al. 2014).

This dynamic model is used to develop a new conceptual model of influencers to the eating process for people with dementia in acute hospitals. It depicts how engagement in the mealtime

(occupational performance) can improve or reduce depending on the fit of the person and their individual presentation, the hospital environment and the systems driving this, and the meal as a meaningful occupation. It builds on the current models of eating and drinking difficulties, which present a linear or interactive relationship between the person and the eating environment. The Person-Environment-Occupation model is dynamic and trans-active, demonstrating that the person and the environment do not simply interact but are inseparable. Interventions which change one element of the equation are not enough, a wider approach must be taken. Person, environment and occupation are not linear or separate entities which impact change through being considered individually but are intertwined, overlapping and impact each other in a dynamic structure.

The model can be seen as a whole, applying all the themes from the findings into each category, or it can be used as a visual display when applying an individual example of intervention.
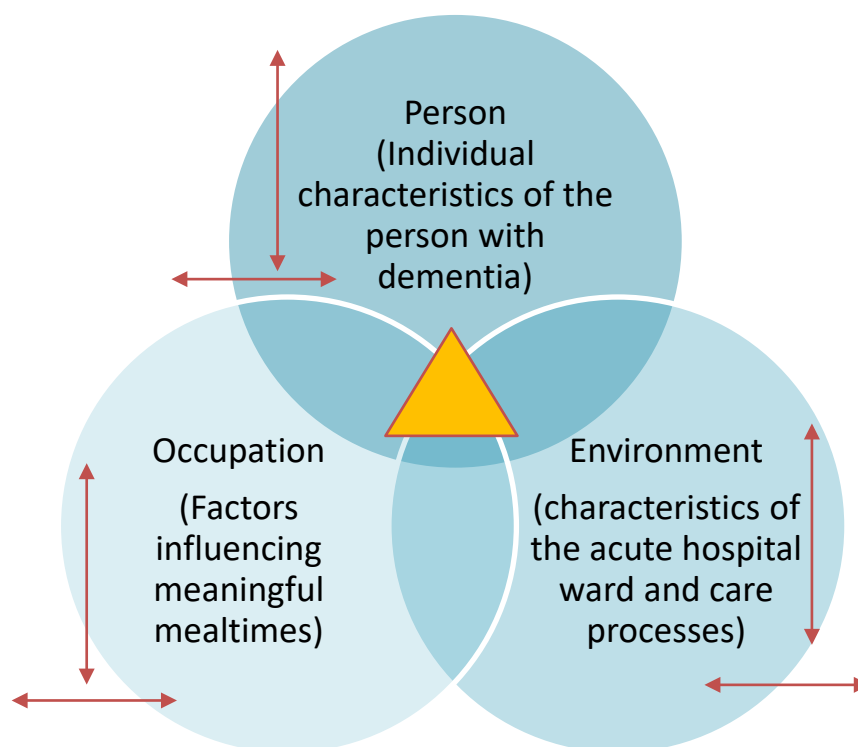
= Occupational Performance (engagement in the eating process) – as the circles move closer or further away due to the factors influencing the mealtime either positively or negatively, the occupational performance increases or decreases.

Figure 14:   The Person - Environment - Occupation Fit model applied to the research findings (Law et al. 1996)

Chapter 8

Figure 15 depicts the model with the example recommendation of open family visiting hours and encouraging their presence at mealtimes. The occupational performance (engagement in the meal) increases as the person, environment and meaningful occupational have a more appropriate fit. This is based on what the research reveals influences that engagement at mealtimes.

PERSON

Familiarity and normality of family member presence. Time required for person with dementia. Personal knowledge of the individual.

OCCUPATION

Set apart activity.
Meaning through familiarity, recognisability.
Time for meaningful occupation instead of rushed task.

ENVIRONMENT

Social environment.
Reduced confusion.
Reduced extraneous cognitive load.
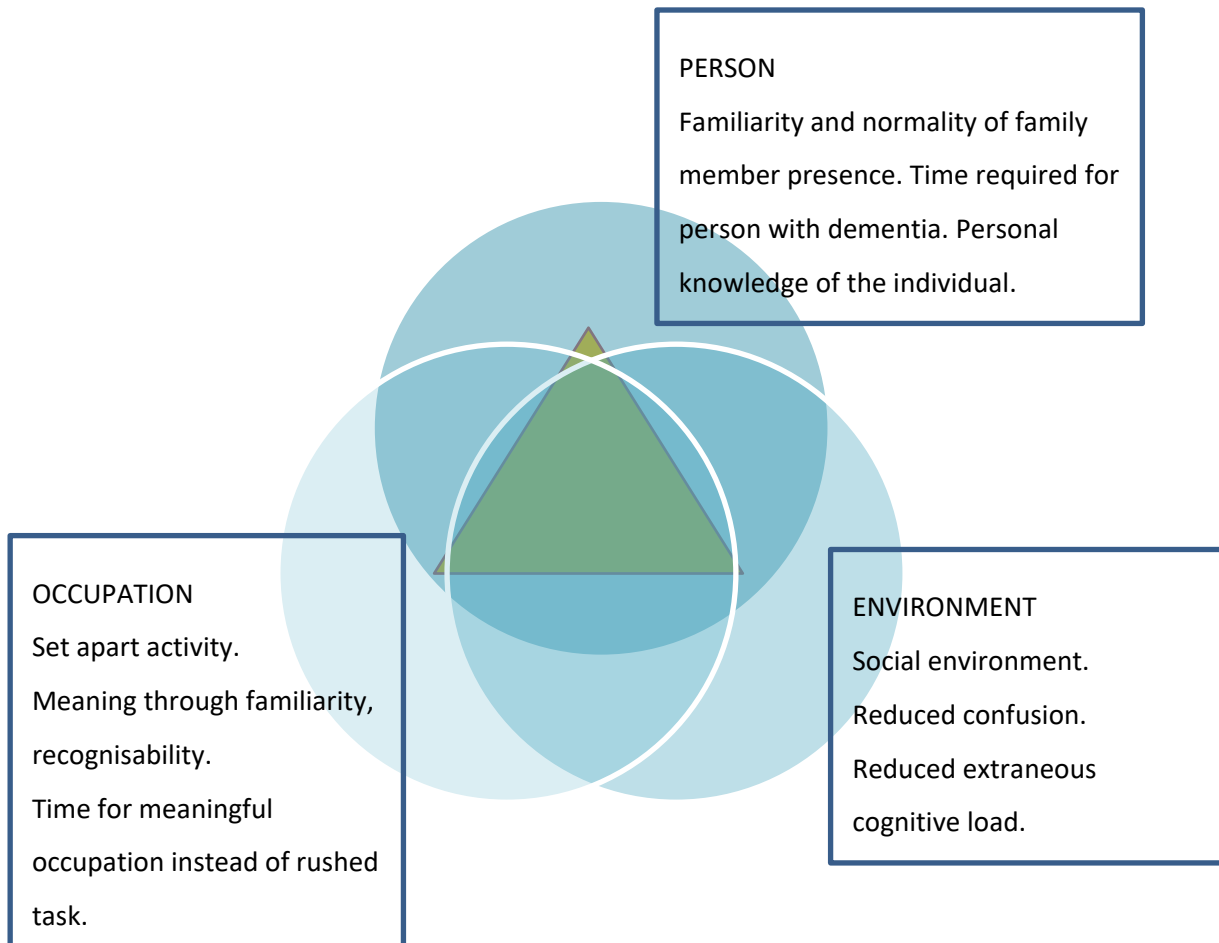
Figure 15: The Person - Environment - Occupation Fit model (Law et al. 1996) exemplifying the influence of visitor presence at mealtimes.

When the family member is taken away from the equation, the circles move further away impacting occupational performance negatively.

The limitation of published intervention studies is one of selecting singular elements of the meal process to try to improve. In fact mealtimes in hospitals need to be addressed considering all aspects of meal access, meal quality and meal experience, as well as the system drivers. Changing one aspect of a meal is unlikely to improve engagement in the eating process significantly (Young

et al. 2018), but there are recommendations that can be made which combine the various elements of the person, environment and occupation.

8.6.1 Practical considerations for improving mealtimes for people with dementia in the acute hospital setting

An essential addition to the existing knowledge about improving mealtimes for the acute hospital setting is to understand how to break down cognitive barriers, reduce the cognitive load and therefore allow cognitive access to food. All the trans-active elements of the Person-Environment-Occupation model need to be adapted by way of bringing them together and improving occupational performance. It is important to acknowledge that, although a wider system review would be beneficial in improving dementia care in hospitals generally, staff within the current system express the desire to improve care and need realistic recommendations for how to do this.

Recommendations for practical changes which would help to bring the person environment and occupation closer in fit are:

- Open visiting times for families and family involvement in mealtimes.
Family and visitors can create a social environment, meaningful to the person, and the family members can reduce the unfamiliarity and confusion of the hospital ward. Families should be allowed to bring in food that is familiar and liked, if it is not provided by the hospital because of cost. John's Campaign is a movement campaigning for the right for family or carers to be able to have a greater involvement in the 24-hour care of their loved ones with dementia (The Gold Standards Framework 2015). Drawing on the principles of the campaign, this could be applied more specifically to improving mealtime and nutritional care.

- Volunteers.
It is evident from the research findings that the use of mealtime volunteers may benefit mealtime care for people with dementia. Hospitals in the NHS broadly appear to have a general volunteer service, but it may benefit hospital to focus on having a specific pool of volunteers with training in improving mealtimes for people with dementia (Howson et al. 2018).

