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**Understanding Factors Affecting Optimal Nutrition and
Hydration for People Living in Specialised Dementia Care Units:
A Qualitative Study of Caregivers' Perceptions**

A thesis presented in partial fulfilment of the requirements for the degree
of

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Debra Nell
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Abstract

Background: Worldwide, 35.6 million people have dementia. The current aging world population means prevalence of dementia is expected to almost double every 20 years. Weight loss, undernutrition and dehydration are common in people with dementia especially among those who reside in specialised dementia care units (SDCUs). There are currently no foodservice guidelines specifically for SDCUs in New Zealand.

Aim: To understand factors affecting optimal nutrition and hydration for individuals living in SDCUs. **Objectives:** To explore the perceptions of caregivers regarding factors influencing intake of food and fluids, and to provide a range of potential recommendations for foodservice providers.

Methods: Qualitative descriptive study, using semi-structured interviews with 11 caregivers at 2 SDCUs. Data were analysed using a general inductive approach.

Findings: Environmental factors (relating to the surroundings of the dining environment, the social aspects to dining, and the need for and provision of support with mealtime activities), and individual factors (appetite, food appeal, and cognitive and functional abilities) affect food and fluid intake in people with dementia living in SDCUs.

Conclusion: Factors affecting the nutrition and hydration status of people living in SDCUs are complex and inter-related. Organisations providing specialised dementia care, their staff, and foodservice providers can take a number of steps to ensure optimal nutrition and hydration for the people they care for.

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Abbreviations

Abbreviation	Meaning
ARRC	Age-related residential care
SDCU	Specialised dementia care unit
WHO	World Health Organisation
AD	Alzheimer's disease
BMI	Body mass index
CDR scale	Clinical Dementia Rating scale
NASC	Needs Assessment and Service Coordination
MUHEC	Massey University Human Ethics Committee

1.0 Introduction

Optimal nutrition and hydration requires the individual to consume sufficient energy, protein, and other nutrients including fluids to maintain body processes and to protect the body from ill health. For many people in age-related residential care (ARRC) achieving and maintaining adequate nutrition and hydration status is a constant challenge, and unfortunately the situation is worse for those individuals with dementia (Holm & Söderhamn, 2003). People with dementia have at least the same requirements for good nutrition as the rest of the population. However, they may face more challenges when it comes to eating a healthy diet even when it is provided for them (Curfman, 2005). Many studies have shown that people with dementia are more likely to have poor nutritional status than those without dementia. There is also significant evidence that poor nutritional status is related to many conditions that can reduce the quality of life, cause illness, and eventually premature death (Aukner, Eide, & Iversen, 2013).

To present this study in context, it is necessary to consider a background to the topic. This chapter begins with an overview of the researcher's interest in the research topic. It then explores the definition of dementia, its prevalence both in New Zealand and internationally, its causes, and established care practice and guidelines. It provides a brief background to undernutrition associated with dementia and discusses current foodservice practice in specialised dementia care units (SDCUs) in New Zealand. This chapter also presents the research aim and objectives and provides a general overview of the thesis.

1.1 Researcher's Interest

Many qualitative researchers believe it is impossible to remain entirely objective (Minichiello, 1999). However, Finlay (2002) considers subjectivity to be transformed from a problem to an opportunity with the practice of reflexivity. This involves exposing assumptions and personal perspectives, which are bound to personal experiences (Holloway, 1997). Therefore, a researcher's background is of relevance to the research they undertake. This section provides an overview of my personal experiences in relation to the research topic.

Before I had ever considered a career in healthcare, I was studying to be an Architectural Technician when I landed a Saturday job as a catering assistant at a local private hospital which was part of an age-related residential care (ARRC) facility. This job provided an introduction to healthcare, to food service, and to working with older people. My experiences in this job paved the way for my interest and eventual move - some ten years later - away from architecture and into the field of health and nutrition.

I had been living in London, then Dubai for most of these years, working in a corporate environment and living the 'big city' life. Through my own experience dealing with irritable bowel syndrome, experimenting with various fad diets, and talking with friends in the healthcare industry (including a dietitian), I came to realise my passion was for understanding how the human body worked and how nutrition affected it. You could say I was more interested in helping to create better (healthier) bodies than helping to create better buildings and this realisation was the driving force for my

move back to New Zealand in 2005. In 2009, I graduated with a Bachelor of Science majoring in Human Nutrition.

Following this, I again worked in foodservice but this time at an ARRC facility in Melbourne, Australia. I remember learning for the first time about texture modified diets, thickened fluids, and different diets such as 'low potassium' or 'low fibre' for medical reasons. I also remember hearing from the nursing staff that residents on the lower floor (the 'standard' service level) had a tendency to drop weight after arriving whilst residents on the upper level (the more expensive, 'extra' services level) had a tendency to gain weight. In this facility there was also a third level, specifically for people with dementia. Residents on this floor tended to be of particularly slight build. Perhaps not surprisingly, then, they were also generally what I would have called "small eaters". It became apparent to me that nutrition played a key role in maintaining good health for older people especially those with dementia.

In 2012 I enrolled in the Master of Science, Nutrition and Dietetics programme at Massey University and part of this programme included completing a 90 credit research project. The topic for this particular research was proposed by dietitians at Compass Group – a company that provides foodservice to many ARRC facilities including SDCUs around New Zealand. My experiences with foodservice, older people, and people with dementia enabled me to see how valuable this research could be and inspired me to become involved.

1.2 Background and Justification for the Research

In 2010 the total number of people worldwide with dementia was estimated at 35.6 million. People worldwide are living longer and this global trend is expected to result in an increased prevalence of dementia in years to come. The World Health Organisation (WHO) expects the number of people with dementia to double by 2030 and more than triple by 2050 (2012). It is estimated that 2-8% of people over 60 years of age have dementia (World Health Organisation, 2012). In 2011 it was estimated that 1.1% of the total population of New Zealand (approximately 48,000 people) had some form of dementia and it was estimated there will be over 74,000 by 2026 (Alzheimers New Zealand, 2012).

Dementia is one of the major causes of disability and dependency among older people worldwide (World Health Organisation, 2012). Although dementia usually affects older people, it is not a normal part of ageing (World Health Organisation, 2012). Dementia is a syndrome, usually chronic or progressive in nature. It is characterised by a decline in cognitive function beyond that expected from normal ageing. This may include: altered behaviour; deterioration in memory, thinking, orientation, comprehension, learning capacity, language, and judgement; as well as the ability to perform activities of daily living. Deterioration in emotional control, social behaviour and motivation are also commonly seen with dementia (World Health Organisation, 2012). As dementia is a progressive disease, an individual's symptoms will increase over time until most functions of the brain are affected (Ministry of Health, n.d.).

Dementia can be caused by a number of diseases or injuries affecting the brain (World Health Organisation, 2012) and it is likely that a number of other factors including age, genetics and the environment are also involved (Alzheimers New Zealand, 2012). Alzheimer's disease (AD) is the most common cause, estimated to contribute to 60-70% of dementia cases (World Health Organisation, 2012). Other major causes are vascular dementia, dementia with Lewy bodies, Parkinson's disease, and frontal lobe dementia (Jacques & Jackson, 2000). The line between different forms of dementia is blurred, with more than one form often present (World Health Organisation, 2012). Each cause tends to affect different areas of the brain and will result in different changes in the individual's behaviour (Ministry of Health, n.d.).

Unwanted weight loss is a common occurrence in people affected by dementia (Guérin et al., 2005). Undernutrition has many negative health consequences and it often leads to reduced health-related quality of life (Aukner et al., 2013). The prevalence of undernutrition in residents of hospitals and ARRC is reportedly between 10 and 70% (Corish, Flood, Mulligan, & Kennedy, 2000; McWhirter & Pennington, 1994; Saletti, Lindgren, Johansson, & Cederholm, 2000; Wang et al., 2004). This large range is due to a lack of any universal criteria for identifying undernutrition; therefore, estimates vary depending on study groups and methodology (Stratton et al., 2004). A significant association between low body mass index (BMI) and atrophy of the part of the cerebral cortex involved in control of eating behaviour has been found (Grundman, Corey-Bloom, Jernigan, Archibald, & Thal, 1996). The reasons for unwanted weight loss in people affected by dementia are likely to be multi-factorial and the mechanisms

involved will vary depending on the type and stage of the disease as well as environmental conditions surrounding the individual (Aukner et al., 2013).

The predicted future increase of dementia cases will challenge healthcare systems worldwide (World Health Organisation, n.d.). The already high cost of dementia is expected to increase even more quickly than the prevalence (World Health Organisation, n.d.). The WHO (2012) recognises dementia as a public health priority. In Australia, dementia was recognised as a National Health Priority in 2005, with funding provided by the government for dementia research (Commonwealth Department of Health and Ageing, 2005). The New Zealand Ministry of Health has recognised a need for improvements in dementia care. However, to date little research has been undertaken on dementia care within New Zealand.

Although there is currently no cure for dementia, much can be done to support and improve the lives of people with dementia. The WHO sets out the principle goals for dementia care as optimising physical health, cognition, activity, and well-being, diagnosing cases early, detecting and treating behavioural and psychological symptoms, and providing information and long-term support to caregivers (World Health Organisation, n.d.).

Terminology used to describe different residential care settings varies around the world. In New Zealand, there are four types of ARRC for people with dementia, including rest homes, specialised dementia care units (SDCUs), long-term care hospitals, and specialised long-term care hospitals (Alzheimers New Zealand, 2010).

SDCUs are specifically set up to accommodate people with dementia by providing an environment ideally suited to their special requirements. They also function to protect those ARRC residents without dementia (Alzheimers Association, n.d.).

Good nutrition is essential to the health and quality of life of older adults (Weddle & Fanelli-Kuczmariski, 2000). Although ARRC facilities generally provide adequate quantities of food, many people with dementia may struggle to consume sufficient amounts (Parvizi & Nymon, 1982). Dietitians from foodservice providers Compass Group believe that people with dementia are likely to have specific mealtime requirements that differ from those individuals in general ARRC. These requirements are likely to be based on barriers and facilitators to eating and drinking commonly experienced by people with dementia. In New Zealand, the current menu typically provided in SDCU is no different to that of general ARRC. This may be due to a lack of any foodservice recommendations or guidelines specifically for SDCU. Compass Group proposed this research topic to Massey University as they were interested in offering a specialised menu to their dementia care clients.

1.3 Research Aim and Objectives

Aim: To understand factors affecting optimal nutrition and hydration for individuals living in SDCUs.

Objectives:

1. To explore the perceptions of caregivers regarding factors influencing intake of food and fluids for people living in SDCUs.

2. To provide a range of potential recommendations for foodservice providers in an attempt to ensure optimal nutrition and hydration for people living in SDCUs.

1.4 Structure of the Thesis

Chapter One: Introduction

Chapter One has introduced the study, and revealed the main researcher's interest in the topic. It has contextualised the research by providing a background and justification for the research, and outlined the aim and objectives. This overview of the thesis completes the chapter.

Chapter Two: Literature Review

Chapter Two presents a critical review of the literature relating to factors affecting the nutrition and hydration status of people with dementia. This review concentrates on research relating to SDCUs.

Chapter Three: Research Design

Chapter Three is presented in two parts. Firstly, the theory and rationale of the study design are presented with an overview of the qualitative descriptive approach. The second part presents a description of the actual execution of the study including the ethical approval process, details of the sampling strategy, data collection, sample size, data analysis, and data presentation.

Chapter Four: Findings

Chapter Four presents the findings following data analysis from semi-structured interviews with the study participants. A discussion of the main-themes and sub-themes identified is presented along with direct participant quotes and references to the literature to support the discussion.

Chapter Five: Discussion

In this chapter findings are discussed in relation to the literature and research question. Recommendations for foodservice providers based on the findings are presented, as are recommendations for future research. Limitations and strengths of the study are acknowledged and a concluding statement is presented.

1.5 Summary

Dementia is recognised by the WHO as a public health priority, with a predicted future increase in its prevalence set to challenge healthcare systems worldwide. Unwanted weight loss is a common occurrence in people affected by dementia and the reasons for this are likely to be multifactorial. However, much can be done to support and improve the lives of these people. Understanding why they struggle to eat and drink sufficient amounts is a vital step in the pathway to improved nutrition and hydration status.

A general ARRC menu is typically provided at SDCUs in New Zealand despite an acknowledged difference in the needs for this population compared to that of other

ARRC. This lack of a menu specific to the needs of people with dementia is due to a lack of guidelines or recommendations for dementia foodservice provision. The purpose of the present study was to understand factors affecting optimal nutrition and hydration for individuals living in SDCUs, with the intention to provide potential recommendations to foodservice providers to SDCUs. The following chapter provides a critical review of the literature relevant to the research topic.

2.0 Literature Review

2.1 Introduction

The following review discusses the literature relating to factors affecting optimal nutrition and hydration for people living in SDCUs. Literature was accessed primarily through the article database Scopus. Scopus was selected as it is a multidisciplinary database containing a comprehensive collection of international health and medical science journals, and also includes access to Medline. To expand the search and ensure an unbiased collection of literature was reviewed a second article database - Web of Knowledge was also searched. Key search terms used included: dementia, cognitive impairment, Alzheimer's, nutrition, food intake, hydration, fluid intake, foodservice, dining, mealtime, eating, and feeding. A variety of sources were used, including, qualitative and quantitative studies, review articles and books. The search was not limited to full-text documents. However, Google Scholar was used as necessary to assist in locating full-text articles unavailable through Scopus or Web of Knowledge. To reduce gaps in electronic searches, Scopus' electronic citation tracking feature was used and reference lists of key articles were read to locate additional articles. Only articles in English were considered in this review. To ensure literature used was the most current, there was an emphasis on literature published in the past ten years. However, older articles including seminal works have also been included. Further literature pertinent to the study was accessed from the World Health Organisation, and the New Zealand Ministry of Health websites. Consistent with the nature of qualitative research, the search continued through the research process

(mid-2012 to late-2013) in an open-ended iterative manner whereby the topic was developed over time with the emerging evidence (Finfgeld-Connett & Johnson, 2013).

This literature review begins with a background to dementia and nutritional issues commonly faced by people with dementia. This background section starts with a description of dementia, and how it affects individuals, it then outlines the prevalence and incidence of dementia both worldwide and in New Zealand. It outlines the types of residential care available to people with dementia in New Zealand and the foodservice provisions and requirements at these facilities. The dietary intake and nutritional status of people with dementia is discussed next, with a particular focus on those residing in residential care facilities. The main body of this review presents and discusses the literature regarding factors affecting nutrition and hydration for people with dementia living in ARRC and SDCUs. Finally, gaps in the literature are discussed and limitations of this review are highlighted.

2.2 Background to Dementia and Nutritional Issues for People with Dementia

2.2.1 What is dementia?

The World Health Organisation defines dementia as:

A syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function

is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation (World Health Organisation, 2012, para 1).

Dementia mainly affects older people, even so, it is not a normal part of ageing (World Health Organisation, 2012). Dementia has a dramatic effect on the lives of people affected by the illness as well as those surrounding them. Symptoms of dementia vary in different people and at different times, and care needs change as the disease progresses (Alzheimers New Zealand, 2008). With the current ageing population, the impact is felt in social, economic and health terms. Although there is currently no cure for dementia, much can be done to improve the quality of life of people affected (Alzheimers New Zealand, 2008).