- A separate dining environment.
Sitting up at a table in the bay, or ward, to eat with others may be an alternative suggestion if the use of a separate day room is not feasible. This would still provide a social environment and the social and environmental cues of a meaningful mealtime. A separate dining environment takes the person away from their bed space where all other activities occur, and potentially away from the noisy or unpleasant bay. In a separate place the occupation becomes recognisable and

meaningful. Having a separate dining environment also provides scope for further sensory interventions before and during the meal.

- Training and education for staff

Educating staff beyond nutrition and safe feeding techniques, to include the Person-Environment-Occupation Fit model, may be beneficial in equipping staff to feel confident and able to improve occupational performance at mealtime. Specialist training and education for dementia care practice in hospitals could include, communication, how to promote independence in food choices, and the meaningful nature of mealtimes as an occupation. These are all ways of practically promoting the evidence provided by the research project presented in this thesis.

- Menus and food selection processes can be improved

Dementia friendly presentation of menu choices may be beneficial in promoting independent food choices. Changes to menus for people with dementia need to be considered beyond the current provision of finger food or textured diets. The way in which choices are presented should be challenged.

Adams and Gardiner (2005) suggest communication techniques that promote understanding and autonomy for people with dementia, which could be applied to mealtimes and food selection choices:

- Reducing sensory stimuli which may be distracting from the interaction.
- Promoting equal participation through non-power positioning, such as next to and at the same height at the person with dementia.
- Allowing time for full participation from the person with dementia.
- Being aware of facial and social cues which may suggest the person with dementia wants to contribute.

Other practical tips suggested for communicating with people with dementia to overcome cognitive barriers include: the use of shorter sentences, repetition of instructions or choices, calm and slower vocal tone to avoid confusion and allow for processing time, maintain eye contact and use touch to keep focus and attention (Stanyon et al. 2016).

Although there is scope for application of the research findings to practice, there are also limitations to the research project processes which are important to recognise.

8.7 Limitations of the study

Dementia Care Mapping (DCM) was selected as a tool which quantified both engagement in and experience of mealtimes. This was a novel approach which provided new and rich understanding of mealtimes for people with dementia at mealtimes in hospitals, but is not beyond critique. The tool was initially developed for clinical practice assessing individuals and has limited evidence to support it as a research tool to collect a group measure of experience. However, DCM has been used as a research tool to measure the relationship between behaviours and the surrounding activities, a key aim of the research (Sloane 2007). The research aimed to be inclusive of people with dementia unable to verbally express their views, or self-report engagement. Field notes alone have the risk of being too subjective and swayed by the views of the researcher (Emmerson 1995). The addition of DCM meant the view of the person with dementia was at the core of what was being observed. DCM is the only dementia specific tool identified to use observations which achieves this (Algar 2016).

Used alone DCM was not adequate to meet the aims of the research. Having further, in-depth field notes, plus interviews with staff was essential. Having one Behaviour Category Code (BCC) and Mood and Engagement (ME) score for each five-minute time-frame arguably restricted the true reflection of activities. The use of operational rules to use one code above another may have prevented some behaviours or expression of well/ill-being to be captured. However, this limitation was reduced by the combination of qualitative and quantitative observations, and interviews. Selected quality considerations presented by Creswell and Plano-Clarke (2018) are used to further evaluate the limitations to the research project presented in this thesis.

8.7.1 Planning and design quality.

Planning and design quality consider the extent that the study design is feasible, transparent, situated in published literature, and suitable for the study purpose (O'Cathain 2010). In view of the existing literature highlighting person factors for people with dementia influencing eating and drinking, more could have been done to collect descriptive characteristics, such as the type and severity of dementia, in the observation participants. This could have allowed for further quantitative analysis, and comparisons, to support existing literature about how dementia type or severity may influence resistance or disengagement in the eating process (Amella 2002).

A limitation in using the Dementia Care Mapping tool is the way it combines mood and engagement into one score. For the purpose of the research, understanding engagement and well-being as separate scores may have given deeper knowledge of the influences on eating and drinking. The well-being scores would also give further potential for analysis in understanding the

relationship between well-being and engagement in the eating process. This would involve a major adaptation to the tool which has not been explored and may reduce validity of the tool.

8.7.2   Data quality

Considering data quality involves assessing if the methods of sampling, data collection, analysis, and integration of findings are adequate and rigorous. The quantitative element of a similar research project could be made stronger in the sampling methods. A larger sample size, calculated through statistical calculation, may add rigour to the quantitative findings, and create potential for more in-depth statistical analysis. In order to achieve this, the timings and number of observations would need to be exactly the same for all participants. In a larger research project, with adequate statistical calculation of sampling, the Dementia Care Mapping observations would require including different mappers and continual monitoring of inter-rater reliability co-efficient scores. The qualitative nature of the sampling strategy limited statistical generalisation of the overall findings.

8.7.3   Inference transferability

The research project was conducted across two large NHS hospital hospitals, under management from different NHS Trusts. However, the geographical area, and consequently demographic of participants, was restricted to a small area. To improve the application of findings to other hospitals, a larger scale project may be beneficial.

Chapter 9   Future potential

9.1   Novel contribution

The methodological approach to the research presented in this thesis was one that has not previously been applied to exploring eating difficulties for people with dementia. The Dementia Care Mapping (DCM) tool, combined with qualitative field notes, provided the opportunity to explore the positive and negative influences to engagement and experience of mealtimes. The observations looked beyond the difficulties expressed by people with dementia or their carers and considered the system within which the meal was being provided. Such research was yet to be conducted in the acute hospital wards for older people. As such, the systematic factors identified in influencing engagement in the eating process were unique and the complexity unrivalled in other settings. The finding representing system driven mealtimes highlighted the lack of recognition of mealtimes as a protected and meaningful occupation within the hospital routines and processes.

The occupational perspective of the research presented in this thesis lead to conclusions focused on meals as a meaningful occupation. The findings reflected the occupational approach in recognising the importance of individualised, meaningful interventions to improve mealtime engagement and experience. In taking an occupational stance, the research presented in this thesis is the first to suggest the further value of the role of Occupational Therapy in improving mealtimes for people with dementia in hospital. A reflection of how the researcher, an Occupational Therapist, has had an opportunity to apply this in practice is presented at the end of this thesis.

Applying the Person-Environment-Occupation Fit model to mealtimes in the acute hospital setting is a different approach to conceptualising mealtime difficulties to any presented before in the published literature. There is no other mealtime model which places occupational performance at the centre, while still valuing the important contribution of intrinsic factors relating to the person with dementia and their cognitive capacity.

Cognitive access to the eating process at mealtimes for people with dementia has not previously been explored. This opens up a new avenue of potential research, and development of cognitive load theory applied to mealtimes for people with dementia in the acute hospital setting. The focus on breaking down cognitive barriers to accessing meals in one which could be added to the

knowledge base used for training and education of staff supporting people with dementia in the hospital environment. There is also a challenge to the inflexible structures, processes and routines of the hospital system, to enable further interventions which are person-centred and reduce cognitive load.

9.2   Further research

Key areas for improvement emerged from the research presented in this thesis, and further questions which could be explored through future research. Overall the concept of breaking down cognitive barriers to accessing food and drink at mealtimes could be developed. Further research has the potential to include the development of specific interventions, such as multi-sensory or environmental changes. Exploring specific cognitive barriers, beyond what has emerged through the research in this thesis may also be feasible.

A key feature distinguishing the research from other studies was the acute hospital setting. As the interview transcripts were analysed, it became clear mealtimes hold differing priorities across different settings, even within the acute hospital setting. The prominent example given was the acute stroke ward. This raised the question whether attitudes on older person's medicine wards are different. Further research, comparing people with dementia's experiences in the wider acute hospital, not just older person's medicine, may be beneficial.

Within other settings in the hospital, the role of Occupational Therapy was also different. In the older person's medicine wards Occupational Therapist interview participants went as far as expressing guilt or feeling judged if they considered mealtimes a priority among the other expectations laid on them. There is little published literature giving an evidence base of Occupational Therapy interventions for people with dementia in the acute hospital setting. Further research would be valuable in exploring the view of Occupational Therapists, and the scope of their role at mealtimes for people with dementia. The concept of meaningful mealtimes is a key theme from the research which could be further explored in research into the Occupational Therapy role.

The value of visiting friends and family at mealtimes was another area where further research may be beneficial. Anecdotal evidence of the value of family presence has been widely acknowledged through John's Campaign (The Gold Standards Framework 2015). The founders of the campaign argue that the personal knowledge of the person can be used to improve their care and experiences during the hospital setting. Further research to evidence these claims, and to explore the effectiveness of using visitors to improve engagement and experience for people with dementia, may be beneficial.

9.3   Publications

To date the researcher has disseminated the research methods and findings through conference presentations. These have included:

- A poster presentation at the UK Dementia Congress, October 2016.
- A poster presentation at the Southern Health NHS Foundation Trust Allied Health Professional's conference, November 2016.
- An oral presentation at the 27th Alzheimer Europe Conference in Berlin, October 2017.
- An oral presentation at the Alzheimer's Association International Conference in Chicago, July 2018.
- An abstract has been accepted for an oral presentation at the Royal College of Occupational Therapy Annual Conference 2019.

Due to the novel methodological approach and contribution to understanding improving mealtimes for people with dementia in the acute hospital setting, the researcher aims to publish the research in various forms. Topics for proposed publications include:

- the use of the DCM tool in the acute care setting, reflections and potential changes,
- a mixed methods publication of the results from phase 1,
- a qualitative publication focusing primarily on the findings from the field notes of phase 1 and interviews of phase 2,
- the introduction of the Person-Environment-Occupation Fit model applied to mealtimes for people with dementia in acute hospitals,
- a literature review exploring the existing knowledge of the role of Occupational Therapy, and effectiveness of Occupational Therapy interventions, for people with dementia at mealtimes in the acute hospital setting.