2.2.2 Prevalence and incidence of dementia

Dementia affects approximately 35.6 million individuals worldwide, this number is expected to double by 2030 and triple by 2050, due to the increased life-span expectancy (Coppedè, Bosco, Fuso, & Troen, 2012; World Health Organisation, 2012). In 2008 there was estimated to be 40,746 people (1% of the population) with dementia in New Zealand and an estimated 12,333 new cases being diagnosed that year (Alzheimers New Zealand, 2008). By 2011 the number of people affected by dementia had risen to 48,182 (1.1% of the population) (Alzheimers New Zealand, 2011). It is predicted there will be 74,821 people (1.5% of the population) with dementia in New Zealand by 2026 and 146,699 people (2.7% of the population) by 2050, with 0.8% of the population being diagnosed with dementia each year

(Alzheimers New Zealand, 2011). In 2008, 92.7% of people in New Zealand with dementia were of European or other ethnicity, 3.6% were Maori, 3.0% were Asian and 1.7% were Pacific; of the total, 39.8% were male and 60.2% were female (Alzheimers New Zealand, 2008). The prevalence of dementia in people under 60 years of age is 0.01%, this increases to nearly 34% of those aged 90 years and over (Alzheimers New Zealand, 2008).

In New Zealand, approximately 55% of dementia cases are estimated to be mild (significant impact on daily activities but still able to undertake daily activities), 30% moderate (independent living is not possible without assistance), and 15% severe (permanent supervision required) based on The Clinical Dementia Rating (CDR) scale which is typically used to ascertain progression of dementia (Alzheimers New Zealand, 2008). The CDR scale uses a structured-interview protocol to assess a person's cognitive and functional performance in six areas, these are: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care (Morris, 1993).

In New Zealand, when a person with dementia can no longer be supported to live at home safely, based on an assessment by a Needs Assessment and Service Coordination (NASC) worker, they will typically move into ARRC. NASC are contracted by the New Zealand Ministry of Health to work with disabled people to help identify their needs and outline what disability support services are available to them. NASC will advise which type of ARRC facility is most appropriate based on the individual's needs.

2.2.3 Residential care for people with dementia

Behavioural problems are considered the most challenging issue in the care of people with dementia (Lai, Yeung, Mok, & Chi, 2009). Staff at SDCUs are usually specifically trained in caring for people with dementia and are therefore more tolerant of and better equipped to deal with behavioural issues (Lai et al., 2009). SDCUs are typically located within an ARRC facility providing a physical environment that is segregated from other areas. They usually have specially designed activity programmes and encourage family involvement (Lai et al., 2009).

In 2002, the Ministry of Health estimated there were approximately 35,000 licensed ARRC beds in New Zealand, with about 60-70% of people living in ARRC facilities having some form of dementia (Ministry of Health, 2002). This means some 21,000-24,500 individuals with dementia are being cared for in ARRC facilities around New Zealand. However, many of these individuals are not residing in SDCUs. In 2008 there were approximately 2,800 beds specifically designated to dementia care in New Zealand, this is expected to increase by 160% to 7,200 beds by 2026 (Grant Thornton, p. 91).

2.2.4 Foodservice in ARRC facilities including SDCUs

Scientific evidence increasingly supports that good nutrition is essential to the health and quality of life of older adults (Weddle & Fanelli-Kuczmariski, 2000). Therefore, food and eating are critical components of ARRC facilities (Lengyel, Smith, Whiting, & Zello, 2004). In fact, the American Dietetic Association regards eating as one of the most important aspects of daily life for older adults residing in ARRC facilities (Weddle & Fanelli-Kuczmariski, 2000). According to Lilley and Gaudet-LeBlanc (1992) the major

determinants of nutritional status for people in ARRC are food availability, food consumption, and the biological utilisation of food. It is generally agreed that ARRC facilities provide adequate quantities of foods that meet the residents' nutritional requirements, however, many residents do not consume adequate amounts of the food (Parvizi & Nymon, 1982). Parraga (1990) suggests food intake is dependent not only on quality and quantity of food provided but also on factors such as appetite, meal pattern habits, environment, health, and psycho-social functioning. Therefore, ARRC facilities, SDCUs, and their foodservice providers have the opportunity to promote nutritional intake by providing optimal dining environments, pleasing sensory experiences, and appropriate diagnosis and intervention for eating difficulties (Lilley & Gaudet-LeBlanc, 1992).

In New Zealand, foodservice in ARRC facilities including SDCUs must comply with the Health and Disability Sector Standards for nutritional adequacy (Standards New Zealand, 2008). Approval must also be obtained from the local District Health Board, and (unless an exemption has been granted) they must also comply with the current food safety legislation.

2.2.5 Dementia - dietary intake and nutritional status

Feeding difficulties related to cognitive impairment are common in people with dementia (Manthorpe & Watson, 2003). Reduced ability to eat and drink independently, make a person susceptible to malnutrition and dehydration (Lengyel et al., 2004). Malnutrition contributes to the lowering of general health status, and to the frequency and severity of multiple complications that impair independence, quality of

life and ultimately survival (Guérin et al., 2005; Jesus et al., 2012). More specifically, these complications include weight loss, infection, impaired wound healing, immune deficiency, and development of pressure sores (Volicer, Warden, & Morris, 1999). Dehydration can lead to constipation, urinary tract infections, renal disease, pneumonia, hypotension, and delirium (Spangler & Chidester, 1999; Volicer et al., 1999). These issues have long been recognised as serious problems among hospitalised patients and people living in ARRC, particularly among those with dementia (McWhirter & Pennington, 1994; Van Ort & Phillips, 1995).

Poor nutrient intake and nutritional status are common complications of dementia and have been extensively reported in the literature (Berlinger & Potter, 1991; Burns, Marsh, & Bender, 1989; Guérin et al., 2005; Keller et al., 2008; Niskanen, Piirainen, Koljonen, & Uusitupa, 1993; Singh, Mulley, & Losowsky, 1988). However, there is currently no universal measure for identifying undernutrition in people with dementia, therefore, estimates vary depending on methodology and the population studied (Aukner et al., 2013). Some studies have investigated dietary intake, while others have assessed weight loss and malnutrition.

Researchers in the United States (Reed, Zimmerman, Sloane, Williams, & Boustani, 2005) investigated food and fluid intake of 407 people with dementia in 45 ARRC facilities. They found 54% had low food intake (consumed $\leq 75\%$ of food served) and 51% had low fluid intake ($\leq 250\text{ml}$ consumed during the mealtime). However, a limiting factor of this study was that it only looked at amount of food and fluid consumed; it did not consider nutritional composition of the food and fluid. Therefore,

it did not assess nutritional quality or appropriateness relative to the residents' nutritional needs. Furthermore, resident's intake was only observed during the course of one meal, rather than over a full day or multiple days. A prospective cohort study in the United States found weight loss in approximately 40% of people with AD at all stages of the disease (Wallace, Schwartz, LaCroix, Uhlmann, & Pearlman, 1995). In Taiwan, Wang et al (2004) found more than 50% of people with AD developed weight loss, and overall had poorer nutritional status than those without AD. They were also more likely to have a poor appetite, and were significantly thinner. Researchers in Sweden (Holm & Söderhamn, 2003) found approximately half of a convenience sample of 59 people with mild dementia living in the community reported weight loss during the last year, and that weight loss was associated with severity and progression of the disease. In Sweden energy and/or protein malnutrition was found in 50% of people with severe dementia residing in ARRC facilities (Sandman, Adolfsson, Nygren, Hallmans, & Winblad, 1987). In a cross-sectional study involving 83 participants with dementia living in a SDCU, Chang and Roberts (2011a) found 90% of participants were at risk of malnutrition, and 19% were actually malnourished. Canadian researchers (Carrier, West, & Ouellet, 2007) found nearly 70% of the 263 cognitively impaired ARRC residents they screened were at risk of malnutrition.

Dehydration has been identified as the most common fluid-and-electrolyte disorder of people living in ARRC (Kayser-Jones, Schell, Porter, Barbaccia, & Shaw, 1999). Kayser-Jones et al. (1999) found nearly all of the 40 ARRC residents they studied had an inadequate fluid intake. They also found at the time of data collection 25 out of 40 residents had illnesses or conditions that could be related to dehydration. Two other

studies found dehydration in up to 60% of residents in ARRC facilities in the U.S. (Fries et al., 1997; Holben, Hassell, Williams, & Helle, 1999).

2.3 Dementia and Eating

2.3.1 Introduction

The majority of studies investigating factors affecting dietary intake or nutritional status in people with dementia have focused on identifying eating or feeding behaviours, or eating, feeding or mealtime difficulties. These terms have slightly different meanings, although they appear to be used somewhat interchangeably in much of the literature. According to the U.S. National Library of Medicine, eating is the act of eating, and eating behaviour is the manner of eating, similarly for feeding, and feeding behaviour (2013). Their definition of eating behaviour (and feeding behaviour) is, “behavioural responses or sequences associated with eating including modes of feeding, rhythmic patterns of eating, and time intervals” (U.S. National Library of Medicine, 2013). Amella, Grant, and Mulloy (2008) believe this definition to be limiting when considering older adults who have a lifetime of evolved eating habits. They identify that it overlooks the complex social and environmental issues involved in eating problems. Siebens et al. (1986) adds to the discussion by differentiating between eating and feeding, they describe feeding as, “...the process of getting the food from the plate to the mouth. It is a primitive sense without concern for social niceties”.

Studies often involved analysis of data gathered during mealtime observations or by means of interviews with staff or residents. A number of studies have observed

behaviour during mealtimes to establish the most common feeding difficulties in people with dementia residing in either ARRC or SDCUs (Altus, Engelman, & Mathews, 2002; Chang & Roberts, 2008a, 2008b; Durnbaugh, Haley, & Roberts, 1996; Philpin, Merrell, Warring, Gregory, & Hobby, 2011). Other studies have assessed behaviour in relation to food intake (Amella, 1999; Desai, Winter, Young, & Greenwood, 2007; Dunne, Nearing, Cipolloni, & Cronin-Golomb, 2004; Lin, Watson, & Wu, 2010; Reed et al., 2005; Suski & Nielsen, 1989). Finally, other studies have investigated mealtime behaviour in relation to weight loss as a measure of nutritional status (Berkhout, Cools, & Van Houwelingen, 1998; Wong, Burford, Wyles, Mundy, & Sainsbury, 2008).

This section begins by presenting the literature relating to changes to eating habits commonly seen in people with dementia and how these changes result in difficulty managing eating, feeding and mealtimes. It then presents key models from the literature used to explain mealtime difficulties in this group. Following this is an outline of person-centred care (an overarching concept in caring for people with dementia), and a discussion of five key themes identified in the literature as affecting nutritional status of people living in SDCUs is provided.

2.3.2 Changes to eating as dementia progresses

Altered eating patterns are common in people with dementia (Cullen, Abid, Patel, Coope, & Ballard, 1997). In the early stage of dementia individuals may forget to eat, they may become depressed and may lose their appetite, or they may become easily distracted and leave the table without having finished eating or without having eaten at all (Curfman, 2005). As the disease progresses, individuals may be unable to sit

through an entire meal (Curfman, 2005) or may forget they have already eaten (Amella et al., 2008). Increased wandering and motor restlessness at this stage is estimated to result in an additional 600 calories (2,500 kilojoules) being required to maintain energy balance (Curfman, 2005).

As neuro-degeneration continues, individuals with late stage dementia may resist or become indifferent to food (Finucane, Christmas, & Travis, 1999). They may lose the ability to coordinate self-feeding activities (Amella et al., 2008), and the voluntary and involuntary oral-motor skills required for chewing and swallowing (Curfman, 2005). Enteral tube feeding is sometimes used in these cases, with the intention to prevent aspiration pneumonia, malnutrition and its resulting conditions and to provide comfort (Finucane et al., 1999). However, numerous studies have found that artificially feeding persons at this stage of dementia does not lengthen life, reduce comorbidities, or increase nutritional health (Engel, Kiely, & Mitchell, 2006; Finucane et al., 1999; Sanders et al., 2000). Most importantly, the decision to forego tube feeding has been positively correlated with increased satisfaction with end-of-life care (Engel et al., 2006; Sanders et al., 2000). Artificial or tube feeding is not common practice in SCU in New Zealand and has therefore not been considered further in this literature review. This literature review concentrates on factors affecting oral intake of food and fluid in people with dementia.

Researchers in the United Kingdom examined the prevalence and associations of altered eating patterns in 105 community dwelling people over the age of 65 with mild or moderate dementia. They found 21% had increased food consumption, 22% had

decreased food consumption, 3% tried to eat inedible substances, 11% had an increased preference for sweet foods, 8% became fussier about their food choices and 5% became less fussy. They found an increased preference for sweet foods was significantly associated with a diagnosis of AD. Decreased intake was significantly associated with less severe cognitive impairment and was related to depression in some people. Increased intake was not significantly associated with any of the variables investigated (Cullen et al., 1997).

There is a recognised circadian shift in food intake patterns as we age, with a greater proportion of the daily food intake consumed earlier in the day in older, compared to younger adults (De Castro, 2002). For individuals with cognitive impairment, these naturally occurring circadian shifts are compounded with worsening cognition and behavioural control as the day progresses (Desai et al., 2007). People with dementia often become more disoriented and distracted after the sun goes down, a condition commonly referred to as sundowning (Dorner, 2005). Sundowning is one of many factors that may interfere with food intake, particularly at dinner and supper (Dorner, 2005; Young & Greenwood, 2001).

2.3.3 Models relating to mealtime difficulties

Many inter-related factors affect our food and fluid intake as we age. Morley (1997) discussed factors related to ageing that affect nutritional intake in the general population by separating them into physiological and non-physiological factors. Physiological factors, although not yet clearly understood, arise through normal ageing of the regulatory system that controls food intake and through alterations to the

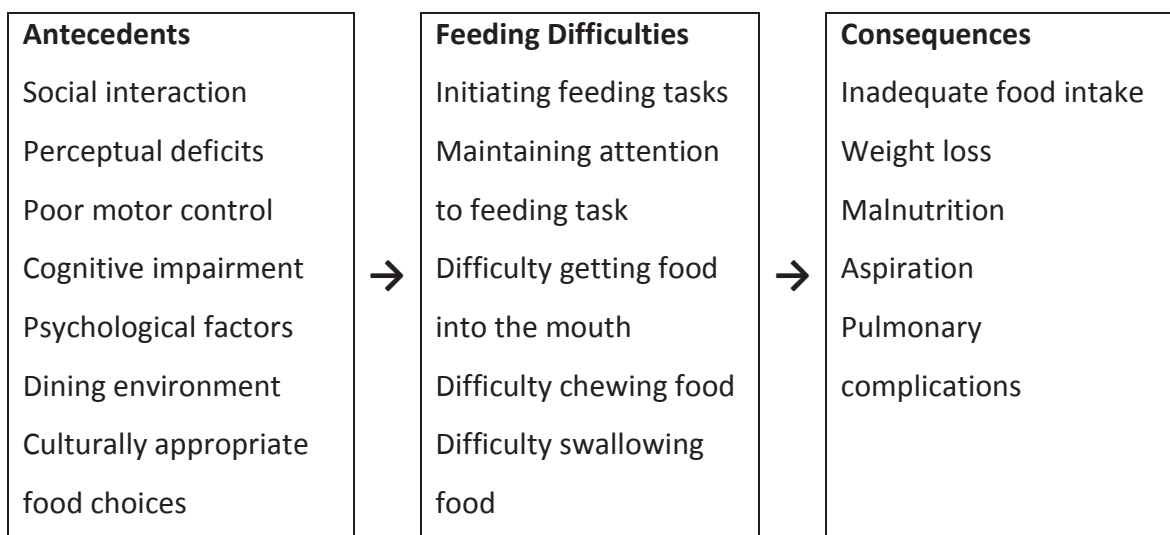
perceived hedonic qualities of food. These physiological factors are considered a normal part of ageing. On the other hand, non-physiological factors include a variety of social factors such as poverty, functional impairment limiting daily activities, social isolation, elder abuse, poor nutritional knowledge, psychological factors, and medical conditions. These physiological and non-physiological factors are further complicated for individuals with dementia (Morley, 1997). Although the exact cause of undernutrition and weight loss in dementia is multi-factorial and difficult to identify, the mechanisms involved will vary depending on the type and stage of the disease as well as environmental factors such as living situation (Aukner et al., 2013).