9.4   The clinical academic role: a reflection

The thesis began with a reflection of why I, the researcher, pursued a clinical academic pathway, in particular researching the care for people with dementia in the acute hospital setting. As the Clinical Doctoral Research Fellow role ends a reflection of the experience to date, and the future potential in pursuing a clinical academic career, concludes the thesis.

The first clinical post taken within the Clinical Doctoral Research Fellow role was in a community team for adults, primarily older people. At first, it was difficult to marry these roles, the research topic being so specific to people with dementia in the acute hospital setting, practicing in the

community setting. I found myself treating the two aspects of my role as separate entities, compartmentalising my clinical life and academic life, focusing on developing my skills in the two areas. In many ways I treated the clinical role as secondary to completing my PhD. As my research skills developed I was able to begin to integrate them into my clinical work through conducting reviews of evidence based practice, auditing and service evaluation. I began to apply the use of critical analysis skills and understanding data.

By the final year of the PhD process I was able to start a new role, which I had formulated to integrate my advancing clinical and academic skills: a dementia specialist Occupational Therapist on medical wards for older people. Within this role I made connections with the nutrition group for the hospital, which included all clinical professions, kitchen staff, and the catering managers. Through the support of these meetings, I began to implement change in the mealtime processes, lead on a culture of sitting people up at a table to eat, encouraged family visitors to be present at mealtimes and provide information or bring in food preferences, and conducted dementia training including communication involved in the presentation of menus.

Within the dementia specialist Occupational Therapy post I worked with the ward managers to facilitate and implement an Enhanced Care project for people admitted to hospital with dementia. This brought together nursing and therapy team responsibilities in providing appropriate care for people with dementia and delirium at all times of the day and night. Occupational Therapy staff were supported to set up activity groups, which were used in part to stimulate anticipation of the mid-day meal. Part of the project involved the adaptation of the unused, messy day room, into a dementia-friendly, homely and non-clinical environment, suitable for an alternative eating setting. Furthermore, using my academic skills developed through the research, I evaluated the training, and general role, through staff surveys and observations of patient well-being. The outcomes of this role will be presented at the Royal College of Occupational Therapy annual conference in June 2019.

The integration of academia into my clinical role inspired the next steps of my clinical academic career. I have recently started a role as a Team Lead Occupational Therapist in a frailty rehabilitation unit for older people. Within this role there is scope for service development, implementation of positive change in the care for people with dementia, and an opportunity to lead on increasing the research capacity within the hospital and other connected settings. Expanding my research activity within and beyond my research role has also included joining a steering group for an Occupational Therapy research Priority Setting Partnership conducted by the Royal College of Occupational Therapists. Taking a clinical academic pathway has created an opportunity to continue in research activity while continuing a clinical career. Academic skills can

be used in clinical practice. The research presented in this thesis has the potential to influence practice to improve mealtimes for people with dementia, and to produce further research from the findings.

Appendix A   The Mixed Methods Appraisal Tool (MMAT)

Mixed Methods Appraisal Tool (MMAT) (2011) from Pace et al 2012

Screening questions

(for all types)

☐Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?

☐Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).

Further quality appraisal may be not feasible when the answer is 'No' or 'Can't tell' to one or both screening questions.

1. Qualitative

1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?

1.2. Is the process for analysing qualitative data relevant to address the research question (objective)?

1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?

1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?

2. Quantitative randomized controlled (trials)

2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?

2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?

2.3. Are there complete outcome data (80% or above)?

2.4. Is there low withdrawal/drop-out (below 20%)?

3. Quantitative non-randomized

Appendix A

3.1. Are participants (organizations) recruited in a way that minimized selection bias?

3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?

3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?

3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?

4. Quantitative descriptive

4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?

4.2. Is the sample representative of the population understudy?

4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?

4.4. Is there an acceptable response rate (60% or above)?

5. Mixed methods

5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?

5.2. Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)?

5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results) in a triangulation design?

Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.

Appendix B   Table of study characteristics of published empirical research selected for literature review

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
Amella 1999 Nursing home in USA	Examine the extent to which care giver interactions during feeding influenced proportion of food consumed by nursing home residents with dementia.	Observations of weighed food. Recruitment unclear. Statistical analysis. Quality of resident – CNA relationship: Interaction Behaviour Measure	53 residents 53 experienced Certified Nursing Assistants Culturally diverse. Written permission from "guardians" when resident lacked capacity.	Quality of the relationship – significantly positively related to quantitiy of food consumed. Only significant scores were from resident not carer Empathy – not significantly	Reciprocal interaction and relationship between carer and person with dementia during feeding.	Limited to breakfast times although 88% care givers stated behaviours same at other meals. Recruitment strategy unclear. Sample calculations not stated.

Appendix

Table: study characteristics of published empirical research selected for review.						
Study and setting	Aim	Design/methods	Sample/recruitment	Results	Factors which influence eating and drinking	Limitations
		CNA Empathy: Interpersonal Reactivity Index CNA Power: Control subscales of the Fundamental Interpersonal Relations Orientation – Behaviour (FIRO-B) Discusses good reliability, IRR and validity of tools.		correlated or related. Power – no significant relationship to consumption. Collective – higher quality of relationship = higher empathy and lower need for power = more food eaten.		
Amella 2002 Nursing home in	Are physiologic characteristics of mental status,	Selected outcomes of previous study (Amella 1999)	53 residents with late stage dementia 53 CNAs	23 people were "resistors" and 30 people "acceptors"	Appropriate positioning	As above No SALT review of

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
USA	functional status, oral health and swallowing associated with resistance behaviour at meals by people with late stage dementia? Does interaction between CNA and resident influence resistance behaviours?	EdFED-Q – was used to quantify resistive meal time behaviours Interactions measured as above Weighed food.		Average: Resistors consumed 51% in 18 minutes Acceptors consumed 72% in 13.8 minutes Resistors had more dysfunctional relationships with CNAs.	==**Interactions and relationships** between carer and resident as above.==	physiological issues which may influence swallow.
Batchelor-Murphy et al 2017	To compare efficacy of 3	Randomized into 3 groups. 540 meal	30 nursing home residents with eating	No reported significant effect of	==**Technique used to assist with eating.**==	Interpretation of, and reasons for,

Table: study characteristics of published empirical research selected for review.						
Study and setting	Aim	Design/methods	Sample/recruitment	Results	Factors which influence eating and drinking	Limitations
11 nursing homes in south eastern USA	handfeeding techniques for assisting nursing home residents with dementia at meal times.	times observed Outcome measures: time, meal intake, feeding behviours (EdFED) Field notes to document resident responses. Analysis : descriptive statistics, non-directional statistical tests.	difficulties or dependent on others for eating assistance.	handfeeding technique on the mean time spent giving assistance. Direct Hand feeding and Under Hand technique had significantly higher food intake than Over Hand technique. Over Hand technique related to more feeding behaviours scoring higher on the	<mark>Perception of control.</mark> (Over Hand was perceived as controlling and more feeding behaviours observed) <mark>Encouraging independence</mark> – direct <mark>feeding was not quicker.</mark> <mark>Relationships and knowledge of patient</mark>	feeding behaviours is subjective. No recorded sample size calculation.

Table: study characteristics of published empirical research selected for review.						
Study and setting	Aim	Design/methods	Sample/recruitment	Results	Factors which influence eating and drinking	Limitations
				EdFED than UH and DH.		
Chang & Roberts 2008 Nursing home in Taiwan	What are the feeding difficulties among residents with dementia in a Taiwanese nursing home? What feeding strategies are used to address difficulties? What are the interactions between nursing assistants and	Observations of Nursing Assistant to resident dyad using the EdFED Field notes of observations. Structured interviews with Nursing Assistances straight after the meal. Analysis of field notes = content	31 experienced nursing assistants 48 residents with dementia.	27 residents had no feeding difficulties according to the EdFED. 93% Nursing Assistants reported feeding residents with dementia was time consuming. Nursing Assistances reported lack of enough staff, or appropriate	**Distractions from eating.** **Drowsiness.** **Rushing or too big spoonfuls.** **Verbal encouragements helped.** **Quality of interactions between carer and resident.** **Mixing feeding with**	1 nursing home only. Other factors which influencing food intake not considered.

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
	residents during feeding assistance? What is the meal time environment in a Taiwanese nursing home?	analysis.		knowledge. Environment was crowded and noisy. Residents had no choice of where they ate. NAs stood to feed which impacted interactions and attitudes.	other tasks. Dining environment. Staff training.	
Chang et al 2006 Nursing homes in Taiwan	To test if Nursing Assistants who complete a feeding skills training program have more knowledge,	Questionnaires. Formal Caregivers' Behaviours in Feeding Dementia Patients	Nursing homes chosen at random by flipping a coin 67 nursing assistance Treatment group	Knowledge: significant increase in knowledge after training. Intention: significantly higher	Staff training impacting time allowed to eat and Communication Dining environment	Randomisation of control groups not clearly. No discussion of culture or attitude

Table: study characteristics of published empirical research selected for review.

Study and setting	Aim	Design/methods	Sample/recruitment	Results	Factors which influence eating and drinking	Limitations
	positive attitude, perceived behaviour control in feeding dementia	Observation Checklist.	n=31 Control group n=36	in treatment group. Behaviours of feeding: significantly better in treatment group than control group who had no training. Attitude and perceived control – insignificant findings. 84% said training was helpful.	**Multi-factorial**	or prior training of different nursing home employees. Nursing Assistants expressed feeling pressure from training administrator which could have impacted their questionnaire results. Low reliability of specific questionnaires.

Appendix

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
						Larger sample needed and longer post-training measurement of efficacy.
Chang 2012 Nursing homes in Taiwan	To establish prevalence rate of feeding difficulties. To understand the factors associated with feeding difficulties among people with dementia.	Cross-sectional design. Demographic data, nutritional data, cognition and independence also collected. Observations using the EdFED. Observations of types of food	93 residents with dementia	Prevalence of feeding difficulty was 60.2% (EdFED cut off 5). EdFED scores above 5 correlated to a significantly longer duration, lower BMI, greater cognitive impairment.	<mark>Eating environment – to reduce distractions form the task of eating.</mark>	Convenience sample and small sample size limit generalizability. Cross-sectional design is one snap shot in time.

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
		presented utensils used, duration of eating time and feeding difficulties. Analysis: descriptive statistics and multiple regression.				
Chang et al 2017 Long term care facilities in Taiwan	1. Identify the best cut off point for the Chinese Feeding Difficulty Index (Ch-FDI) 2. Evaluate	Cross-sectional design. Interviewed participants to gain demographics, cognition (MMSE),	213 residents with dementia Convenience sample from 8 long-term care facilities.	Food intake significantly correlated with cognition, independence in ADLs and length of	**Dining environment** – low light and high sound negatively impacted eating. **Distractions. Time of day/specific meal times** – due to	Selection bias in the selection of long term facilities used.

Table: study characteristics of published empirical research selected for review.

Study and setting	Aim	Design/methods	Sample/recruitment	Results	Factors which influence eating and drinking	Limitations
	prevalence of food intake difficulties. 3. Recognize factors associated with eating behaviours in residents with dementia.	independence in ADLs (Barthel), and depression status. Dining environment measured through illuminance and sound volume. Interactions with caregivers measured through observations. Food intake - weighing food BMI.		time. Food intake at dinner time significantly correlated with cognition, illuminance level, sound volume and eating time. Depression status had no correlation with food intake difficulties.	Sundowning symptoms? Cognitive function Time for eating required – not rushing the meal	

Table: study characteristics of published empirical research selected for review.						
Study and setting	Aim	Design/methods	Sample/recruitment	Results	Factors which influence eating and drinking	Limitations
		Observation of feeding difficulties – Ch-FDI and EdFED. Observed length of time. Analysis: SPSS. Descriptive statistics, inferential statistics, multiple regression.				
Edahiro et al 2012 2 Dementia wards in a hospital in	Investigate factors affecting self-feeding in elderly patients with	Eating behaviour, cognitive assessment and neurological	150 residents – 13 men, 137 women.	Severity of dementia and presence of dysphagia	Severity of dementia – reduced cognitive function.	Only applicable to Alzheimer's disease. Disproportionate amount of men and

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
Japan	Alzheimer's disease.	examination by specialist physicians. Vital function test. Basic info survey. Eating behaviour – observations. Data analysis: descriptive statistics and logistic regression		significantly impacted eating ability.		women = generalizability. Is discussed and justified as no difference between genders.
Gilmore-Bykovski 2015 2 Nursing homes	To identify sequential associations between caregiver person-centred	Video recorded observations of naturally occurring interactions: person centred and	Video recording = 33 observations including 12 residents and 8 CNAs.	Behavioural symptoms significantly more likely (19-21%) to occur following	Person centred or task centred approach. Timing of positive and person-centred	Small sample size. Sample size calculation not stated.

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
in Wisconsin USA	actions, task centred action, and resident behavioural symptoms and the temporal variations within these associations. To explore possible antecedent-consequence relationships between task-centred caregiver actions and	task centred inventories. Behaviour measured using Pittsburgh Agitation Scale Analysis: Time series analysis		task-centred action, and 2% likelihood following person-centred action.	<mark>interactions.</mark>	

Table: study characteristics of published empirical research selected for review.

Study and setting	Aim	Design/methods	Sample/recruitment	Results	Factors which influence eating and drinking	Limitations
	behavioural symptoms					
Hammar et al 2016 Nursing home in Sweden	To illustrate meanings within caregiver's experiences of care for people with dementia at meal times. Food intake and weight measured to gain additional perspective	Body weight and lunch food intake, recorded over 6 weeks. 4 Focus group interviews.	12 caregivers 9 residents – randomly selected. Medium to severe dementia.	Focus groups showed care givers struggle between having knowledge and not having opportunity. Caregivers felt concerned and guilty about whether person had eaten enough to avoid malnutrition. Felt alone and	Organizational structures Low staffing numbers	1 nursing home – the feelings of abandonment from senior nursing staff could be the culture of that home. Only 9/40 potential residents included. Limited explanation of exclusion reasons. No clear reason given for including

Table: study characteristics of published empirical research selected for review.						
Study and setting	Aim	Design/methods	Sample/recruitment	Results	Factors which influence eating and drinking	Limitations
				abandoned by management in meal time situations – having full responsibility to solve the problems. Try to be positive and make the atmosphere as inviting as possible.		quantitative measures or integration of results.
Hanssen & Kuven 2016 2 geriatric institutions in Norway.	To learn about the meaning of traditional food to institutionalised patients with dementia	Open narrative interviews with nurses and patient's families – "proxy informants".	Purposeful sampling strategy – experienced care givers for people with dementia. Bergen – 3 nurses	3 central subthemes: - awakening of memories - improved appetite	<mark>Cultural considerations and significance of food choices.</mark> <mark>Reminiscence, including sensory elements of</mark>	Only caregivers interviewed, did not include people with dementia. Not all conducted in interviewees

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
4 nursing homes in South Africa			Sami – 8 family members, 9 nursing staff Tshwane – 18 family members, 19 nurses.	- food reminiscence	eating Social aspects of eating	primary language. Small qualitative sample reduces generalisation of findings.
Hung & Chaudhury 2011 Long-term care facilities in Canada	Explore the concept of personhood in dining experiences of residents with dementia living in long term care facilities.	Conversational interviews. Observations recorded through field notes. Focus groups with staff. Data analysis: integrated deductive-inductive	2 facilities purposefully recruited because of differences. Residents – 20 (10 at each site) Theoretical sampling as themes emerged. Eventually reached data saturation.	Themes from data framed by Kitwood's work. Additions to Kitwood's work – "stimulation" and "distancing/ connection"	Person centred care. Relationship/connection between care giver and resident. Timing – rushing or outpacing residents at meal times	Interviews – excludes people with dementia who cannot verbally express their views.

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
		approach. Framed by Kitwood's malignant social psychology.			**Physical environment**	
Lea et al 2017 Residential homes in Australia	To examine the awareness of residential care staff regarding the food and fluid needs of older people – an emphasis is on daily care practices. Appraisal of staff perceptions of how the quality of care	Semi-structured interviews with staff. Data analysis: thematic analysis in NVivo. Multiple reviewers. Also a staff nutrition training and education questionnaire analysed	11 care home staff from a range of professions, who volunteered in response to flyers or word of mouth.	Perceptions of current food and fluid care practices included: physical eating environment, responsiveness to requests and needs, social eating environment. Suggestions for improvement: less	**Physical and social eating environments.** **Working together and flexibility of kitchen and care staff.** **Consistency of attempts to increased experiences and food intake** **Food preferences** **Staff education and attitudes**	Purely staff perceptions – does not include people with dementia. 1 residential home only. Small sample size – lack of transferability or generalizability but rich data from the qualitative data –

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
	could be improved.	descriptively.		regimented timings, enhancing the physical and social eating environments. Barriers to implementing improvements: insufficient staff levels, staff attitudes, professional hierarchy. Overcoming barriers: staff education,		scope for more research is valid.

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
				opportunities for staff to meet.		
Lee & Song 2015 Long term nursing facilities in Seoul, Korea.	To explore the degree of eating ability in people with dementia and identify what factors affect their eating ability. Examine the relationship between cognitive function, physical function and degree of eating ability.	Descriptive cross-sectional survey design. Semi-structured interviews and screening tests. Observations with use of structured questionnaires. Cognitive function measured using MMSE-K (to include Korean subjects). Physical function	149 participants – exclusions accounted for.	Most participants had severe dementia and most had a severe dependency for physical function. Cognitive function, physical function, duration of illness, eating place and diet type significantly predicted eating ability.	<mark>Severity of dementia</mark>	- Doesn't discuss Sample size calculation Strength: applicable to practice, paves way for further research into interventions.

Table: study characteristics of published empirical research selected for review.						
Study and setting	Aim	Design/methods	Sample/recruitment	Results	Factors which influence eating and drinking	Limitations
		measured using Korean Activities of Daily Living Scale – dependence. Discusses reliability. Eating ability – Eating Behaviour Scale translated into Korean. Analysis: SPSS – descriptive statistics. Post-hoc analysis using the Duncan test. Parson correlation				

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
		coefficient used to analyse correlation between cognitive physical and degree of eating ability. Multiple regression analysis used to identify factors influencing eating ability.				
Lin et al 2010 Long term dementia care facilities in Taiwan	To explore risk factors of institutionalised older people for developing low	Observational study – eating behaviour checklist. EdFED (eating	477 residents from 9 facilities	Significant difference noticed with low food intake and: frequency of family	Age and gender Family presence	Strength: clear definitions and explanation of outcome measures and data collection

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
	food intake – with dementia.	difficulty and level of nursing input), MMSE, BMI and Barthel Index. Analysis: Statistical analysis. Chi-square test and t-test used to compare characteristics between low and not low food intake. Forward Stepwise logistic regression model – to		visits, eating difficulty, feeding assistance, age, functional ability. 80.2% prediction of low food intake associated with: family visit frequency, eating ability, feeding assistance and moderate dependency. Eating difficulty = most significant predictor of low		tools. No clear reporting of sampling or recruitment strategy. - "Feeding assistance" is not defined and is unclear if it is counted as a predictor of eating difficulty. - Stepwise regression often avoided as each

Table: study characteristics of published empirical research selected for review.