A number of models have been proposed to describe eating difficulties in people with dementia. In their review *Poorly served? Eating and dementia*, Manthorpe and Watson (2003) identified much of the research had focused on individual difficulties people with dementia encounter in relation to eating, and that the literature neglected the social, environmental and cultural aspects of meals and eating. Five years later, Amella et al. (2008) identified eating behaviour among older adults with dementia as a multifactorial phenomenon determined by an interplay between individual, and social and environmental issues. They identified individual issues as having physiological, pathological and psychological components, and social and environmental issues being lifelong practices, preferences, cultural or ethnic rituals, availability, affordability, and the dyad interaction between the person with dementia and their caregiver.

At this time, Chang and Roberts (2008b) reviewed the literature to identify characteristics of feeding difficulties. They found the common practice of assessing

feeding difficulties did not differentiate between feeding difficulties (problems getting food to the mouth, chewing or swallowing) and their antecedents (recognising food and that it should be eaten). They developed a conceptual model of feeding difficulties in older adults with dementia (see figure 2.1). Their model differentiates between feeding difficulties, their antecedents, and consequences.

Figure 2.1 Model of feeding difficulty



Reproduced from Chang and Roberts (2008b, p. 2269) by permission of John Wiley and Sons (© 2010 Blackwell Publishing Ltd).

Aselage and Amella (2010) built on Chang and Roberts (2008b) concept of feeding difficulties, with the broader view that, “mealtimes encompass more than the physical act of feeding” (p. 33). They identified antecedents, attributes, and consequences of mealtime difficulties in older adults with dementia. Their proposed model of ‘mealtime difficulties’ (see figure 2.2) considers mealtime patterns, dyad interaction,

mealtime environment, dementia, and aversive feeding behaviours as attributes of mealtime difficulty. According to Aselage and Amella feeding difficulties are an aspect of mealtime difficulties. They identify the key difference between their model of mealtime difficulty and Chang and Roberts' (2008b) model of feeding difficulty, is that the feeding difficulty model considers environmental factors and factors relating to the interactions between the caregiver and care receiver as antecedents to feeding difficulty. Whereas Aselage and Amella's model considered these factors to be attributes of mealtime difficulty.

Figure 2.2 Model of mealtime difficulty

Antecedents	Attributes	Consequences
Social considerations Cultural factors Lifelong eating patterns	Mealtime patterns Dyad interaction Mealtime environment Dementia Aversive feeding behaviours	Dyad stress Compromised nutritional status Loss of eating ability Tube vs. hand-feeding Death

Reproduced from Aselage and Amella (2010, p. 34) by permission of John Wiley and Sons (© 2010 Blackwell Publishing Ltd)

2.3.4 Factors affecting nutritional status of people with dementia

Drawing guidance from the literature reviews mentioned above (Amella et al., 2008; Aselage & Amella, 2010; Chang & Roberts, 2008b; Manthorpe & Watson, 2003), the following section presents the literature supporting five inter-related factors, and one

overarching concept identified as key themes affecting nutritional status among people living in SDCUs. These five themes are individual, social, cultural, physical environment, and assistance. The overarching concept is person-centred care. Figure 2.3 presents a model showing the relationship of the person-centred care concept to the five influencing themes and to the outcome of nutrition and hydration status.

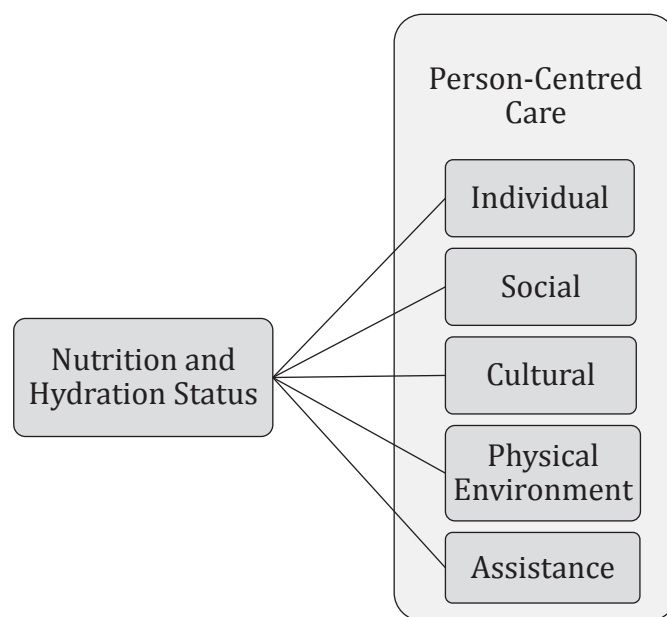


Figure 2.3 Key themes from the literature affecting nutrition and hydration status of people living in SDCUs

2.3.5 Person-centred care

The organisational structure and style of care at ARRC facilities including SDCUs has traditionally focused on “tasks” (Chaudhury, Hung, & Badger, 2013). However, in recent years there has been a change to a more person-centred approach to caring (Chaudhury et al., 2013). Person-centred care is a care philosophy recognizing that individuals have unique values, personal history, and personality, it is a best practice

concept guiding efforts to improve residents' quality of life (Chaudhury et al., 2013). 'Personhood' is a central idea in person-centred care. Kitwood (1997) defined personhood as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (p. 8). Kitwood (1997) was one of the pioneers who developed the philosophy of personhood in dementia care (Brooker, 2007). Mealtimes are important opportunities to support personhood when caring for people with dementia (Hung & Chaudhury, 2011). An enjoyable dining experience affects the individuals perception of well-being and is inseparably linked to their quality of life (Briller, Proffitt, Perez, Calkins, & Marsden, 2001). Preservation of personhood through person-centred care involves considering each of the key factors to be discussed in this literature review. For example, an unsupportive physical environment contributes to common behavioural issues such as spatial disorientation and anxiety in people with dementia (Chaudhury et al., 2013). Similarly, social interaction in the form of assistance at mealtimes is closely linked to personhood for the individual with dementia. As caregivers can spend quality time with residents building relationships, they have a chance to acknowledge each individual's unique qualities and support their particular needs (Hung & Chaudhury, 2011).

2.3.6 Individual

According to Amella et al. (2008) individual issues influencing eating behaviour among older adults with dementia have physiological, pathological and psychological components. Chang and Roberts (2008b) identified individual factors of perceptual deficits, poor motor control, cognitive impairment and psychological factors as fundamental contributors to feeding difficulties in this population. People with

dementia are also more likely to have a poor appetite than those without dementia (Wang et al., 2004). This section discusses the literature on factors that may affect the nutritional status of people living in SDCUs that relate specifically to the individual person.

An individual's ability to manage meals independently is affected by their degree of cognitive impairment (Amella et al., 2008). Feeding difficulties related to cognitive impairment are common in people with dementia (Manthorpe & Watson, 2003). Feeding difficulties are defined as specific behaviours elicited while the caregiver is feeding the individual (Chang & Roberts, 2008b). Reducing feeding difficulties may help prevent medical complications, prolong independence, and improve quality of life for people with dementia (Dorner, 2005).

Cognitive impairment affects an individual's ability to remain focused at mealtimes (Chang & Roberts, 2008b). Researchers in the US, Durnbaugh, Haley, and Roberts (1996), observed self-feeding behaviours in 20 people with moderate AD residing in four ARRC facilities. The most common mealtime behaviour problem they observed was distraction. They noted distractions were abundant and included noise, other residents, and staff engaging in non-mealtime activities such as taking vital signs or giving medications. They found participants stopped eating for significant times because of distraction. They also noted the most frequently observed style of eating was with the hands. This was commonly seen with non-finger foods such as ice cream, spaghetti, and soup. They also noted participants often played with food and non-food items alike. Participants frequently ate pieces that were too big, although (with

some difficulty) they were able to manipulate the food without choking. Eating dessert and sweets but neglecting other foods was another common observation, as was using utensils incorrectly, unfocused staring, impatient behaviour, eating other residents' food and verbally refusing to eat. Durnbaugh et al. also noted, in all facilities studied, texture modified foods were visually unappealing and did not look like food. Cluskey and Kim (2001) investigated 147 dietitians and nursing directors perceptions of strategies for enhancing food and nutrient intakes in ARRC, as well as the existence of obstacles to implementing these interventions. Compared to other strategies assessed, minimising noise and distractions in the dining room was considered difficult to implement or maintain by the largest number (43%) of respondents. However, factors which were considered obstacles for other interventions were not considered obstacles in minimising noise and distractions in the dining room. The obstacles investigated were, barriers of additional costs to implement the intervention and lack of support from administration. It was not clear from this research what factors were considered obstacles to minimising noise and distractions in the dining room.

An increased preference for sweet foods has been associated with progression of dementia (Mungas et al., 1990). More specifically, Greenwood et al. (2005) observed shifts in eating patterns towards a higher carbohydrate and lower protein consumption were strongly associated with the presence of irritability, agitation, and disinhibition in people with AD in ARRC. They highlight this practice places individuals at increased risk for inadequate protein intake. They suggest providing high-protein dinner foods may help these people to achieve their protein requirements. However, Young, Greenwood, Van Reekum, and Binns (2005) found provision of a high-

carbohydrate meal at dinner increased total energy intake in people in ARRC with AD related cognitive and behavioural difficulties. Importantly, they noted the increase in carbohydrate intake was not at the expense of protein consumption, in fact 12 out of 32 participants increased protein intake at the intervention meal. They suggest the increased intake may be as a result of a shift in preference for high-carbohydrate foods, although their intervention foods were not only high-carbohydrate but also happened to be mostly finger-foods including bread and jam, hard-boiled eggs, muffins and pastries, cheese slices and fruit. This may have influenced intake as higher physical disability is associated with poor intake at dinner but not at breakfast or lunch, indicating that people requiring feeding assistance may benefit from finger-foods at dinner (Young & Greenwood, 2001).

Chang and Roberts (2008a) observed 48 people with dementia and 31 caregivers at a Taiwanese SDCU. Observations included residents' eating behaviours, the dining environment, and interactions between caregivers. They also interviewed the caregivers and obtained residents' nutritional data from medical charts. They found refusal to eat was the most common feeding difficulty, and strategies used by caregivers were limited. Caregivers stated they needed more training to address feeding difficulties in people with dementia. Chang and Roberts concluded that future research should focus on the interface between the person being cared for and the carer, who must be able to identify various feeding difficulties and select appropriate interventions.

Lin, Watson, and Wu (2010), observed mealtimes of 477 people with dementia in ARRC facilities in Taiwan. They found eating difficulty and moderate dependence were independent factors associated with low food intake. Suski and Nielson, (1989) assessed the nutritional intake and problems associated with feeding of 19 women with severe AD, who resided in an ARRC facility. They recorded dietary intake and feeding practices for a three-day period. They found capitalising on the midday meal when cognitive abilities were at their peak was one of four major factors that promoted optimal intake. The other three factors relate to assistance from caregivers and are presented later in this review. Kayser-Jones et al. (1999) found cognitive and functional impairment contributed to low fluid intake in ARRC residents. Researchers at a Dutch ARRC facility (Berkhout et al., 1998) who studied resident's with dementia over a two year period, found a strong inverse relationship between the residents' ability to choose food and weight loss.

Canadian researchers (Young, Greenwood, Van Reekum, & Binns, 2004) found a mid-morning supplement drink intervention increased 24-hour energy, protein, and carbohydrate intake in 21 of 31 people with AD in ARRC. However, people with increased cognitive and behavioural difficulties (and lower BMI) were more likely to compensate for the supplement by reducing energy intake at lunch. Similarly, an earlier Canadian study (Young, Binns, & Greenwood, 2001) found energy consumed was positively correlated with energy delivered in people with AD in ARRC. Although those with a low BMI were typically delivered more energy, the impact of energy delivery on energy consumed decreased as energy delivered increased. Interestingly, they found people with higher levels of behavioural difficulties and cognitive

deterioration were most affected by excess energy offered at breakfast and least affected at dinner.

As well as cognitive decline, people with dementia may also experience a decline in functional abilities, which may contribute to feeding difficulties (Chang & Roberts, 2008a). Higher levels of functional disability in people with AD in ARRC are associated with lower food intakes at lunch and dinner (Greenwood et al., 2005). Functional issues may include impaired motor skills, impaired visual function, dental issues, difficulty chewing and swallowing, and smell and/or taste losses (Gilmore, Wenk, Naylor, & Koss, 1994; Liu et al., 2007; Pfeiffer et al., 2005; Suh, Kim, & Na, 2009; Waite, Broe, Grayson, & Creasey, 2000).

Researchers in Australia (Waite et al., 2000) found motor function disability in 482 out of 537 people with dementia. Impaired motor skills may cause difficulty with managing eating utensils. Degree of difficulty manipulating dishes, lids, and food packaging was positively correlated with risk of malnutrition in a Canadian study of 263 people with dementia living in ARRC (Carrier et al., 2007). Berkhout et al. (1998) also found a strong relationship between weight loss and ability to physically bring food to the mouth, and to chew it, in people with dementia living in ARRC. The greater these difficulties were, the lower the body weight. Finger-foods have been proposed as a way to promote optimal nutrition in people with difficulty managing eating utensils (Barrat & Gatt, 2001; Manthorpe & Watson, 2003).

Another barrier to adequate nutritional intake for people with dementia is visual impairment. Research suggests that AD results in a disruption of visual signals (Gilmore et al., 1994) including deficient contrast sensitivity (Dunne et al., 2004) and that this deficit in visual processing is associated with progression of the disease. This understanding prompted U.S. researchers (Dunne et al., 2004) to investigate food and fluid intake using different coloured tableware. They studied a small sample of nine older men with AD residing in an ARRC facility. Findings showed a significant increase in food and fluid intake with high-contrast red and high-contrast blue compared to white, and low-contrast red, and low-contrast blue tableware. High-contrast red tableware enhanced food intake by 25% and fluid intake by 84%.

People with dementia are likely to develop dysphagia at some point during the course of the disease (Suh et al., 2009). Kayser-Jones et al. (1999) found undiagnosed dysphagia contributed to low fluid intake in ARRC residents. Causes of dysphagia are likely to differ between different types of dementia. Suh et al. (2009) used videofluoroscopy to compare the swallowing functions of people with AD to those with vascular dementia. They found differences between the two groups which indicated swallowing disorders of people with AD may result from sensory impairment, whereas swallowing disorders of people with vascular dementia may primarily be caused by motor impairments. In a convenience sample of 59 community living individuals with suspected early stage dementia Holm and Söderhamn (2003) found predictors of nutritional status were eating smaller portions, reduced ability to self-feed, and having a dry mouth. Smaller portion size was the most influential factor associated with nutritional status at the beginning of the disease. They point out that

this finding reflects a low food intake and may be partly related to having a dry mouth which can cause difficulties in swallowing, pain and diminished enjoyment of food (Baum & Ship, 1994). On the other hand, a dry mouth can also be a consequence of low food and fluid intake (Holm & Söderhamn, 2003).

This review did not find literature related to overcoming sensory losses specifically in people with dementia. However, Pfeiffer et al. (2005) identified a number of interventions to overcome losses of taste and smell, reported to be successful at improving mealtime enjoyment and dietary intake at a number of ARRC facilities in the United States. They found aromatherapy (with the aroma of coffee, toast, and baked goods) was used in the dining room at one facility to stimulate appetite to combat weight loss. Another facility introduced a mobile buffet cart bringing food from the kitchen to the dining room for dishing out. This allowed food to be seen and smelt by residents in the dining room. This intervention was found to increase appetite, resulting in a drop in weight loss, it also increased socialisation in the dining room, and increased numbers of visitors joining residents for meals. Another facility found the use of flavour enhancers such as bouillon cubes in sauces and gravies, and fruit extract in desserts increased mealtime enjoyment, and food consumption. Food moulds simulating the form of the original foods were used to improve presentation of pureed foods at another facility.

A variety of individual factors may affect the nutrition and hydration status of people with dementia living in SDCUs. Individual factors include those related to cognitive impairment such as distractions, refusal to eat, reduced ability to choose food, and

reduced appetite. Other individual factors include those related to functional disabilities such as impaired motor skills, impaired visual function, dental issues, difficulty chewing and swallowing, and reduced taste and smell. These factors are inter-related and may ultimately result in weight loss, malnutrition or dehydration. A number of social factors may also influence nutritional outcomes. The following section discusses those social issues relevant to people with dementia.

2.3.7 Social

Eating is generally a social activity (Amella & Lawrence, 2008), indeed it is the most social of all activities of daily living (Amella, 1999). Amella et al. (2008) believe the social context of mealtimes provides invaluable observational cues to the person with dementia residing in ARRC or SDCUs, allowing for recognition of food and mimicking of appropriate eating behaviours. However, without appropriate support people with dementia may choose to avoid social situations where they may feel unsafe or vulnerable, potentially affecting their dietary intake (Holm & Söderhamn, 2003).

Close social interactions between a person with dementia and their caregiver, family or friends may be essential as people with dementia are often unable to communicate their feeding difficulties, the assistance they need, or their food preferences (Chang & Roberts, 2011b). Dining in a shared dining room and visits from family and friends have been shown to play an important role in nutritional status for people with dementia. Reed et al. (2005) found having meals in a public dining area was associated with higher food and fluid intake in 407 people with dementia across 45 ARRC facilities in the U.S. Fewer family visits were a significant predictor of low food intake in a study of

477 people with dementia living in SDCUs in Taiwan (Lin et al., 2010). In another study, a lack of social support was associated with low fluid intake in ARRC residents (Kayser-Jones et al., 1999).

Communication between caregiver and resident has also been associated with food intake in people with severe dementia living in ARRC facilities (Amella, 1999). Amella (1999) studied 53 caregiver/care receiver dyads to examine how the quality of the interaction between caregiver and care receiver influenced the proportion of food consumed by persons with late-stage dementia. Weighed food records and mealtime observations were used to assess the quality of the dyad interactions, caregiver empathy, and caregiver control. Specific resident behaviours and the caregivers' ability to allow another person to control a relationship were most strongly associated with the proportion of food consumed. Caregiver empathy was not correlated significantly to the proportion of food consumed, and the quality of the dyad interaction accounted for 32% of the total variance in the proportion of food consumed. Amella concluded that interactional components of meals within the caregiving dyad need to be examined when an individual with severe dementia has inadequate oral intake.

Foodservice style can affect social interactions at mealtimes. A number of researchers have investigated the effects of different foodservice styles on varying nutritional indicators for people with dementia. Studies that have assessed the socio-cultural context of mealtimes, appropriate communication and mealtime participation, energy intake, and risk of malnutrition in relation to foodservice style are discussed below.

Clarke (2009) improved overall mealtime experiences at a day-stay centre for people with dementia, from an initiative involving a number of changes to the social context of food and dining, and to the physical environment. They noticed guests often left the table early simply because the person sitting next to them had finished and left. Interventions included the more social 'family-style' dining, and a 'slow-eaters' table, and a number of social eating related activities involving shopping for, preparing and cooking basic foods. Results showed guests were more settled, they took their time to eat and enjoy meals, and no longer appeared to regard lunch as a chore or something to fear or dread. However, this research does not report on energy intake or any other direct measures of participants' nutritional status. It also does not report on sample size or methods of assessing changes in guest's behaviour.

Philpin et al. (2011) studied the socio-cultural context of nutrition in ARRC. They interviewed 19 staff and 16 residents with mild dementia at two ARRC facilities. They found the introduction of 'family-style' dining (residents were presented with serving bowls at the table and empty plates for self-service) enhanced sociability and enjoyment at mealtimes, this in-turn encouraged eating. They also found residents sharing in food preparation conferred a sense of normality, community and identity. However, as only two ARRC facilities were studied transferability of the findings are limited. Also of note is that views and experiences of people with moderate to severe dementia were not included in the study. The authors do not mention what foodservice style was used prior to the introduction of family style dining.

Altus et al. (2002), observed a modest increase in appropriate communication and mealtime participation in six people with dementia in an ARRC facility with an intervention of 'family-style' dining. They compared this to the baseline practice of serving meals already plated. A considerable increase in appropriate communication and mealtime participation was observed during a further intervention which included prompting and praising from nurse assistants during a second 'family-style' dining intervention. However, this study only investigated resident participation and communication at mealtimes; it did not investigate effects on food intake or any other indicator of nutritional status.

Desai et al. (2007), compared energy intake over 21 consecutive days in 48 cognitively impaired older adults at an ARRC facility receiving meals either by traditional "tray delivery system" or a "bulk food delivery system" (which shows the food available to residents and allows them to choose what and how much to eat) with accompanying changes to the physical environment (from institutional to a more home-like environment). They found the "bulk food delivery system" group had a significantly higher 24 hour energy intake than the "tray delivery system" group. Interestingly they found individuals with the lowest initial BMIs were more sensitive to the type of foodservice. The increase in energy intake was more apparent in individuals with lower BMIs, whereas subjects with higher initial BMIs did not show substantial changes in intake. Similarly, use of a tray-delivery system was found to increase risk of malnutrition compared with bulk-delivery systems in a study of 263 people with dementia in Canadian ARRC facilities (Carrier et al., 2007). Charras and Frémontier

(2010) reported significant weight gain in people with dementia living in a SDCU, with an intervention involving staff joining residents daily for a shared family-style lunch.

A variety of social factors may affect the nutrition and hydration status of individuals with dementia who reside in SDCUs. These include: shared dining rooms allowing for observational cues and mimicking of appropriate eating behaviour, visits from family and friends, good communication between caregiver and care receiver, and bulk foodservice system or family-style dining over tray meal deliveries. These factors are inter-related and may ultimately impact weight loss, malnutrition or dehydration. A number of cultural factors may also influence nutritional outcomes. The following section discusses those cultural issues relevant to people with dementia.

2.3.8 Cultural

Mealtime customs are based on cultural habits (Sidenvall, 1999), where culture is a descriptive concept referring to the knowledge and sets of values that are shared between people in a defined group (Leininger, 1991). An individual's background, their customs, religion and recreational activities and their memories of how food was used to celebrate special occasions are carried into old age (Evans, Crogan, & Shultz, 2005). Recognising this cultural connection to food can impact on nutritional care for individuals in SDCUs, as familiar foods are a source of comfort that can play an important role in recovery from illness or successful transition to long-term care (Evans et al., 2005).

However, it's not just the people living in a facility that have a particular culture. SDCUs generate a culture of their own. Dutch researchers (Pasman, The, Onwuteaka-Philipsen, Van Der Wal, & Ribbe, 2003), describe this culture as a product of a combination of factors such as workload, teamwork, degree of hierarchy, and personal attitudes of staff (for example, being open to giving and receiving feedback).

Culturally appropriate food and mealtime organisation, such as how meals and snacks are timed throughout the day, has the potential to improve food intake (Sidenvall, 1999). For example, Wong et al. (2008) found an increase in BMI when dietary 'grazing' was encouraged in older adults with dementia in a short-stay assessment unit in New Zealand.

If a caregiver providing mealtime assistance has different cultural ideas from those of the care receiver, it may reduce the quality of the individuals dining experience as well as their dietary intake (Sidenvall, 1999). Sidenvall (1999), investigated mealtime procedures at an ARRC facility in Sweden. She found residents naturally had their own mealtime customs, but were expected to comply with the institutions culture towards mealtimes. Meals in the ward were organized in line with that of family meals in society, and both the residents and the nurses strove towards civilized manners and order. By complying with the facilities procedures, residents suffered a loss of their own habits and culture surrounding mealtimes.

Increasing the variety of foods served was recommended by Canadian researchers in order to influence an individual's dietary intake, health and perceived quality of life in

ARRC facilities (Lengyel et al., 2004). Lengyel et al. suggested this could be accomplished by introducing a 'residents choice' meal weekly or biweekly, or by special meals to celebrate special occasions such as residents' birthdays.

The ways in which menu selections are made can be considered part of the culture of a care facility. Interestingly, Carrier et al. (2007) found people with dementia in ARRC facilities where menu selections were made closer to mealtimes (less than six days) were more likely to be at risk of malnutrition than those at facilities where standard practise was to make menu selections greater than six days in advance. Carrier et al. were unable to explain the reasons for this. However, they suggest, since caregivers make selections on behalf of cognitively impaired residents, perhaps if this is done further in advance the caregiver takes greater care in selecting choices matched to the individuals preferences.

The degree of dependence expected of older adults relating to meal preparation and feeding differs between cultures. According to Chang and Roberts (2008a), in Chinese culture, providing adequate food and maintaining good nutritional care is not only related to physical care, but is also an expression of caring for the individual. Consequentially, individuals in care are expected to be dependent even when they are not, and caregivers are expected to assist as an expression of caring. They highlight that these expectations may affect the existence, identification and assessment of mealtime difficulties as well as choice of intervention. Similarly, in the Korean culture older adults both expect and are expected to become dependent as part of normal aging (Yeon, 2000). In contrast to these Asian cultural norms, Western culture places

greater emphasis on independence (Yeon, 2000). This could result in caregivers being more likely to assist older adults to feed themselves, rather than provide full feeding assistance (Chang & Roberts, 2011b).

A variety of cultural factors may affect the nutrition and hydration status of individuals with dementia who reside in SDCUs. These include: culturally appropriate food and mealtime organisation, cultural background of the individual caregiver, and care receiver, including their shared cultural norms, and the mealtime culture and cultural expectations of the facility and its foodservice system. These factors are inter-related and may ultimately impact weight loss, malnutrition or dehydration. A number of physical environmental factors may also influence nutritional outcomes in people with dementia; these are discussed in the following section.

2.3.9 Physical environment

Cognitive and functional impairment associated with dementia increase the individuals vulnerability to environmental influences (Briller et al., 2001). The dining room at ARRC facilities and SDCUs can often be loud and over stimulating places, however, a well-designed supportive physical environment can reduce challenging behaviours and foster positive ones in people with dementia (Briller et al., 2001). Positive effects can include reduced agitation, increase in social contact, and less dependence in conducting activities of daily living (Briller et al., 2001; Chaudhury et al., 2013). In recent years ARRC facilities including SDCUs have been endeavouring to provide a physical environment as home-like as possible allowing them to become more person-centred in order to enhance resident's quality of life (Geboy, 2009; Hung & Chaudhury,

2011; Mitchell & Kemp, 2000). Reed et al. (2005) found the presence of non-institutional features (such as use of tablecloths, and not eating off a tray) was associated with higher food and fluid intake in people with dementia in ARRC facilities in the U.S.

Physical environmental features of the dining room and the social context of mealtimes are inter-related factors that influence the overall mealtime experience of residents (Chaudhury et al., 2013). For example, a smaller more home-like dining room catering for fewer residents would likely facilitate more familiar social experiences and allow for staff to offer a more personalised and flexible care approach (Chaudhury et al., 2013).

Clarke (Clarke, 2009) noticed guests at a day-stay centre for people with dementia had commonly lost the ability to think for themselves. When asked what they would like for lunch, they would often choose the same thing as the person sitting next to them, believing this to be the correct answer to the question. They found changes to the food and dining environment (introduction of a set of picture card menus, and a sensory garden with herbs) as well as changes to the social context of mealtimes (discussed earlier in this review), improved overall mealtime experience.

Noise may be highly distressing to people with dementia (Chaudhury et al., 2013). A calmer environment may be created by turning off the television, loud music, and public announcements (Ullrich, McCutcheon, & Parker, 2011). However, quiet music may be beneficial, as it has been found to reduce agitated behaviour during mealtimes

among a group of older adults in a SDCU (Denney, 1997). Hicks-Moore (2005) had similar results from studying the relationship between relaxing music and agitated behaviours among people with dementia living in ARRC facilities. Furthermore, music may have positive effects on food intake as an increased time spent eating dinner was seen when soothing music was played during mealtimes (Ragneskog, Kihlgren, Karlsson, & Norberg, 1996). However, these studies had small sample sizes and did not assess nutrient intake or nutritional status.

Limited research has been carried out to assess the effects of the physical environment on dietary intake or nutritional status directly. Thomas and Smith (2009), and Wong et al. (2008) are among the few to investigate the relationship between music and dietary intake among people with dementia. Although only a small sample size of 12 was studied, Thomas and Smith (2009) found caloric consumption increased by 20% when familiar music was played at mealtimes compared to dining without music. They noted extra calories consumed were primarily from carbohydrate foods. Similarly, a well-executed study conducted in New Zealand by Wong et al. (2008) found increased total energy consumption and BMI in older adults with dementia in a 22 bed short-stay assessment unit with an intervention of improving dining room ambiance by playing soothing music. Interestingly, they found an increased intake at lunch and dinner, but reduced intake at breakfast. They also conducted two other interventions, these were, encouraging dietary 'grazing', and using volunteers to feed patients. They observed an increase in BMI with all three interventions. In comparison, a drop in BMI was seen in the 'control group' (an initial phase observing the existing system). Investigating the possibility of a cumulative benefit if the interventions were run together was identified

by the researchers as an area for further study. Additionally, Ragneskog et al. (1996) found dinner music appeared to have an effect on staff members who were observed paying increased attention to residents. Nevertheless, musical taste can vary greatly, and as the definition of soothing or relaxing music is largely subjective, it may be difficult for ARRC facilities to cater for the musical preferences of all residents (Johnson & Taylor, 2011). The previously discussed study by Dunne et al. (2004) which showed using high-contrast tableware enhanced food and fluid intake remarkably compared to low-contrast tableware is another example of how physical environmental factors can affect mealtimes for people with dementia.