Study and setting	Aim	Design/methods	Sample/recruitment	Results	Factors which influence eating and drinking	Limitations
		investigate predictors or low food intake and BMI.		food intake.		predictor is assessed based on other variables in the model.
Liu et al 2016 Long term care in USA	Describe the prevalence of compromised eating performance and examine the association of specific multi-level factors with eating performance.	Secondary analysis of 2 RCTs	199 residents in 4 nursing home or assisted living facilities. Clear inclusion criteria.	Neither agitation nor depressive symptoms were associated with eating performance. Level of cognitive impairment significantly influenced eating dependence.	Severity of dementia/ cognitive impairment Physical ability 1:1 eating assistance for prompts and encouragement.	Unclear about randomisation and baseline characteristics of the groups Secondary analysis of an RCT not designed to measure factors associated with eating performance.

Appendix

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
Liu et al 2017 Long term care in Kansas state, USA	To examine the association between environmental stimulation and eating performance.	Secondary analysis of an RCT Dependant variable - Level of Eating Independence Scale Independent variables - Person Environment Apathy Rating – Environment subscale.	8 long term care homes, 36 videos of 15 residents and 18 CNAs	Stimulating specificity is important for improving eating performance – individualised dining environments. Interaction involvement and environment feedback showed no significant association with eating performance.	<mark style="background-color:purple">**Severity of dementia**</mark> <mark style="background-color:cyan">**Dining environment**</mark>	Secondary analysis limited the availability of videos. Videos were from a communication study so specific interactions had been recorded. Types of environmental stimulations not clarified.

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
Murphy et al 2017 Nursing home in UK	Provide a research informed model of nutritional care in care homes for people with dementia – to inform and upskill those responsible for delivering food and nutrition.	9 focus groups, 5 semi-structured interviews Data analysis: thematic based on Braun and Clarke stages of analysis.	Purposive sampling. Variety of professions and family members from 27 care organisations –	7 domain areas made up the model. Person-centred care at the centre. Outer circle: availability of food and drink; tools, resources and environment; relationship to others when eating; participation in activities; consistency of care;	Personal preferences for food. Knowing the person. Relationship with care staff – consistency of care. Staffing levels if in an institution. Menu presentation and time to make choices. Familiarity of tools and utensils. Using activities around the meal time to	Single method – focus groups and interviews, same topics and questions. Did not include people with dementia. Only comments relevant to the research question were transcribed – risk of missing detail in an inductive analysis – could be bias in analysis and

Table: study characteristics of published empirical research selected for review.

Study and setting	Aim	Design/methods	Sample/recruitment	Results	Factors which influence eating and drinking	Limitations
				provision of information.	stimulate appetite	findings. 1 nursing home – not generalizable.
Nell et al 2016

Specialised Dementia care units in New Zealand | Explore the perceptions of staff caregivers regarding factor affecting optimal nutrition and hydration. | Semi structured interviews, analysed using an inductive thematic approach. | 11 experiences caregivers in 2 specialised dementia care units

Convenience sample. | 2 main themes – "it's about the individual" and "It's about the environment"

Nutrition and hydration is complex and multifactorial – inter-related factors. | Person centred care – appetite, food appeal, cognitive and functional abilities, Sundowning symptoms.

Environmental factors

Activity levels during the day influencing appetite. | Did not include people with dementia. Limited generalizability. |
| Reed et al 2005 | To describe prevalence, | Structured observation using | 407 residents, 45 | Significantly less food and fluid | Dining environment | Doesn't go into depth about |

Table: study characteristics of published empirical research selected for review.						
Study and setting	Aim	Design/methods	Sample/recruitment	Results	Factors which influence eating and drinking	Limitations
Residential care/ assisted living/ nursing care in USA	assessment and treatment of food and fluid intake as well as characteristics associated.	Structured Mealtime Observation tool. Measure food and fluid intake not nutritional value. Analysis: Bivariate linear and logistic regression	facilities, 4 states.	intake in Nursing care than RC/AL. Still 50% prevalence of poor food and fluid intake over all.	<mark>Cognitive impairment</mark> <mark>Levels of staff assistance and support.</mark>	characteristics and outcome of SMO tool – focussed on prevalence of eating. Sample and recruitment methods in another paper.
Slaughter et al 2011 Nursing homes in Calgary, Canada	Estimate incidence and identify predictors of eating disability.	1 year, prospective cohort study. Ability to eat monitored every 2 weeks. Observed ability to eat. Medications and	120 nursing home residents with middle-stage dementia, variety of dementia types Sample size calculation – 96	No statistically significant predictors of excess eating disability	<mark>Severity of dementia</mark> <mark>Comorbidities</mark> <mark>Supportive environment</mark>	Not eating was considered loss of ability but does not consider other possible reasons.

Appendix

Study and setting	Aim	Design/methods	Sample/recruitment	Results	Factors which influence eating and drinking	Limitations
		demographics collected and changes monitored every 2 weeks. Quality of NH environments used the Professional Environmental Assessment Protocol. Data analysis: Cox regression models, multivariate models,	residents			
Slaughter & Hayduk 2012				Significant effect on disability onset	**Environment**	

Table: study characteristics of published empirical research selected for review.						
Study and setting	**Aim**	**Design/methods**	**Sample/recruitment**	**Results**	**Factors which influence eating and drinking**	**Limitations**
Same study as above				= comorbidities, environment	Comorbidities	
Watson & Deary 1997 Psychogeriatric and continuing care of the elderly wards in UK	To study the relationship between nursing intervention and feeding difficulty.	EdFED-Q completed by nurses working in the wards.	78 participants	Causal relationship not found between nursing intervention and feeding difficulty.		Use of nurses working on the unit – risk of bias, nurses may already know the patients. Raters rate both nursing intervention and feeding difficulty at the same time. Only considering one factor, nursing intervention.

Appendix CTable of study analysis using the MMAT

Study	Study design (MMAT descriptor)	Quality checklist questions
Chang et al 2006	Quantitative RCT	1. Is randomization appropriately performed? *Yes - for the NHs, unclear about the participants but maybe based on the home they were in.* 2. Are the groups comparable at baseline? *Yes – further description of characteristics at baseline are described in the results* 3. Are there complete outcome data? *Yes* 4. Are outcome assessors blinded to the intervention provided? *Not clear* 5. Did the participants adhere to the assigned intervention? *Yes – only 1 drop out clearly explained.*
Liu et al 2016	Quantitative RCT	1. Is randomization appropriately performed? *Can't tell – just states "randomized" but no specific detail.* 2. Are the groups comparable at baseline? *Yes – from the limited info in describing the primary study* 3. Are there complete outcome data? *Yes* 4. Are outcome assessors blinded to the intervention provided? *Can't tell – not specified in the paper for secondary or primary study.* 5. Did the participants adhere to the assigned intervention? *Yes*
Liu et al 2017	Quantitative RCT	1. Is randomization appropriately performed? *Can't tell – just states "randomized" but no specific detail.* 2. Are the groups comparable at baseline? *Yes – from the limited info in describing the primary study*

Appendix

Study	Study design (MMAT descriptor)	Quality checklist questions
		3. Are there complete outcome data? *Yes* 4. Are outcome assessors blinded to the intervention provided? *Can't tell – not specified in the paper for secondary or primary study.* 5. Did the participants adhere to the assigned intervention? *Yes*
Chang 2012	Quantitative non-randomized	1. Are the participants representative of the target population? *Yes* 2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? *Yes – justified and clearly explained, also relevant to the target population in using the Chinese versions* 3. Are there complete outcome data? *Yes* 4. Are the confounders accounted for in the design and analysis? *Yes* 5. During the study period, is the intervention administered (or exposure occurred) as intended? *Yes*
Slaughter et al 2011 / Slaughter and Hayduk 2012 (same study)	Quantitative non-randomized	1. Are the participants representative of the target population? *Yes – sample size calculated and explained, 15 NHs* 2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? *Can't tell – lack of description of what was being observed, other tools for the environment etc reliable and valid.* 3. Are there complete outcome data? *Yes* 4. Are the confounders accounted for in the design and analysis? *Can't tell* 5. During the study period, is the intervention administered (or exposure occurred) as intended? *Can't tell*
Chang et al	Quantitative	1. Are the participants representative of the target

Study	Study design (MMAT descriptor)	Quality checklist questions
2017	non-randomized	population? *Yes – statistical power calculation – required participant number exceeded.* 2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? *Yes – well justified as reliable, psychometrically sound.* 3. Are there complete outcome data? *Yes* 4. Are the confounders accounted for in the design and analysis? *Can't tell – although does discusss findings from previous studies by the same author.* 5. During the study period, is the intervention administered (or exposure occurred) as intended? *Yes*
Amella 1999 / Amella 2002 (same study)	Quantitative descriptive	1. Is the sampling strategy relevant to address the research question? *Can't tell – sample strategy not described.* 2. Is the sample representative of the target population? *Yes – represents typical American urban north-east care home. Good cultural diversity of participants.* 3. Are the measurements appropriate? *Yes* 4. Is the risk of nonresponse bias low? *Yes* 5. Is the statistical analysis appropriate to answer the research question? *Yes*
Edihiro et al 2012	Quantitative descriptive	1. Is the sampling strategy relevant to address the research question? *Yes* 2. Is the sample representative of the target population? *Yes – variety of care settings, large sample size, but disproportionate of men and women.* 3. Are the measurements appropriate? *Yes* 4. Is the risk of nonresponse bias low? *Yes – expert clinicians used to determine participants included, not researcher.* 5. Is the statistical analysis appropriate to answer the research question? *Yes – shows comparison and correlations to*