A variety of physical environmental factors may affect the nutrition and hydration status of individuals with dementia who reside in SDCUs. These include: the presence of non-institutional features, turning off any distracting noise such as television, playing familiar or relaxing music, and colour of tableware. These factors are inter-related and may ultimately impact weight loss, malnutrition or dehydration.

2.3.10 Assistance

Inadequate mealtime assistance is the factor most frequently reported in the literature preventing older adults with dementia from obtaining an adequate dietary intake (Chang, Wykle, & Madigan, 2006; Kayser-Jones et al., 1999; Lin et al., 2010; Reed et al., 2005; Suski & Nielsen, 1989). Assisting individuals to eat is a major task in SDCUs and one that becomes increasingly difficult as the illness progresses (Chang & Roberts, 2008b; Durnbaugh et al., 1996). However, caregivers can make a difference, as inadequate staffing and time to feed residents have been identified as barriers to food

intake (Chang et al., 2006). When caring for a person with moderate to late stage dementia ensuring adequate intake at mealtimes is a goal and a challenge (Amella et al., 2008). Supporting this view, Reed et al. (2005) found staff monitoring of residents was associated with higher food and fluid intake in people with dementia in ARRC facilities in the United States. Similarly, Suski and Nielson, (1989) found the use of skilful feeding techniques and providing adequate time in which to feed promoted optimal intake in women with advanced AD in an ARRC facility. Also highlighting the important role of the caregiver, Lin, Watson, and Wu (2010) found a lack of feeding assistance was an independent risk factor associated with low food intake for institutionalised older people with dementia. Wong et al. (2008) found an increase in BMI when volunteers were used to feed hospitalised patients with dementia. An inadequate number of knowledgeable staff and lack of supervision of certified nursing assistants by professional staff contributed to low fluid intake in people living in ARRC (Kayser-Jones et al., 1999).

Assisting someone with dementia to complete a meal can require 35-40 minutes, regardless of level of dependency (Simmons & Schnelle, 2006). A lack of time, lack of training, high work load, and working short staffed were perceived barriers to residents getting enough food to eat according to nurses and nursing assistants at five nursing homes in the U.S (Crogan, Shultz, Adams, & Massey, 2001). Mealtime assistance should be addressed to optimise opportunities for individual residents to eat well (Baron, 2006). Furthermore, when assisting with feeding, caregivers should be aware of the time that may be necessary to complete the meal (Amella et al., 2008).

The quality and quantity of assistance an individual with dementia receives may affect their nutrition and hydration status. Skilful feeding techniques, adequate time spent feeding, adequate staff numbers, and staff knowledge are all factors affecting nutrition and hydration status of people living in SDCUs. These factors are inter-related and may ultimately impact weight loss, malnutrition or dehydration.

2.4 Summary – What the Literature Tells Us

The purpose of this review was to discuss the literature relating to factors affecting optimal nutrition and hydration for people living in SDCUs. There has been a considerable amount of research on the assessment of feeding difficulties of people with dementia. However, despite a growing interest in this area, fewer studies have examined the effectiveness of interventions to improve nutritional status of these individuals particularly those living in SDCUs. Studies have tended to be observational in nature, and concentrated on identifying feeding difficulties alone, or in some cases comparing mealtime behaviours to nutritional intake. Only a few studies have assessed weight loss as a measure of nutritional status. In particular, this literature review has established there is a lack of research identifying factors affecting nutritional status of people living in SDCUs specific to the New Zealand setting, strengthening the rationale for this study.

Although limited, the research does suggest a range of individual factors including loss of appetite, cognitive and functional issues, social, cultural, physical environmental factors, and availability and quality of assistance may be influential in ensuring optimal food and fluid intake for people in SDCUs. These factors are inter-related and may

ultimately impact weight loss, malnutrition or dehydration. In line with the person-centred care philosophy, interventions and assistance from caregivers should vary depending on the nature of the individual's abilities or disabilities. For example, individuals with poor motor control may only require physical assistance getting food to their mouth, whilst others with feeding difficulties related to inattention may require verbal cueing.

The number of people with dementia is rising at a staggering rate, furthermore, high numbers of people currently affected are malnourished, dehydrated or at risk of malnutrition or dehydration. Thus, it is critically important to expand on the existing knowledge base relating to optimising nutritional status for this dependent group in New Zealand. Understanding factors affecting optimal nutrition and hydration is the first step in understanding how to minimise the risks of malnutrition and dehydration in people residing in SDCUs.

2.5 Limitations of this Literature Review

This literature review is limited to the articles found and chosen from the searches conducted. Every effort was made to catch all relevant publications; however, it is acknowledged that some articles containing useful insights may have been missed. As the literature was limited to articles written in English, relevant research in other languages may have been overlooked. Limited research was located relating specifically to the topics of both the setting of SDCUs and to measures of actual nutritional status. Therefore, studies that reported on interesting related areas such as

people with dementia living in ARRC facilities, and alternative measures of nutritional well-being i.e. mealtime behaviour and food and fluid intake were also included.

The following chapter presents the methodology and rationale to the study design. Included is an overview of the qualitative descriptive approach, and a detailed description of the execution of the study, research validity and rigour are also discussed.

3.0 Research Design

3.1 Introduction

The previous chapter reviewed the literature relating to factors affecting nutrition and hydration in people with dementia. This chapter presents the methodology and rationale to the study design, followed by a discussion of the execution of the study.

3.2 Methodology and Rationale – A background to the Study Design

3.2.1 A qualitative approach

The fundamental way to determine whether a study should be qualitative or quantitative is to check whether the aim is to answer ‘what’, ‘how’ or ‘why’, rather than ‘how many’ or ‘how much’ (Green & Thorogood 2004). Denzin and Lincoln (2011) describe qualitative research as the study of things in their natural settings, where researchers attempt to make sense of, or interpret phenomena in terms of the meanings people bring to them. Although historically, qualitative research has been viewed as producing a low level of relative strength on the hierarchy of evidence, there is growing recognition that it should be a vital part of the decision making processes that directs the development of health policy and practice (Swift & Tischler, 2010). Swift and Tischler, recently reviewed the field of qualitative enquiry in relation to nutrition research, and concluded, “qualitative research is well placed to answer complex questions about food-related behaviour because it investigates *how* and *why* individuals act in certain ways” (2010, p. 559). Furthermore, qualitative approaches are considered particularly pertinent when the aim of the research is to understand the viewpoint of participants (Green & Thorogood 2004). The research question that

guided the present study was: What factors affect optimal nutrition and hydration for individuals living in SDCUs? As the present study asked a 'what' question, a qualitative methodology appeared to be the most appropriate approach.

3.2.2 Qualitative descriptive methodology

There is an increasing array of methods available to a qualitative researcher. A qualitative descriptive methodology as described by Sandelowski (2000) was used for the present study. Sandelowski identifies qualitative description as one of the most commonly used methodological approaches in the practice disciplines. She states that, "qualitative descriptive studies offer a comprehensive summary of an event in the everyday terms of those events" (p. 336). Sandelowski considers qualitative description to be the preferred approach when looking for unembellished description of a phenomenon or candid answers to questions. She provides examples of such questions as: "What are the concerns of people about an event? What are people's responses (e.g., thoughts, feelings, attitudes) toward an event? What reasons do people have for using or not using a service or procedure? Who uses a service and when do they use it? What factors facilitate and hinder recovery from an event?" (p. 337).

Sandelowski (2000) identifies qualitative description as drawing from the general principles of naturalistic inquiry. Patton (2002) describes naturalistic inquiry as the study of real-world situations in which the researcher makes no attempt to manipulate the phenomenon of interest. This is in contrast with controlled experimental designs whereby the researcher controls study conditions and where a limited set of outcome

variables is measured. He also suggests that naturalistic inquiry emphasises openness to whatever emerges, placing no prior constraints on what the findings will be.

3.3 Execution of the Study

The following section outlines the steps taken in carrying out this study.

3.3.1 Ethical considerations

Ethical approval was sought by submitting a detailed ethics application to the Massey University Human Ethics Committee Northern (MUHEC: Northern). MUHEC: Northern granted ethical approval (approval number 12/099) for this study on 20th December 2012, prior to participant recruitment. See appendix A for the ethics approval letter.

In line with the *Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants (Massey University, 2013)*, the following major ethical principles have been applied in this study:

- a) Respect for persons
- b) Minimisation of harm to participants, researchers, institutions and groups
- c) Informed and voluntary consent
- d) Respect for privacy and confidentiality
- e) The avoidance of unnecessary deception
- f) Avoidance of conflict of interest
- g) Social and cultural sensitivity to the age, gender, culture, religion, social class of the participants
- h) Justice. (p. 4)

Respect for persons

Respect for persons involves recognition of personal dignity, beliefs, privacy and autonomy of individuals, including special protection of any individual with diminished competence. In this study potential participants were informed participation was entirely optional, and that they were not required to give reasons for not participating. Participants were also informed they may choose to terminate the interview at any time without penalty.

Minimisation of harm to participants, researchers, institutions and groups

Research participants must not be subjected to unnecessary risks of physical, emotional, social or financial harm or discomfort (Polit & Beck, 2014). Research involving human participants should produce some positive benefit, it should not be carried out simply for its own sake (Murphy & Dingwall, 2001). Researchers should make every attempt to identify and minimise harm, which may include pain, stress, fatigue, emotional distress, embarrassment, cultural dissonance and exploitation. For Maori, minimisation of harm includes these categories as well as minimising harm to whanau (family and community), hinengaro (emotional well-being and state of mind), wairua (spirit), and tinana (the body or physical self) (Massey University, 2013). It was not expected that participating in this study would subject participants to harm or discomfort, however, there is always such a possibility when interviewing research participants. As Polit and Beck (2014) point out, interviewing has the potential to cause psychological harm, for example if the participant is asked to reveal deeply personal information. The present study involved caregivers speaking about factors affecting food and fluid intake of others; questions were not highly personal. However, prior to

conducting the interviews it was noted that when asked to speak in detail about events occurring at their place of work, participants may feel some anxiety or stress relating to employers 'finding out' their views and opinions. If this situation had arisen the participant would have been reminded that the interview was confidential, that participant identities would not be disclosed, and that they may withdraw from the study at any time. A situation such as this did not appear to arise during the interviews. Comparatively, the participants seemed appreciative of being asked for their thoughts on the study topic and enjoyed sharing their opinions during the interviews.

Informed and voluntary consent

Participation in the study was completely voluntary. Caution was taken during all contact with prospective participants so as to not pressure or coerce them in anyway. Participants were provided with an information sheet (see appendix B) stating the participant's rights including the right to; decline to answer any question, withdraw from the study up until 30th May 2013, ask any questions about the study, ask for the audio recorder to be switched off, and the right to anonymity. The information sheet also introduced the research team and gave their contact details, provided a brief background to the study (outlining the purpose and importance of the research). It explained the interview procedure, the inclusion criteria, and outlined how the information provided would be used. The participant's rights were also verbally communicated at the start of each interview, and informed consent was obtained from participants prior to commencing the interviews. Participants were given a \$30 petrol or supermarket voucher as a gesture of appreciation for taking part in the study.

Respect for privacy and confidentiality

Researchers should ensure that their research is minimally intrusive, and that any data obtained is kept in strict confidence (Polit & Beck, 2014). The nature of face-to-face interviews means participants cannot remain anonymous to the researcher, the researcher then has a moral obligation to maintain participants anonymity from others and data collected must remain confidential (Parahoo, 2006). A code number was used to identify audio recordings and transcripts to maintain participant anonymity. At the time of writing up the report, code numbers were exchanged for pseudonyms chosen by the researcher. All references to the participant's employers and place of work have been altered or removed from the data. Participant privacy was also enhanced by the use of two settings for data collection. Following completion of the study, interview recordings and transcripts will be kept in a locked filing cabinet in a locked building at Massey University, Albany Campus. They will be disposed of by a Massey University representative five years after study completion.

The avoidance of unnecessary deception

This study did not involve any covert or deceptive procedures. The true nature of the research was clearly explained at each stage.

Avoidance of conflict of interest

All members of the research team declare no private or professional conflict of interest with research study.

Social and cultural sensitivity to the age, gender, culture, religion, social class of the participants

Researchers have a responsibility to participants and to the wider community to act in a socially and culturally sensitive manner. This was strived for during all encounters with participants. To further assist with ensuring participant's involvement with the study was socially and culturally sensitive to the individual, the information sheet asked potential participants to contact a member of the research team should they have any specific requirements including cultural requirements or concerns about the project, or about being a participant.

Justice

People should not be selected to participate in research simply because they are easy to recruit. The selection of participants should be based on research requirements and not on people's vulnerabilities (Polit & Beck, 2014). This principle protects individuals who are unable to protect themselves to ensure they are not exploited for the advancement of knowledge (Polit & Beck, 2014). The right to fair treatment also encompasses the obligation for researchers to show respect for the beliefs and lifestyles of people from different backgrounds, they must also treat participants courteously at all times (Polit & Beck, 2014). Participants in this study were treated courteously and equitably at all times. They were offered the right of non-participation, to stop the audio recorder at any time, and to withdraw from the study up until 30th May 2013.

3.3.2 The sampling process and accessing participants

Qualitative descriptive studies typically utilise one or more purposeful sampling techniques. In contrast to random selection, purposeful sampling is the deliberate selection of participants in order to generate data which fits the study aims and objectives (Patton, 2002). In the current study, participants were selected using purposeful sampling techniques as detailed below.

Sampling for this study involved a number of steps; firstly, two ARRC organisations with SDCUs were contacted by one of the research supervisors (this supervisor was an employee of the foodservice provider for both organisations). The organisations were informed of the proposed study and were invited to be involved - both accepted the invitation. The researcher met with each organisation to discuss the project. Each organisation offered one SDCU as a research setting. Choosing the setting was guided by practicalities and logistics such as a geographic location accessible to the researcher (i.e. Auckland). Both settings were SDCUs with approximately 20 beds, both were part of larger ARRC facilities. Food was prepared centrally in a main kitchen remote to the SDCU. Food was delivered from the main kitchen to the SDCU kitchen in bulk where it was plated and served to the residents. Meals were typically had in a communal dining room at shared tables, although residents could also choose to eat in the lounge or in their own rooms. Breakfast, morning tea, lunch, afternoon tea, dinner, and supper were served at both units with drinks also provided at each of these times.