Study	Study design (MMAT descriptor)	Quality checklist questions
		determine factors affecting self-feeding in patients with AD.
Gilmore-Bykovski 2015	Quantitative descriptive	1. Is the sampling strategy relevant to address the research question? *Can't tell – clear eligibility criteria but no sample calculation described.* 2. Is the sample representative of the target population? *Yes – all NH residents and care workers.* 3. Are the measurements appropriate? *Yes – good IRR described, appropriate to answer the aims.* 4. Is the risk of nonresponse bias low? *Can't tell* 5. Is the statistical analysis appropriate to answer the research question? *Yes – time series and sequential analysis was appropriate for identifying the temporal factors of person centred and task centred actions before eating behaviours.*
Batchelor-Murphy et al 2017	Quantitative descriptive	1. Is the sampling strategy relevant to address the research question? *Yes – clear inclusion and exclusion criteria, drop outs clearly explained. No power calculations.* 2. Is the sample representative of the target population? *Yes – nursing home residents with Alzheimer's or dementia, across 11 NHs.* 3. Are the measurements appropriate? *Yes* 4. Is the risk of nonresponse bias low? *Yes – different research assistants doing data collection, good IRR.* 5. Is the statistical analysis appropriate to answer the research question? *Yes – lower participant number so descriptive stats used, non-directional*
Hung and Chaudhury 2011	Qualitative	1. Is the qualitative approach appropriate to answer the research question? *Yes – exploratory.* 2. Are the qualitative data collection methods adequate to address the research question? *Yes – rich, in depth, good to have variety of participant type e.g. staff and family members,*

Study	Study design (MMAT descriptor)	Quality checklist questions
		and variety of methods e.g. observations and interviews. 3. Are the findings adequately derived from the data? *Yes* 4. Is the interpretation of results sufficiently substantiated by data? *Yes – quotes and examples from the observations and interviews* 5. Is there coherence between qualitative data sources, collection, analysis and interpretation? *Yes*
Hanssen and Kuven 2016	Qualitative	1. Is the qualitative approach appropriate to answer the research question? *Yes – exploring meanings.* 2. Are the qualitative data collection methods adequate to address the research question? *Yes – open narrative, space for open discussion.* 3. Are the findings adequately derived from the data? *Yes* 4. Is the interpretation of results sufficiently substantiated by data? *Yes – but limited, e.g. not many quotes from the interviews.* 5. Is there coherence between qualitative data sources, collection, analysis and interpretation? *Yes*
Nell et al 2016	Qualitative	1. Is the qualitative approach appropriate to answer the research question? *Yes* 2. Are the qualitative data collection methods adequate to address the research question? *Yes – interviews appropriate as gaining understanding of perspectives* 3. Are the findings adequately derived from the data? *Yes* 4. Is the interpretation of results sufficiently substantiated by data? *Yes – lots of quotes from transcripts.* 5. Is there coherence between qualitative data sources, collection, analysis and interpretation? *Yes*
Lea et al 2017	Qualitative	1. Is the qualitative approach appropriate to answer the research question? *Yes*

Study	Study design (MMAT descriptor)	Quality checklist questions
		2. Are the qualitative data collection methods adequate to address the research question? *Yes – exploring perspectives*
		3. Are the findings adequately derived from the data? *Yes*
		4. Is the interpretation of results sufficiently substantiated by data? *Yes*
		5. Is there coherence between qualitative data sources, collection, analysis and interpretation? *Yes*
Murphy et al 2017	Qualitative	1. Is the qualitative approach appropriate to answer the research question? *Yes*
		2. Are the qualitative data collection methods adequate to address the research question? *Yes - although limited, mixed or multiple methods may have given more detail*
		3. Are the findings adequately derived from the data? *Yes – seems researchers were selective about what bits of interviews/focus groups were transcribed – not allowing for wider extraction from the data.*
		4. Is the interpretation of results sufficiently substantiated by data? *Yes*
		5. Is there coherence between qualitative data sources, collection, analysis and interpretation? *Yes*
Chang and Roberts 2008b	Mixed Methods	1. Is there an adequate rationale for using a mixed methods design to address the research question? *Yes – doesn't specifically state it is a mixed methods study, justifies the use of additional field note observations to fill gaps left by EdFED and addition of interviews with nursing assistants.*
		2. Are the different components of the study effectively integrated to answer the research question? *Can't tell – described separately but not integrated*
		3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? *Yes – clear*

Study	Study design (MMAT descriptor)	Quality checklist questions
		discussion of factors influencing meals 4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? *Can't tell* 5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved? *Yes – clearly justified.*
Hammar et al 2016	Mixed Methods	1. Is there an adequate rationale for using a mixed methods design to address the research question? *Yes – explains theoretical approach although quantitative data does not seem relevant to the research aim of understanding caregiver experiences.* 2. Are the different components of the study effectively integrated to answer the research question? *No* 3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? *No* 4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? *No* 5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved? *Yes. Would have come out stronger if just a quantitative study – unclear about mixed methods value of the quantitative and limited integration of results or discussion.*

Appendix D Table of study analysis using CASP tool

Table of analysis of published literature reviews, using the CASP checklist for systematic literature reviews										
Literature review (reference)	1. Did the review address a clearly focused question?	2. Did the authors look for the right kind of papers?	3. Do you think all the important relevant studies were included?	4. Did the review's authors do enough to assess quality of the included studies?	5. If the results were combined was it reasonable to do so?	6. What are the overall results of the review?	7. How precise are the results?	8. Can the results be applied to the local population?	9. Were all important outcomes considered?	10. Are the benefits worth the harms and costs?
Aselage 2010	YES Aim: to examine instruments currently available for clinical use to assess meal time difficulties	YES Integrative review – both qualitative and quantitative included	YES Wide range of data bases searched. Up to 2010.	YES Includes reliability, validity and feasibility of use in clinical practice	N/A	12 observational instruments found. Most reported valid and reliable assessment tool = the EdFED	Discusses each tool individually and thoroughly	YES Limited as no papers included hospital setting	YES	YES Valuable for clinical practice and further research into the topic.
Aselage & Amella 2010	YES Aim: to identify a	CAN'T TELL	YES within the dates 1988-2008	YES Included more than	YES	48 sources. Uses Chang and Roberts 2008a to	In depth	YES Limited as no papers	YES	YES Comprehensive summary of

Table of analysis of published literature reviews, using the CASP checklist for systematic literature reviews

Literature review (reference)	1. Did the review address a clearly focused question?	2. Did the authors look for the right kind of papers?	3. Do you think all the important relevant studies were included?	4. Did the review's authors do enough to assess quality of the included studies?	5. If the results were combined was it reasonable to do so?	6. What are the overall results of the review?	7. How precise are the results?	8. Can the results be applied to the local population?	9. Were all important outcomes considered?	10. Are the benefits worth the harms and costs?
	broad scope of antecedents, attributes and consequences of meal time difficulties			suggested number for evolutional concept analysis		frame results.		included hospital setting		factors influencing meal time difficulties.
Bunn et al 2016	YES Aim: assess effectiveness of interventions aimed at improving/ maintaining/ facilitating	YES Intervention studies	YES Worldwide MEDLINE +12 more databases. Searched bibliographies	YES Narrative synthesis	YES	56 interventions from 51 papers. Intervention types: - environment and food service - education or training - behavioural	Comprehensive tables of characteristics.	YES Worldwide representative. Limited to nursing homes, does not include	YES	YES

Appendix

Table of analysis of published literature reviews, using the CASP checklist for systematic literature reviews										
Literature review (reference)	1. Did the review address a clearly focused question?	2. Did the authors look for the right kind of papers?	3. Do you think all the important relevant studies were included?	4. Did the review's authors do enough to assess quality of the included studies?	5. If the results were combined was it reasonable to do so?	6. What are the overall results of the review?	7. How precise are the results?	8. Can the results be applied to the local population?	9. Were all important outcomes considered?	10. Are the benefits worth the harms and costs?
	food and fluid intake					interventions -exercises - multicomponent		hospital setting.		
Chang & Roberts 2008a	YES Aim: to identify characteristics of feeding difficulties, to provide direction for assessment and management	YES Keywords appropriate to aim.	YES Could have been wider search of databases but still included relevant ones	YES Concept analysis	YES	71 articles included. Model of feeding difficulties : Antecedents, Attributes and Consequences.	Model presents a clear precise summary of the results and discussion.	YES	YES	YES
Cipriani et al	YES	YES	YES	CAN'T TELL	YES	89 articles include	Very	CAN'T TELL	CAN'T TELL	YES

Table of analysis of published literature reviews, using the CASP checklist for systematic literature reviews

Literature review (reference)	1. Did the review address a clearly focused question?	2. Did the authors look for the right kind of papers?	3. Do you think all the important relevant studies were included?	4. Did the review's authors do enough to assess quality of the included studies?	5. If the results were combined was it reasonable to do so?	6. What are the overall results of the review?	7. How precise are the results?	8. Can the results be applied to the local population?	9. Were all important outcomes considered?	10. Are the benefits worth the harms and costs?
2016	Aim: to explore generalized problems with nutrition, diet, feeding and eating reported among people with dementia	Covered all types of dementia.\n\nWide range of key word searches	Only MEDLINE and Google Scholar, but Google Scholar is a wide search engine so should cover other data bases. Bibliographies searched.		To summarise the different types of dementia.	Dietary changes occur with deteriorating cognitive dysfunction and as dementia progresses.	comprehensive description	No study characteristics included.		Combined with other results, building a valuable understanding of eating and drinking difficulties.
Douglas & Lawrence 2015	YES:\nTo evaluate research on environmental based interventions	YES	YES\nMultiple key databases searched, but limited search	YES\nClearly described and tabulated.	YES	30 articles included.\nValue of volunteers for feeding assistance. Meal service	Included statistics to evidence study results.	YES\nWide variety of settings and geographical areas.	YES	YES\nInforms practice of effective interventions.

Table of analysis of published literature reviews, using the CASP checklist for systematic literature reviews										
Literature review (reference)	1. Did the review address a clearly focused question?	2. Did the authors look for the right kind of papers?	3. Do you think all the important relevant studies were included?	4. Did the review's authors do enough to assess quality of the included studies?	5. If the results were combined was it reasonable to do so?	6. What are the overall results of the review?	7. How precise are the results?	8. Can the results be applied to the local population?	9. Were all important outcomes considered?	10. Are the benefits worth the harms and costs?
			terms. Still, reference lists searched for wider inclusion.			delivery style influenced meal times.				
Herke et al 2018	YES Aim: to assess the effects of environmental or behavioural modification s on food and fluid intake in people with dementia	YES Relevant databases including Specialized Register of Cochrane Dementia and Cognitive Impairment	YES Wide search of databases and reference lists.	YES Clear tools and methods listed.	YES Intervention groups.	9 studies, 1502 participants. Overall quality of evidence was low.	Detailed	YES	YES	YES Identifies further research needed to inform interventions.
Leah 2016	YES	YES	YES	YES	YES and	22 articles	Clearly	YES	YES	YES

Table of analysis of published literature reviews, using the CASP checklist for systematic literature reviews

Literature review (reference)	1. Did the review address a clearly focused question?	2. Did the authors look for the right kind of papers?	3. Do you think all the important relevant studies were included?	4. Did the review's authors do enough to assess quality of the included studies?	5. If the results were combined was it reasonable to do so?	6. What are the overall results of the review?	7. How precise are the results?	8. Can the results be applied to the local population?	9. Were all important outcomes considered?	10. Are the benefits worth the harms and costs?
	Aim: to identify the best ways of supporting people with dementia to eat	Clear framework used to address the questions: PICOTS. Variety of search terms. Controlled trials.	Potentially limited by quantitative papers only but that was expected of the type of review.	2 independent reviewers

Quality Assessment tool clearly described | justification given. | included. Interventions identified: educational, environmental, assistance with eating, mixed interventions. | displayed and quality tools used, in depth. | All relevant to dementia settings, but primarily long term care and nursing homes. | | |
| Liu et al 2014 | YES to evaluate effects of interventions on meal times difficulties in older adults with | YES 9 RCTs out of 22 studies. Variety of study types | YES Wide range of data bases, Google Scholar and bibliographies searched. | YES Quality assessment tools clearly described | YES | 22 studies included.

Low evidence for improved food and fluid intake with interventions identified. | | YES Specific to older people and dementia. | YES Detailed in the paper. | YES |

Table of analysis of published literature reviews, using the CASP checklist for systematic literature reviews

Literature review (reference)	1. Did the review address a clearly focused question?	2. Did the authors look for the right kind of papers?	3. Do you think all the important relevant studies were included?	4. Did the review's authors do enough to assess quality of the included studies?	5. If the results were combined was it reasonable to do so?	6. What are the overall results of the review?	7. How precise are the results?	8. Can the results be applied to the local population?	9. Were all important outcomes considered?	10. Are the benefits worth the harms and costs?
	dementia									
Liu et al 2015	To evaluate the effectiveness of interventions on eating performance for older adults with dementia	YES Appropriate data bases and key words	YES within the dates: January 1980 – June 2014.	YES Quality assessment tool	YES Grouped into intervention types	11 intervention studies. 4 strong quality, 4 moderate quality, 3 weak quality. Adequate meal times assistance and training programs targeting older adults demonstrated good evidence in decreasing feeding difficulty.	Good – describes study methods and outlines quality assessment	YES Older adults with dementia. Limited to long term care.	YES	YES Informative for answering research question. Applicable to practice.

Table of analysis of published literature reviews, using the CASP checklist for systematic literature reviews

Literature review (reference)	1. Did the review address a clearly focused question?	2. Did the authors look for the right kind of papers?	3. Do you think all the important relevant studies were included?	4. Did the review's authors do enough to assess quality of the included studies?	5. If the results were combined was it reasonable to do so?	6. What are the overall results of the review?	7. How precise are the results?	8. Can the results be applied to the local population?	9. Were all important outcomes considered?	10. Are the benefits worth the harms and costs?
McGillvray & Marland 1999	YES To review literature on assisting people with dementia with feeding difficulties; to consider the implications for nursing practice; outline the process of change required for implications for nursing.	CAN'T TELL No clear search method described.	CAN'T TELL Just one search database used. Reference lists also checked.	CAN'T TELL Quality criteria not reported but study methods described throughout the review.	YES To fit the categories discussed.	Organizational and staff factors, meal time social factors, all considered influential to feeding difficulties. Implications for nursing practice includes the need for staff education and training, further research needed for assessing feeding difficulties.	Good descriptive detail in text. No tables or statistics presented.	YES Older people with dementia	CAN'T TELL	YES Although quality and methods not clear, findings support other studies and literature reviews which have been completed since 1999. Clear implications for practice.

Appendix

Table of analysis of published literature reviews, using the CASP checklist for systematic literature reviews

Literature review (reference)	1. Did the review address a clearly focused question?	2. Did the authors look for the right kind of papers?	3. Do you think all the important relevant studies were included?	4. Did the review's authors do enough to assess quality of the included studies?	5. If the results were combined was it reasonable to do so?	6. What are the overall results of the review?	7. How precise are the results?	8. Can the results be applied to the local population?	9. Were all important outcomes considered?	10. Are the benefits worth the harms and costs?
Watson and Green 2006	YES Is there evidence for any effective interventions to assist older people with dementia to feed?	YES Clear relevant search terms	YES Range of appropriate databases. Unavailable papers through other university access.	YES Quality criteria outlined in table.		13 papers addressing interventions. 1 RCT. Lack of statistical power. Too many confounding variables to know what is individually effective .	Focused on behaviour aspects of eating. Clear tabulation of results.	YES	Yes Clearly tabulated	YES Applicable to practice and further research implications.
Whear et al 2014	YES Examine effectiveness of interventions	YES Clear and comprehensive list of search terms.	YES 14 databases, included grey	YES Quality guidelines described Reviewed	YES Groups of intervention types.	11 articles included. Poor quality of studies meant	Table of study characteristics.	YES But focusses on reducing agitation rather than		YES

Table of analysis of published literature reviews, using the CASP checklist for systematic literature reviews

Literature review (reference)	1. Did the review address a clearly focused question?	2. Did the authors look for the right kind of papers?	3. Do you think all the important relevant studies were included?	4. Did the review's authors do enough to assess quality of the included studies?	5. If the results were combined was it reasonable to do so?	6. What are the overall results of the review?	7. How precise are the results?	8. Can the results be applied to the local population?	9. Were all important outcomes considered?	10. Are the benefits worth the harms and costs?
	aimed at reducing agitation at meal times for people with dementia		literature. 2 reviewers selecting papers.	by 3 reviewers and discrepancies resolved.		difficulty drawing conclusions.		improved engagement in meal times.		

Appendix E DCM blank raw data sheet

Blank raw data sheet

Date:		Time period:		Place:	

Total number of service users:		Number of staff:		Observer:	

Participant name	Time																						Total ME
																							Total TF
	BCC																						
	ME																						
	BCC																						
	ME																						
	BCC																						
	ME																						
	BCC																						
	ME																						
	BCC																						
	ME																						

Appendix F Participant Information Sheet – observations

PARTICIPANT INFORMATION SHEET: OBSERVATIONS

Title: Improving meal time experiences for people with dementia on acute hospital wards.

You are being invited to take part in this study. Please read the information before deciding whether to take part or not.

What is the research about?

- People with dementia may struggle to eat and drink enough to meet their body's needs. This can be especially worrying when people are unwell in hospital.
- The research you are being invited to join is part of a PhD project at the University of Southampton.
- The main aim is to understand the big picture of what is happening at meal times in hospital and how people with dementia experience this. It aims to look into what may influence how much people eat or drink.

Why have I been chosen?

- As you know what it is like to have dementia your insight is extremely valuable for the study.
- The nurses on the ward/your loved ones have concerns that you are finding it difficult to eat enough while you have been in hospital.
- Seeing your experiences of the meal times in hospital will help start to understand the big picture.

What will happen to me if I take part?

- It is completely up to you if you want to be part of the study or not.

- If you choose to take part in you will not have to do anything other than your normal daily activities.

- The PhD student doing the research will approach you to ask if you are happy for her to sit and watch over the meal time.
- She will ask you to sign a consent form to prove you have agreed.
- She will sit on the ward for about 3 hours over a meal time and take notes.
- As the research does not involve any other direct contact with you, there are no risks involved in you taking part.