Discussions were had with the two care organisations regarding the best way to obtain information required to answer the research question. There is increasing consensus

in the literature that people with dementia should be included in research as active participants, not simply as subjects (Downs, 1997; Hellström, Nolan, Nordenfelt, & Lundh, 2007; Hubbard, Downs, & Tester, 2003). However, people with dementia may have reduced vocabulary, impaired linguistic reasoning, changes in word association patterns, empty speech, and disordered discourse (Bourgeois, 1991; P. Whitehouse, 1999; P. J. Whitehouse et al., 1997). Furthermore, regarding capacity to provide informed consent, many people with dementia are able to express a desire to participate in research, however, the insidious nature of dementia progression reduces the individual's ability to understand and appreciate the consequences of involvement (Cubit, 2010). Above all, researchers must have sound justification for including people with dementia in their research (McKeown, Clarke, Ingleton, & Repper, 2010). Caregivers provide nearly all feeding assistance in long-term care settings (Chang & Roberts, 2011b). Caregivers may be the first to recognise an individual's feeding difficulties as people with dementia are often unable to verbalise their feeding difficulties, the assistance they require, or their food likes and dislikes (Chang & Roberts, 2011b). Having considered the issues presented above, both of the two organisations involved, the researcher and research supervisors felt it would not be suitable to interview the people with dementia themselves. These discussions established caregivers as the group best placed to provide information-rich data relating to the study aim. Caregivers in both SDCUs were involved with residents extensively throughout the day including providing assistance at meal times.

A convenience sampling strategy was employed to obtain suitable participants to interview from each setting. Convenience sampling is a type of purposeful sampling

where, as the name implies, participants are selected on the basis of convenience rather than in an attempt to gain a random sample representative of the population (Hultsch, MacDonald, Hunter, Maitland, & Dixon, 2002). According to Hultsch et al. in this approach participants are generally recruited by soliciting volunteers via advertisements or appeals to community groups. Hultsch et al. go on to explain, an effort is often made to obtain quotas of individuals with particular demographic characteristics; similarly individuals with particular characteristics may be excluded. However, a researcher will typically attempt to include a sufficient range of individuals to allow generalizability to a broader population.

Nurse Managers at both settings were initially informed of the study by their employers. They were asked to briefly inform caregiving staff of the study and to arrange meetings between the researcher and the caregivers. During these meetings the researcher was able to formally introduce the study to the caregivers and invite them to participate. Caregivers were asked to express their interest in taking part in the study by providing their contact details on a participant sign-up sheet. At this time they were also provided with an information sheet. Email, telephone and text messaging was used to communicate with participants to arrange interview times.

Researchers should endeavour to collect a range of views on the research topic, as those participants who produce contrasting data can often be central to modifying themes (Seale, 2004). Keeping this in mind, both morning and afternoon staff were invited to take part, to ensure data collected covered factors affecting food and fluid intake over the whole day. At least two caregivers from the morning shift and two

from the afternoon shift from each facility were sought. Furthermore, inclusion criteria were set to ensure participants had a suitable amount of relevant experience to adequately speak about the research topic. Inclusion criteria were: aged 18 years or over, have worked in current role caring for dementia residents for at least one year, and must be involved with residents at meal times.

All thirteen caregivers who attended presentations signed-up to participate. Two subsequently pulled out prior to the interviews due to health, and family commitments. The remaining eleven were interviewed for the study. A number of caregivers not directly spoken to had heard about the study from their colleagues and expressed interest in taking part. An informal apology was made to these individuals, and they were informed that they may be contacted if more participants were required.

3.3.3 Data collection – semi-structured interviews

The present study used semi-structured interviews to collect data from participants. Semi-structured interviews are a style of in-depth interview. In-depth interviews are often used to explore, analyse and understand the 'meanings' people use in everyday life, "as when finding information out about people – the best way is to ask them!" (Yates, 2004, p. 156). Yates also points out the meaning of the word interview: "Interview, literally means to develop a shared perspective and understanding (view) between (inter) two or more people" (2004, p. 156). This implies that the interviewer and interviewee(s) develop a shared understanding of the topic discussed. Semi-structured interviews use a schedule of questions as a guide only, ordering of

questions is flexible, interviewers are free to probe areas of interest and can follow participant's interests and concerns (Yates, 2004).

For the present study, interviews were carried out at the participant's place of work at a time that suited them, and their employer. This was typically before or after the participant's shift. After introductions, the objectives of the study were briefly discussed and the interviewer ensured the participant had read and understood the information sheet, which was provided previously and again at this time. Participant confidentiality was addressed and the participant consent form (see appendix C) was signed with a reminder that the interview would be recorded, that participating was entirely optional, and that participants could ask to be withdrawn from the study up until 30th May 2013. Participants were assigned a code by the researcher which was used to label the interview recording, and the transcription. Interviews took between 30 and 50 minutes excluding the introduction time, (See appendix D for the interview schedule of questions). In keeping with the semi-structured interview approach, interviews all started with an open-ended question, 'Can you please tell me what happens here at meal times?' This proved to be an effective way to elicit talk from interviewees with little interruption required by the interviewer. Participants were given the time to talk freely about what ever topics they felt were important relating to meal times. As the interview progressed, prompts and probes were used as required by the interviewer to elicit further discussion. A digital audio recorder was used to record the interviews. The researcher downloaded each audio file from the recorder to her secure private computer on the same day as the interview and deleted them from the recorder at this time.

3.3.4 Sample size and data saturation

In qualitative research, the collection of data continues until saturation is achieved (Tolich & Davidson, 2011). This occurs when subsequent interviews cease to illuminate new insights. Eleven participants were interviewed for the present study, this was the point at which the researcher determined adequate qualitative data had been collected, and data saturation had occurred.

3.3.5 Data transcription

Transcribing of the audio recordings was completed by a professional transcriber employed by the researcher with funding from Massey University. The transcriber signed a confidentiality agreement (see appendix E). Digital audio recordings were uploaded to a secure web-based file sharing facility (Dropbox), and the transcriber was given access to them. The transcriber sent completed transcripts to the researcher via email. Transcripts were printed and proof read by the researcher whilst listening to the audio recordings. At this time corrections were made to the transcripts in places where the transcriber had either misinterpreted words or been unable to decipher parts of the audio recording. There are some words that remained undecipherable, these were omitted from the transcripts, but their omissions do not impact the overall quality of the data.

The returning of transcripts to participants for editing is common practice in qualitative research, and MUHEC typically considers this an ethical right of the participant. However, when the researcher considers editing of the transcripts to be inappropriate given the study aims and objectives, this process may not be necessary

(Massey University, 2013). Forbat and Henderson (2005) write, the returning of transcripts to interviewees can be useful in certain circumstances, for example if the researcher wishes to capture the participant's reflection on the interview. However, the practice can have wide ranging implications, as seeing one's own spoken words written down is a powerful experience which can elicit feelings not only of ownership and empowerment but also those of surprise and embarrassment (Forbat & Henderson, 2005). In this study, transcripts were not returned to participants for editing as the researcher was interested in the participant's initial perceptions on the topic, rather than reflected perceptions.

3.3.6 Data analysis – A general inductive approach

Qualitative research typically involves simultaneous collection and analysis of data whereby each shapes the other (Sandelowski, 2000). For the present study, either one or two interviews were carried out per day, at the end of each day the researcher listened to the interview recordings and wrote reflective notes. A deeper understanding of the data were gained during this process which guided the on-going data collection.

Qualitative data analysis is usually data-derived, meaning it moves from specific cases to a more general conclusion, this approach provides analyses grounded in data that is not speculative or abstract (Schwandt, 2007). This style of analysis is said to be carried out using an inductive approach. The current study used a general inductive approach to data analysis as described by Thomas (2006). This approach involves condensing raw text data into a brief summary format, and then establishing clear

links between the research objectives and the summary findings. Thomas' approach allows development of a model or theory about the underlying structure of experiences or processes which are evident in the raw data. Thomas believes the general inductive approach is appropriate when qualitative data analysis is to be guided by specific objectives, such as in the present study. He highlights its suitability for researchers unfamiliar with traditional approaches to qualitative analysis, as it provides a systematic set of data analysis procedures. Thomas outlines five procedures used for the general inductive approach to qualitative data analysis, these are:

1. Preparation of raw data files (data cleaning): Format the raw data files in a common format (e.g., font size, margins, questions or interviewer comments highlighted) if required. Print and/or make a backup of each raw data file (e.g., each interview).
2. Close reading of text: Once text has been prepared, the raw text is read in detail until the evaluator is familiar with its content and gains an understanding of the themes and events covered in the text.
3. Creation of categories: The evaluator identifies and defines categories or themes. The upper-level or more general categories are likely to be derived from the evaluation aims. The lower-level or specific categories will be derived from multiple readings of the raw data, sometimes referred to as in vivo coding. In inductive coding, categories are commonly created from actual

phrases or meanings in specific text segments. Several procedures for creating categories may be used. When using a word processor, marked text segments can be copied into the emerging categories.

4. Overlapping coding and uncoded text: Among the commonly assumed rules that underlie qualitative coding, two are different from the rules typically used in quantitative coding: (a) one segment of text may be coded into more than one category, and (b) a considerable amount of the text (e.g., 50% or more) may not be assigned to any category, because much of the text may not be relevant to the research objectives.
5. Continuing revision and refinement of category system: Within each category, search for subtopics, including contradictory points of view and new insights. Select appropriate quotations that convey the core theme or essence of a category. The categories may be combined or linked under a superordinate category when the meanings are similar (2006, pp. 241-242).

As in stage one of Thomas' (2006) model, transcripts were prepared and printed. All transcripts arrived (via email) from the transcriber in a common format. (e.g., font size, margins, interviewer and interviewee text identified). Through the data collection and transcription process the researcher listened to each audio recording twice, allowing her to become particularly familiar with what was said during the interviews as well as the manner in which it was said. Fade (2003) writes, "The way that something is said is often just as important as what is said". As Thomas outlines in stage two; transcripts

were read until the researcher was familiar with their content and an understanding had been gained of the topics covered. The next stage of data analysis was coding and the creation of themes. Text of interest in each transcript was highlighted and a brief summarising note was made in the margin. Main-themes and sub-themes were identified based on the brief summary notes. During this process investigator triangulation was used. Investigator triangulation is “the use of two or more researchers to analyse and interpret the data set” (Polit & Beck, 2014). All transcripts were read by the two main research supervisors, one of which has extensive experience in the field of qualitative research. Coding decisions were discussed numerous times with the two research supervisors until an agreement was reached. A new document was created with the themes, and highlighted text was copied and pasted into the relevant theme. As Thomas (2006) outlines in step four, segments of text that were not of interest to the study topic were left uncoded, and other text was coded to more than one category when appropriate. In stage five, the final stage of data analysis, transcripts were scanned again for new insights, and coded text was reviewed for contradictory points of view. Main-themes and sub-themes were revised accordingly. Appropriate quotes that conveyed the essence of a theme were selected. A description of the meaning of each main-theme and sub-theme was developed to be presented along with the quotes. An overview of the inductive coding process is shown in table 3.1.

Table 3.1 The Coding Process in Inductive Analysis

Initial reading of text data	Identify specific text segments related to objectives	Label the segments of text to create categories	Reduce overlap and redundancy among the categories	Create a model incorporating most important categories
→	→	→	→	→
Many pages of text	Many segments of text	30 to 40 categories	15 to 20 categories	3 to 8 categories

Source: Adapted from Thomas (2006, p. 242)

3.3.7 Presenting the findings

The requirements of the qualitative descriptive researcher are to comprehensively and accurately detail the data content, presenting the findings as a straight descriptive summary of the data. Although ‘deeper’ or ‘further’ interpretations of data may be possible, it is not required in qualitative descriptive studies. Furthermore, data should be presented in a logical way that will be most relevant to the intended readers. This makes qualitative descriptive study findings valuable primarily as end-products and, secondarily as entry points for further study.

Two main-themes and six sub-themes emerged from the data; these are presented in Chapter Four. A detailed description of the meaning of each main-theme and sub-theme is included. Quotes from the data are used to further illustrate the theme meaning and to provide a fuller understanding of the participant’s views. Dross has been edited from quotes to improve readability. Dross is irrelevant information that is often produced by open-ended questions (Field & Morse, 1985). All efforts were made

to ensure editing did not alter the participant's apparent meaning. Following is an example of a participant's quote, firstly unedited then in its edited form.

Original quote:

Iryana: We don't have music. We do have music but noisy area, it does distract them a lot. I have to say that we don't eat quietly – of course we don't, it's a Dementia Unit and you can't do much. All you can do is we direct them and reassure them and we do Grace in the afternoon, which is good. But we don't make any noise, we don't put the TV on. The radio we can but just quiet. At the same times we do talk, we do tell them stuff.

Researcher: What do you think would happen if there was music playing?

Iryana: No-one's going to eat, it distracts them. It does upset a lot of them, the music. Too much noise is not good here. Too much drama too (Iryana, p.6).

Quote as presented (after editing):

...it does distract them a lot. ...But we don't make any noise, we don't put the TV on. The radio we can but just quiet. At the same times we do talk, we do tell them stuff. ...No-one's going to eat, it distracts them. It does upset a lot of them, the music. Too much noise is not good here. Too much drama too (Iryana, p.6).

Table 3.2 presents the main themes and sub-categories that emerged from analysis of the data, examples of data extracts in each category are also provided.

Table 3.2 Themes and example extracts

Main-theme: “It’s about the individual”	
Sub-theme	Example extract
Appetite	<i>It depends on the time and the day and the mood they’re in (Ngaire, p3).</i>
Appeal	<i>...presentation is always first, it’s the taste that comes after (Ngaire, p9).</i>
Ability	<i>They don’t swallow properly or they don’t know how to chew and swallow (Devi, p2).</i>

Main-theme: “It’s about the environment”	
Sub-theme	Example extract
Surroundings	<i>...we have music sometimes. We have it low pitch. ...It makes them relax. ...It can be positive but it depends what kind of music of course. Some of the TV can distract, we like to have the TV off (Caroline, p.12).</i>
Social	<i>...we try and bring everybody to the table because when they’re sitting with everybody they’ll drink more, they’ll eat more (Devi, p.5).</i>
Support	<i>Yeah, I think sometimes she forgot she’s supposed to eat it. But if you sit there and push her to eat it, she will eat it and after that she says thank you. She wants to eat but sometimes it’s just the mind, you know (Maeva, p2).</i>

3.3.8 Research quality – validity and rigour

All research should be judged on the quality of the methods used (Fade, 2003). Qualitative research pioneers Lincoln and Guba (1985) simply ask, “Are the findings of the study worth paying attention to, and worth taking account of?” (p. 290). Validity is the term used to describe the extent to which qualitative research accurately reflects that to which it claims (Porter, 2007). Rigour refers to the criteria for trustworthiness of data collection, analysis, and interpretation (Prion & Adamson, 2013). Rigour is essential to any scientific endeavour to ensure validity (Whittemore, Chase, & Mandle, 2001).

There has been considerable debate among researchers as to appropriate strategies and terms used for assessing quality in qualitative research (Fade, 2003). Whittemore et al. (2001) integrated the many views of quality strategies commonly used in qualitative research, including those views of Lincoln and Guba (1985). They proposed four strategies (credibility, criticality, authenticity and integrity) as primary validity criteria necessary to all qualitative inquiry. Fade (2003) suggests these same four strategies for addressing quality in qualitative research in the field of human nutrition and dietetics. Explanations of each of the four strategies are discussed below, including how they have been applied in the current study.

Credibility

Credibility is an overriding goal of qualitative research (Lincoln & Guba, 1985). Credibility is “a criterion for evaluating integrity and quality in qualitative studies, referring to confidence in the truth of the data” (Polit & Beck, 2014, p. 378). In order

for a piece of research to be credible it must reflect the experience of participants or the context in a believable way (Lincoln & Guba, 1985). Credibility was established by reflexivity, whereby the researcher provided an overview of her background and interest in the research topic thus exposing any personal perspectives.