What happens if I change my mind?

- The consent form does not mean you are tied into anything.
- You can leave the study at any time, before, during or after the observations.
- Neither your hospital care nor legal rights will be effected if you choose to leave the study.

Are there any benefits in my taking part?

- There will be no benefit to you directly.
- The study is aiming to benefit many more people in the future.
- It is hoped that the outcomes from the research will be able to impact how people are cared for when they go into hospital.

Will my participation be confidential?

- Nobody other than the researcher will know if you have agreed to take part in the research or not.
- There will be nothing in the notes taken during observations to give away who, or where, you are.
- After each session on the ward the information collected will be put into a spreadsheet which will protected with a password.
- When the research is published, nothing written there give away who or where you are.

Where can I get more information?

The nurses on the ward will have information about the research so they may be able to answer any questions.

You, your nurse, or your family can contact Naomi Gallant at any time during the day.
Email: ng1f14@soton.ac.uk
Phone:

Thank you for your interest in this study.

Appendix G   Consent form – observations

CONSENT FORM

Study title: Improving meal time experiences for people with dementia on acute hospital wards.

Researcher name: Naomi Gallant

Ethics reference:

*Please **initial** the box if you agree with the statement(s):*

I have read and understood the information sheet and have had
the opportunity to ask questions about the study.

I agree to take part in this research project and agree for my data
to be used for the purpose of this study.

I understand my participation is voluntary and I may withdraw at
any time without care or legal rights being affected.

I am happy to be contacted regarding other unspecified research
projects. I therefore consent to the University retaining my
personal details on a database, kept separately from the research
data detailed above. The 'validity' of my consent is conditional
upon the University complying with the Data Protection Act and I
understand that I can request my details be removed from this
database at any time.

Data Protection

*I understand that information collected about me during my participation in this study will be stored
on a password protected document and that this information will only be used for the purpose of
this study. All files containing any personal data will be made anonymous*

Name of participant (print name)…………………………………………………

Signature of participant……………………………………………………………..

Date……………………………………………

Appendix H   Consultee Information Sheet

CONSULTEE INFORMATION SHEET: OBSERVATIONS

Title: Improving meal time experiences for people with dementia on acute hospital wards.

Your family member/friend/patient is being invited to take part in this study. Due to their lack of understanding of what the study is about, you are being asked to decide whether or not they would want to take part.

Please read the information before making the decision.

What is the research about?

- People with dementia may struggle to eat and drink enough to meet their body's needs. This can be especially worrying when people are unwell in hospital.
- The main aim is to understand the big picture of what is happening at meal times in hospital and how people with dementia experience this. It aims to look into what may influence how much people eat or drink.
- The research is part of a PhD project at the University of Southampton. It is funded by the National Institute of Health Research (NIHR), Wessex Collaboration of Leadership in Applied Health Research and Care (CLAHRC)

Why have I been chosen?

- You are being asked to make this decision as your family member/friend does not understand enough to make the decision for themselves.
- You will be asked to sign a form of assent on their behalf.
- As your family member/friend knows what it is like to have dementia their insight is extremely valuable for the study. Concerns that they are finding it difficult to eat enough while they have been in hospital have

    been raised. Seeing their experiences of the meal times in hospital will help start to understand the big picture.

What will happen to the person who takes part?

- It is completely up to you if feel they would want to be part of this research.

- If they take part in they will not be expected to do anything other than normal daily activities.

- The PhD student doing the research will approach to ask if they are happy for her to sit and watch over the meal time. This is the only time there will need to be any contact with her.

- As the research does not involve direct contact, there are limited risks involved in taking part. The person being observed may become distressed at the presence of the researcher, at which point the observation would stop.

What happens if I change my mind?

- The consent form does not mean you are tied into anything.
- The study can be left at any time, before, during or after the observations.
- Any signal that the person is not happy for the researcher to be in the room will be noted and the observation will stop.
- Leaving the study will not affect the care received or legal rights.

Are there any benefits in taking part?

- There will be no direct benefit to the person being observed.

- The study is aiming to benefit many more people in the future.

- It is hoped that the outcomes from the observations will be able to impact how people are cared for when they go into hospital.

Will participation be confidential?

- Nobody other than the researcher will be told if you have agreed to somebody taking part in the research or not.

- There will be nothing in the notes taken during observations to give away who, or where, they are.

- After each session on the ward the information collected will be put into a spreadsheet which will be protected with a password.

- When the research, or related papers, are published, no published information will give away who or where the participants were.

Where can I get more information?

The nurses on the ward will have information about the research so they may be able to answer any questions.

You can contact Naomi Gallant at any time during the day.
Email: ng1f14@soton.ac.uk
Phone:

Thank you for your interest in this study.

Appendix I Consultee Agreement Form

CONSULTEE AGREEMENT FORM

Study title: Improving meal time experiences for people with dementia on acute hospital wards.

Researcher name: Naomi Gallant

Ethics reference:

*Please **initial** the box if you agree with the statement(s):*

I have read and understood the information sheet and have had the opportunity to ask questions about the study.

I agree for my family member/friend to take part in this research project and agree for my data to be used for the purpose of this

I understand their participation is voluntary and they may withdraw at any time without care or legal rights being affected.

I am happy to be contacted regarding other unspecified research projects. I therefore consent to the University retaining my personal details on a database, kept separately from the research data detailed above. The 'validity' of my consent is conditional upon the University complying with the Data Protection Act and I understand that I can request my details be removed from this database at any time.

Data Protection

I understand that information collected about my family member/friend during their participation in this study will be stored on a password protected document and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of participant (print name)…………………………………………………

Signature of assent……………………………………………………………..

Date…………………………………………………………………………………

Appendix J Recruitment poster for interviews

Exploring current interventions used to improve meal time experiences for people with dementia on the ward

Are you a….

Health Care Support Worker?

Nurse?

Occupational Therapist?

Doctor?

Physiotherapist?

Therapy Assistant?

Dietitian?

Speech and Language Therapist?

You are being invited to take part in interviews about meal times on the ward and your role in nutritional care.

For more information please contact Naomi Gallant (PhD Student)
Email: ng1f14@soton.ac.uk

Phone: 07…….

Appendix

Appendix K   Participant Information Sheet – interviews

PARTICIPANT INFORMATION SHEET: INTERVIEWS

Title: Improving meal time experiences for people with dementia on acute hospital wards; and describing current interventions used to improve food and fluid intake.

You are being invited to take part in this study by being interviewed about meal times on the ward.

Please read the information before deciding whether to take part or not.

What is the research about?

- People with dementia may struggle to eat and drink enough to meet their body's needs. This can be especially worrying and problematic when people are unwell in hospital.

- The main aim is to understand the big picture of what is happening at meal times in hospital and how people with dementia experience this. It aims to look into what may influence how much people eat or drink and if there are any interventions being used at present.

- The role of the different professions in the multidisciplinary team is of particular interest. You will be asked about how you consider your role to impact eating and drinking for people with dementia.

- The research is part of a PhD project at the University of Southampton. It is funded by the National Institute of Health Research (NIHR), Wessex Collaboration of Leadership in Applied Health Research and Care (CLAHRC)

Why have I been chosen?

You are being invited to take part in the research as you work with people with dementia on acute hospital wards. Your insight into what happens at meal times and current interventions used will be valuable to the overall findings of the study.

What will happen to me if I take part?

- It is completely up to you if want to be part of this research or not.
- If you agree to take part you will be asked to sign a consent form to prove you have agreed to be interviewed.
- The researcher will contact you to arrange an interview time.
- The interview will last 30 to 60 minutes and be recorded with an audio-recording device.

What happens if I change my mind?

- The consent form does not mean you are tied into anything.
- The study can be left at any time, before, during or after the interview.
- Leaving the study will not affect your legal rights.

Are there any benefits in taking part?

- There is not direct benefit to you taking part in the study.
- The study is aiming to benefit many more people in the future.
- It is hoped that the outcomes from the research will be able to impact how people are cared for when they go into hospital.

Will participation be confidential?

- Nobody other than the researcher will be told if you have agreed take part in the research or not.
- There will be nothing in the notes taken during interview to give away who, or where, you are.
- The interview recording will be transcribed at the earliest possible opportunity. It will be typed up into a password protected document and kept on a password protected computer.

- During the write up and publication of the research findings, direct quotes from your interview may be helpful to use as an example. In this case you will be given the opportunity choose your own pseudonym name to be used so you cannot be identified.

- Nothing which gives any clues to your identity will be included in the write up of results.

Where can I get more information?

Please contact Naomi Gallant at any time during the day (9am-5pm).
Email: ng1f14@soton.ac.uk

Phone:

Thank you for your interest in this study.

Appendix L   Consent Form – interviews

CONSENT FORM

Study title: Exploring current interventions used to improve meal time experiences for people with dementia on the ward.

Researcher name: Naomi Gallant

Ethics reference

*Please **initial** the box if you agree with the statement(s):*

I have read and understood the information sheet and have had
the opportunity to ask questions about the study.

I agree to take part in this research project and agree for my data
to be used for the purpose of this study.

I understand my participation is voluntary and I may withdraw at
any time without care or legal rights being affected.

I am happy to be contacted regarding other unspecified research
projects. I therefore consent to the University retaining my
personal details on a database, kept separately from the research
data detailed above. The 'validity' of my consent is conditional
upon the University complying with the Data Protection Act and I
understand that I can request my details be removed from this
database at any time.

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected document and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of participant (print name)…………………………………………………

Signature of participant…………………………………………………………..

Date…………………………………………………………………

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