As previously mentioned, the data analysis process involved investigator triangulation with the two main research supervisors. This process enhances credibility and validity of the findings. A deeper understanding of the data was also obtained by analysing the data by hand as opposed to using analytical computer software. Adding further to the studies credibility, the over-arching study design, sampling strategy, data collection, analysis and re-presentation techniques are all well recognised qualitative processes. Each of these processes have been openly presented and referenced in this chapter, moreover, a clear rationale for their selection has been discussed.

Authenticity

Authenticity is the extent to which the research reflects the meanings and experiences as they are lived and perceived by the participants (Sandelowski, 1986). Authenticity is enhanced through the use of an 'emic' approach to data collection (Fade, 2003). Emic refers to the researcher seeking to present an insider perspective on the subject being studied. Put simply, this means, the researcher ensures the participants are free to talk about issues that are important to them rather than issues that are important to the researcher. This was achieved in the current study by the use of broad open questions during the semi-structured interviews. In Fade's (2003) discussion of authenticity, she states that qualitative researchers should ensure they use sufficient

raw text to communicate a clearly perceptible picture and support each point made in the analysis. The term 'thick description' is often used to express this idea. In the present study, the use of 'thick description' in the findings further enhances authenticity.

Criticality

Criticality is a strategy commonly used to demonstrate validity in qualitative research. To assess a piece of research for criticality one can ask the question "has the inquiry involved critical appraisal and reflexivity?" (Polit & Beck, 2003, p. 437). Criticality was demonstrated in the current study by demonstrating reflexivity, and investigator triangulation as previously discussed.

Integrity

The matter of integrity was addressed primarily by the submission and subsequent approval of a detailed ethics application from the Massey University Human Ethics Committee. Integrity was enhanced by ensuring participants understood and signed participant consent forms outlining the semi-structured interview process including that; they can refuse to answer any question or to terminate the interview at any time, the audio recording would be stopped if they wished, and that they may withdraw from the study up until 30th May 2013. Integrity was also demonstrated in general terms by ensuring credibility, authenticity and criticality.

3.4 Summary

The first part of this chapter presented the theory and rationale for the research design employed in the study. The second part discussed execution of the study. In summary, ethics approval was granted by MUHEC, a qualitative descriptive approach was used, a purposive sampling strategy was utilised to recruit caregivers as study participants until the point of data saturation. Data were collected through semi-structured interviews. Data analysis was conducted using a general inductive approach, and findings were presented within a framework of main-themes and associated sub-themes; findings were supported with quotes from the data. Finally, research quality (validity and rigour) was discussed. Two main-themes incorporating six sub-themes emerged from the data. These themes are presented in the following chapter.

4.0 Findings

4.1 Introduction

The purpose of the present study was to understand factors affecting optimal nutrition and hydration for people living in SDCUs. This chapter presents the findings following data analysis from semi-structured interviews with the study participants (11 caregivers at two Auckland SDCUs). A discussion of the main-themes and sub-themes identified is presented along with direct participant quotes and references to the literature to support the discussion.

As discussed in the literature review, evidence to date suggests a range of inter-related factors may ultimately impact weight loss, malnutrition or dehydration for people with dementia in SDCUs. These factors were identified in the current review as; individual factors (including cognitive and functional issues), social, cultural, and physical environmental factors. Additionally, in-line with the person-centred care philosophy, interventions and assistance from caregivers should vary depending on the nature of the individual's abilities or disabilities.

In the current study, two main-themes and six sub-themes emerged from the data (figure 4.1). The first main-theme that will be discussed is *"It's about the Individual"*. This theme incorporates factors relating to the individuals cognitive and functional health which affect their desire for food and their personal likes and dislikes regarding food, as well as their ability to manage the eating process. The findings are presented under the sub-themes of *Appetite, Appeal, and Ability*. The second main-theme to be

discussed is *“It’s about the Environment”*. This theme incorporates factors relating to the dining environment, such as; background music, table settings, and interactions with other residents, staff and visitors, and assistance provided by caregivers. These findings are presented under the sub-themes of *Surroundings, Social, and Support*.

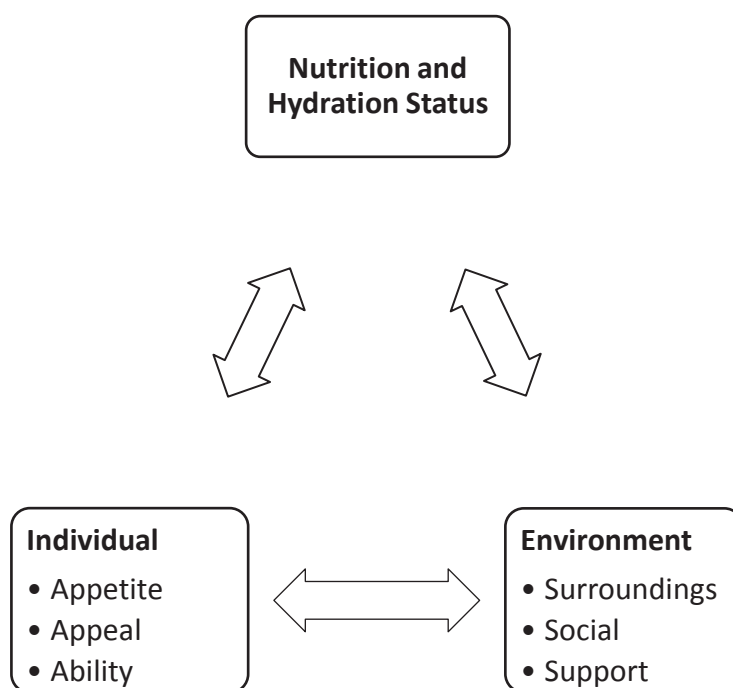


Figure 4.1 Factors affecting nutrition and hydration status of people living in SDCUs

4.2 “It’s about the individual”

“It’s about the individual” is the first main-theme to be discussed. This theme incorporates factors relating to the individual’s current cognitive and physical health which affect their desire for food, their personal likes and dislikes regarding food, and their ability to manage the eating process. Within this main-theme are three sub-themes, *Appetite, Appeal, and Ability*.

4.2.1 Appetite

It depends on the time and the day and the mood they're in (Ngaire, p3).

Reduced food intake due to a decline in appetite is a natural part of ageing (Smith & Greenwood, 2008). However, people with dementia are more likely than those without dementia to have a poor appetite (Holm & Söderhamn, 2003). The factors affecting appetite are multifactorial and may be different or further complicated for people with dementia.

Participants identified a number of factors they believed influence the food and fluid intake of people with dementia which can be attributed to appetite. These issues included being full from the previous meal, the effects of Sundowning, how active they have been during the day, mood, health, and whether or not they need to use the bathroom. A number of participants mentioned that residents did not eat well at dinner, and that they tended to eat better at supper which was served a couple of hours after dinner. Dinner was 4pm at one unit and 5pm at the other unit. Some participants felt this was too early; that lunch, afternoon tea and dinner were not spaced out enough. Some participants felt a barrier to eating well at dinner was that residents were possibly still full from lunch or afternoon tea. Another possibility is that increased confusion and restlessness often seen with sundowning syndrome may affect some residents desire to eat. One participant at the unit which served dinner at 4pm thought that 5pm would be a better time for the residents.

...or it could be they're full from lunch time, especially if they have their afternoon tea (Moana, p10).

Sometimes if the person has good lunch, then they refuse the dinner (Arihi, p8).

But sometimes we give the afternoon tea, sometimes it's very close. They don't want to eat sometimes because they're too full (Maeva, p12).

...when it's during supper time, you can see them, they eat so much. ...Supper time here is around about six thirty. ...They have good appetites and I got shock, far different from dinner – ...Dinner they start here at four o'clock. ... [If I was planning the foodservice] I would change the time. ...I would tell them that it's better if you start at about five o'clock. That's when they get hungry and then eight o'clock is supper. But I don't want to be smart because I have to – but when I saw about six thirty, you see them, they eat so much (Moana, p9).

Lelei noticed that after residents had been on an outing or had been busy with a special activity that they ate more than usual. Comparatively if they had stayed in all morning watching television, they did not eat well at lunch. This makes sense as the increased energy expenditure from being more physically active would increase an individual's appetite.

Sometimes the OT takes them for a walk or go in the bus trip. When they come back they eat all their lunch, it's all finished. ...We can tell because of the

activity they have but if they don't have much activity they all sit and watch TV. When they come for lunch they hardly eat. "Oh, we're still full from the morning tea". ... I think the food is alright, it's just them, it depends if they are full from the morning tea, if they do more activities they have to eat more.... (Lelei, p7).

Caroline and Maeva talked about residents having a poor appetite if they required the bathroom. Participants usually tried to take residents to the bathroom prior to mealtimes. Otherwise, they found residents would get up during the meal to use the bathroom, which disrupted other residents. It also meant that a caregiver had to accompany them, leaving the dining room short staffed. Alternatively, the resident may just sit at the table and not say anything, but may not feel like eating.

Uncomfortable of course if they haven't been to the toilet and getting up wandering. Usually if they get up and wander that's the first thing we do, go to the toilet (Caroline, p2).

I think sometimes when they feel sick and sometimes they need to go toilet. I think that's the most important thing for them. If we can know they need to give them [supplements or laxatives] to help constipation. Sometimes that's a thing, they don't want to eat (Maeva, p4).

Being unwell was another cause of poor appetite. Specific conditions mentioned were constipation, and urinary tract infections. Participants were aware of these issues and looked out for them, for instance, if someone was not eating they knew to check

whether or not that person needed to go to the toilet as mentioned above, or perhaps they were constipated. Similarly if someone was not drinking, it could have been a sign that they had a urinary tract infection and that the pain experienced when urinating was causing them to avoid fluids.

I notice if they couldn't eat, it could be they're constipated or they're not feeling too well. You can tell by their looks (Moana, p7).

Being unwell. When they're sick, UTIs, sore tummies (Ngaire, p5).

I think sometimes when they feel sick and sometimes they need to go toilet. I think that's the most important thing for them. If we can know they need to give them Sups or Lactulose to help constipation. Sometimes that's a thing, they don't want to eat (Maeva, p4).

...UTIs too are another factor. They don't want to drink because don't want to have the pain because they've got a UTI. That's a big factor (Caroline, p13).

I guess you're sort of aware medically what's going on and if their appetite's dropping then you do make a special effort. You might sit next to them and talk or have your lunch next to them so you're sitting there prompting (Teresa, p8).

Some participants talked about the resident's mood affecting their appetite. Two mentioned when residents are feeling sad or down they don't want to eat. Ngaire gave

the example of when residents first arrive at the unit, they feel sad until they get used to the new environment. Lelei explained how they keep meals for residents to have at a later time. Moana and Maeva explain how it's a good idea to make the residents happy before meals by talking, joking or singing with them.

It depends on the time and the day and the mood they're in (Ngaire, p3).

...maybe the change of environment, that might stop them from eating – sadness. They get sad when they first come here. For a couple of days they're sort of nah, nah, nah, don't want to eat, don't want to drink. But they do end up – you've just got to be more of their friend and always up their faces [be visible to them] so they can familiarise with your face and then they'll start trust (Ngaire, p7).

...sometimes when they are really down they don't like eating, they just say I'm not hungry but we just keep the food for later. We know they are hungry, we just take it to their room and they eat it all (Lelei, p10).

...it's good to make them happy before they eat. ...In the dining room. You need to make them feel comfortable, make them feel happy and it's good to sing a song (Moana, p9).

Sometimes just to make them happy. ...You sit there and just talk, just joke and they're happy and they can just eat. (Maeva, p9).

4.2.2 Appeal

...presentation is always first, it's the taste that comes after (Ngairé, p9).

Another key factor influencing food intake is food appeal. In order for food to appeal it must evoke interest or desire in the individual it is presented to. Participants talked about the importance of providing a variety of food and drink to keep residents interested, additionally they often mentioned presentation as influencing a persons' desire to consume the food, and taste and smell of the food was also considered important to how much residents ate.

Most of the participants talked about the importance of providing a variety of menu items to keep residents interested. Specific things mentioned were, offering more variety at breakfast time including cooked breakfasts, include a variety of fresh fruit regularly, sometimes offering biscuits instead of cake at morning and afternoon tea, varying the cold drinks, less egg dishes at supper time, and ensuring the dessert item looks different to the main meal item each day.

Devi highlights an important consideration for foodservice in the residential care setting, particularly relevant for people with dementia. She points out that as these residents typically only eat or drink items provided by the facility, they are likely to forget things they are not exposed to.

...they forget things, they will forget what an apple is, they will forget what fruit that is. So it's good if you give them things every day, change the fruit, not

banana all the time. Change the fruit, today banana, maybe pear or maybe something so they know oh, this is pear. Because they will eat only what they are given. I think they will forget other things like we do give water melon summer time but they should have a variety of things like I said. So it reminds them that these things are available. (Devi, p8).

Ngairé talks about making changes to an individual's regular meal to provide variety. She explains when someone appears to have gone off their food for example at breakfast; she will try offering them a different cereal to their usual – just for a change. Alternatively she may try adding sugar to drinks or cereal to enhance the taste.

Usually in their care plans is what they usually have before they come here but sometimes they sort of get sick of it so we change it a little bit. Instead of having porridge we give them cornflakes and that's how I know when they're not eating their food. So you've got to try and search around to see what else they would like to eat, either put more sugar in their tea or their breakfast. Just change it a little bit (Ngairé, p1).

Devi used breakfast as an example to explain how she would like to see more variety in the menu. She reports residents ask for bacon and eggs at breakfast.

I think I would give more variety in breakfast, just not porridge and sometimes eggs with that because they do ask sometimes. "Oh, can I have bacon and eggs, can I have this..." – I think they should have more variety (Devi, p6).

When asked what they would do differently if they were planning the foodservice, some participants said they would like to provide biscuits to make a change from cakes or muffins. Participants specifically mentioned that the residents liked to dunk biscuits in their tea. Currently at both facilities either cakes or muffins are served for morning and afternoon tea.

I think they would probably be happier with a packet of plain biscuits sometimes, rather than cake all the time. You can't dunk cake. There are some people that are dunkers. ...Whatever comes has been cooked but I think sometimes they would be just as happy if I opened a packet of biscuits for them. Sometimes we buy those cheap wafer biscuits, the pink and chocolate biscuits, they love those. It's easier to eat something like that than it is a piece of cake (Teresa, p9).

Teresa would like to see variety in the cold drinks served. Currently orange cordial and water are the only cold drinks offered. She thought it would be nice to provide soft drinks sometimes or even just to vary the flavour of juice.

Probably a variation on the juice. Sometimes fizzy drink, lemonade in the afternoons would be a real bonus for them. Something different. Just a bit of a variation. Even colour-wise, different flavours of juice might be interesting for them, even if they don't like them at least they can say I don't like it (Teresa, p13).

Participants from one facility spoke of how they would love to see fresh fruit offered to residents. They reported the only fruit residents had was tinned fruit at breakfast time and for dessert on some days. At times family members brought fresh fruit for their relative, and sometimes for everyone to share. Staff also reported supplying bags of fruit for residents to share, and at other times fruit was purchased with money from the 'kitty'. Participants spoke of how much residents enjoyed fresh fruit on these occasions. However, one of these participants also said she did the meal ordering from the main kitchen and had the choice of either fresh fruit or baked items at morning and afternoon tea. It was not clear why she always chose the baked items over the fresh fruit.

I'd really like to see fresh fruit on the menu. It's a real experience for them. That's the one thing you'll hear some of them ask for. "Oh, I just feel like an apple, I just want a mandarin" or they'll zero in on you when they see you eating your lunch with a banana (Teresa, p13).

I find there's too many milky stuff and not enough fruit. This place does not get any fruit. ...I bring in all these to share with them. Those are my fruit up there and I bring it in. ...Yesterday I brought in a bunch of bananas and what I did is chop them all up for them and they love it. They love fruit (Aditi, p17).

Participants talked about variety in regards to the dinner and dessert served in the evening. They felt there were too many egg dishes on the dinner menu, and also that the dessert often looked similar to the main meal item.

Sometimes there's a lot of eggy things that come through but then you'll also have an eggy custard and it's like – blaach (Teresa, p4).

They get too many eggy things, most of the things they have for tea are egg based. We think it's too many eggy things. It's probably healthy because it gives them their protein and what-have-you but – ...It all looks the same, then they have their main and then you give them their pudding and that looks like their main. All the food looks the same. ...[the pudding] That's usually an eggy base too, even a rice pudding can look like scrambled eggs. Just something different. They love pavlovas but they can't have that all the time I suppose. Just little things like that, something a bit different to egg. They have a lot of quiches and things like that (Beth, p9 & 10).

Another important consideration when planning any menu is offering foods that are culturally appropriate to the people who it is intended for. Teresa and Aditi mentioned this in regards to foods that are familiar to the residents given their age and cultural background.

...put a bit of thought into old fashioned – what's appropriate to them, what they would have thought of as something special and things like that (Teresa, p9).

With rice, instead of rice they should have mashed potato because – We've got a lot of Europeans here and they're used to potatoes, they're not used to eating

their meals with rice and that's what gets them, they're counting every bit of rice and as for potato, they know straight away (Aditi, p8).

Caroline told of two times that she added variety into the meal service, improving the appeal of the meal for residents by making a regular meal into something a bit different and special.

They like their fish and chips, depends on how their chips are. One time when I was working on day shift we used newspaper and they loved it, didn't use the plates. I was in one of those moods, good happy mood and okay, 'cos we had about four men here and "oh, I like my fish and chips on the piece of paper". Okay then, so I got out the newspaper and dished it all up on the paper. They loved it. I haven't done that for ages. I should do it again. ... They were smiling and eating. They loved it (Caroline, p7).

It was some special occasion; it was some wedding a few years ago. ...I sat them all around for a special lunch and they had their lunch around the TV. They were good. I don't know if I can do it with these residents now but they enjoyed it (Caroline, p12).

Another participant told of the resident's enjoyment when they had a barbecue. As mentioned above, the residents enjoyed the novelty of having something a bit different to the usual meal service. They also appreciated the cooking smells from the barbecue, which they wouldn't normally get as food preparation and cooking usually

happened at the main kitchen in another area of the facility away from the dementia care unit.

I remember when we had a barbecue, they were "oh yummy" and you could hear them say "yummy". You never heard them say it regular and you can see their eyes, the impression of them in their face. They said oh, they should have had a barbecue once a month, so bring them the smell. I think it's just the smell and eating different from the regular (Lelei, p11 & 12).

Happy hour was suggested as another way to increase variety by introducing a regular special occasion. Beth tells of how they used to have happy hour, and how the residents "love a party".

We used to have happy hour on a Sunday and we used to give them a little bit of sherry with their morning tea on a Sunday. We're thinking of starting it up again, maybe on a Friday afternoon. Give them a few nibbles 'cos they love a party. They love having afternoon teas and things (Beth, p9).

Presenting food well can enhance its appeal; similarly poorly presented food can reduce a person's desire to eat it. Nearly all participants expressed that presentation of food was important. Not only was it important for everybody including themselves but it was particularly important for people with dementia as they may not remember that they like a particular food, they may not remember that it is tasty, so it needs to be eye catching to get their interest and to inspire them to taste it. Participants

specifically identified the importance of presentation by stating that presentation comes first and taste comes afterwards.

Participants believed an important part of presentation was the colour of food, and this was thought to influence how much residents ate and drunk. If the food was nice colours and a variety of colours residents would eat and drink more.

I think that how you present the food to them and the colours, sometimes when you are not hungry if you look at the colours which are presented to you, you'll obviously want to eat. ...if the food looks attractive and nice, the way it's set. A bit of colour like orange, green and white, it will be catch to the eyes and they'll eat. They know, so they'll eat (Devi, p3 & 4).

...their broccoli and pumpkin, it's always a beautiful colour. It's never done to death, it's a beautiful colour. There's a little bit of crunch to their cauliflower. ...veges are done well (Beth, p13).

The way food was placed on the plate was another factor related to presentation believed to affect food appeal and therefore dietary intake.

The thing with dementia, when they look at the plate the salad is like it's all over, but the coleslaw, it's just sitting there and they eat it. ...I think they don't like the food that's spread on the plate. They like the food that just sits nicely on

the plate. ...They love when they see the plate with nice food sitting, you know, not spread around like the salad (Arihi, p13).

What it looks like on the plate would make them want to eat it. If they have food that's just slapped on, they're gonna straight away say to you "oh, this looks yuk". Then you've got to go "taste it, taste it, it's yummy", until they do. ...presentation is always first, it's the taste that comes after (Ngaire, p9).

Yesterday, for example, the pudding looked like a bowl of porridge and we asked the residents, what's it like? They all said it was nice but it just looked like a bowl of porridge? ...we still don't know what it was. I even asked the kitchen lady and she didn't know what it was. They said it looked nice but I had to go and put some cream on it because that was it, it was just that bowl of this sticky stuff. ...Maybe they could have even put a bit of jam in it or put a meringue on it or something. ...Yeah, just so it didn't look like porridge. They used to do beautiful bread and butter puddings but they don't seem to do those anymore (Beth, p10).

The way food is prepared and cooked also affected presentation of the final meal. As Beth highlighted in the excerpt below.

...they just need to make them look a bit nicer. They do a nice scalloped potato on the lunchtime but if it's not cooked properly it's just all water under the

potato. You know how it's supposed to be potato and like cream and it makes it saucy? But they love that 'cos it's got that cheese topping (Beth, p13).

Teresa and Lelei highlight the importance of stimulating all the senses, particularly smell. Teresa believes people would eat more if the pleasant aromas from food could be increased.

Presentation's really quite important, like the smell and the look of food. If you could boost the smell so it stimulates more senses it would be good (Teresa, p8).

There's another meal. Chicken. They fry or bake the chicken in the oven or grill the chicken. Very nice. You just take out the bones and give it to them, they can eat so fast. They love it and I think the smell of the chicken when they grill it (Lelei, p5).

Pureed food is renowned for being difficult to present attractively. Participants commented on how the pureed food was presented. Comments were that it was particularly unattractive on the plate, sometimes with each food stacked on top of the other foods, and that it always looked the same from one day to the next.

We had a lady, she's deceased now but she was on pureed food and it was quite an eye-opener what came every day. It was just green, orange and weird meat coloured variation but she ate it. When she was hungry. But it was really unattractive on the plate and sometimes when the kitchen girls are serving it,

they just plonk each thing on top of each other. It really looked horrible (Teresa, p6).

Participants mentioned that adding flavour to foods was an important factor in increasing the appeal of foods. Sometimes they felt food had not been tasted by the cooks before it came over from the main kitchen. For example, savoury items tasted like they needed salt added. At other times participant's added flavour to try and get individuals to eat certain foods, such as adding sugar to porridge.

I think the kitchen lady probably should taste it first 'cos sometimes it comes just plain, it doesn't have any taste, it needs salt... ...This is dementia and they just realised when they're nearly finished, oh, I need some salt and we don't put salt there [on the tables] (Iryana, p4).

Some pudding, it's like chocolatey custard. Yeah, they do eat it and sometimes they don't eat. Just a mouthful and that's it. And afterwards, if you get to taste it, it tastes really bitter. It's not sweet. So that's why I think the kitchen lady should taste it first. If not, they won't eat it and it's just a waste and they miss out on a meal (Iryana, p8).

...so you've got to try and search around to see what else they would like to eat, either put more sugar in their tea or their breakfast. Just change it a little bit 'cos sometimes, even though you sugar their porridge and that, it's still sour to

them. ...It's just trying anything to get something down them, whether it's sweet or change the taste (Ngaire, p1).

...it's just the quiche on the plate, no gravy or anything. The gravy just comes with the Mouli food and sometimes they eat it, sometimes they don't. Sometimes they don't put salt in it. They should at least – you need to put salt because it doesn't have any taste. I taste it afterwards. One afternoon they have a quiche and only a few of them eat it and the ones that do eat it, we have to feed them (Iryana, p2).

Participants spoke about residents having a sweet tooth and choosing the dessert first over the main if both courses are offered together. For this reason dessert is usually held back until each resident looks like they have finished with the main. The dessert can also provide a back-up if someone is off their food or has not eaten much of the main for whatever reason.

I guess it's more simple for them to cope with if you just do one course at a time. ..One of the things, they seem to develop a real sweet tooth so if you give them dinner and dessert at the same time they're going to go straight for the dessert and probably not go back to the dinner. There's the odd one, they'll eat a little bit of dinner and you'll give them dessert and they'll eat all their dessert but then they'll come back and eat a bit more dinner. So it kind of works for some people but others, they just bypass the main meal and go straight for dessert (Teresa, p7).

...we can't give the pudding because they would eat the pudding before their meal. ...Yeah so we just wait until they're nearly finished and then we give the pudding (Lelei, p8-9).

If you're giving them both together it side-tracks them and straight away they go for dessert. We never have problems with dessert, which is not a problem because what we do, if they don't eat their mains there's always dessert there but we always offer sandwiches first. That's always offered first (Aditi, p1).

4.2.3 Ability

They don't swallow properly or they don't know how to chew and swallow (Devi, p2).

As well as experiencing changes that are a normal part of aging such as a decreased appetite, a person with dementia may suffer changes to the brain affecting seeing, thinking, and moving (Suh et al., 2009). This may cause problems identifying food on the plate, using utensils, moving food from the plate to the mouth, and chewing and swallowing the food. These physical functioning problems may become more apparent as the disease progresses. *Ability* is the third sub-theme presented under the main-theme *"It's about the Individual"*. This sub-theme incorporates the issues faced when cognitive impairment affects physical capability to eat and drink. To demonstrate these issues participants tended to use specific food examples such as in the extract below, Beth tells how peas are difficult for people with dementia to manage. This is an example of how cognitive impairment has reduced a person's ability to use eating

utensils to effectively move food from the plate to their mouth. This reduced ability is recognised as a barrier to optimal nutritional status. Aditi highlights similar issues with peas and also suggests one potential solution to this particular barrier; that by putting the peas in a dish such as a quiche, residents will be able to manage them. In this example she has identified both a barrier and a facilitator to eating.

They get a lot of peas which are very hard for anybody to eat, let alone someone with dementia, they roll off the fork and I think that stops them from eating a lot (Beth, p4).

Peas are no good here. ...There's a lot of fun and games with peas. Trying to get it on their fork or they're grabbing handfuls of them so beans are a better choice than peas. ...they will pick the peas up with the fork or the spoon and you get a few rolling and of course it's all on, they're all under the table trying to chase one pea. ...Unless they put it into a quiche which is okay... (Aditi, p9).

It is common for people with dementia to manage mealtimes with just a spoon or fork as they lose the ability to coordinate both a knife and fork together. Teresa highlights the issues some people experience with utensils.

They lose their ability to cope with the different foods. If it's something that would be easier to eat with a spoon but it's still your main meal, they'll still be using their fork. You can give them a spoon but I guess they lose the ability to cope with things that are difficult like that. A lot of the cutting is really hard. A

lot of them don't eat with a knife and fork, it's just a fork. You know how you put your food on with your knife and fork? ...The coordination goes. ...Arthritis some of them, they've lost the dexterity in their hands a bit (Teresa, p10).

Teresa feels rice is unsuitable as it's served dry rather than sticky, making it difficult to pick up from the plate, she has observed it also causes problems for those residents who have a dental plate. Aditi also feels rice is often not suitable the way it's served, she has found that people chew and chew the rice forgetting to swallow so it builds up in their mouth. She feels rice as a side dish does not work as residents don't know what to do with it and may even start counting each grain, however a dish that has rice mixed through it would be better. Iryana also made comments similar to this; she feels that rice is managed better when served mixed in with something such as mince.

Chopped up sausages – sometimes they like it and sometimes they don't. Sometimes it comes and it's served with rice and the combination is really difficult. ...rice isn't great for them. It's not sticky rice, somehow they've made it so it just all goes everywhere, it's kind of dry (Teresa, p11). I think it gets under their plates if they have got false teeth. It's not particularly great for them (Teresa, p12).

Salad was also mentioned often by participants. Comments were that residents did not like the way salad spreads out over the plate, in comparison to coleslaw which sits nicely in one place on the plate. Another participant commented that only a few of

them can eat the salad, and another feels salad is not suitable for people with dementia as they have difficulty chewing and swallowing it.

Even salad's not suitable here for a lot of them because what's happening is you put the lettuce in there and the mind is already tuned out so of course the lettuce is still sitting there and they've forgotten to keep chewing and chewing, so you've got certain residents that can have salad and certain [ones] that won't be able to keep up (Aditi, p5).

Participants talked about residents not coping well with dinner items being served on toast, for example baked beans, spaghetti or mince; the problem being that residents would eat the two items separately. Therefore, they were not having mince on toast, but rather toast and then mince or vice versa. Participants found that all-in-one type meals such as cottage pie or fish pie were better managed by the residents as there was no confusion about what to eat first.

Get something they can pick up with a fork only. Baked beans, they'll eat the baked beans then eat the toast. It's two separate things, they shouldn't be separate. They'll pick up the toast and eat the toast first before – what's this, I'll eat this too. It's not a good meal. But they do eat it. They do eat the baked beans and toast or the spaghetti and toast but like I said, they'll eat the toast first unless we cut it up. And we cut it. Most of the meals that come like that we have to cut (Iryana, p12).

They have mince on toast. I mean, making Shepherd's pie or something instead of just putting the mince on there and then the toast because that becomes another problem. Using the toast, that's just too hard for them to eat and so with the bread, they're just confused, where do they put the mince, on the piece of bread or do they put the bread in their mouth first and then put the? ...But we found if they do more like a cottage pie then it's all there together. A cottage pie and a serving of vegetables (Aditi, p11).

Participants mentioned the difficulty residents have coping with sandwiches with multiple fillings, primarily salad sandwiches which often fall apart when residents try to pick them up. Hamburgers were also mentioned for this same reason. Again, both a barrier and a facilitator were identified, the barrier being the inability to pick the sandwich up without it falling apart, and the facilitator identified by participants was to only provide sandwiches with minimal fillings so the sandwich holds together well. Iryana spoke of how the staff make butter or jam sandwiches for residents if the salad sandwiches provided by the kitchen fall apart when they were handing them out.

...when you have maybe three fillings in there. So by picking a sandwich up everything's falling out. What we do, in this unit we only have one filling per sandwich but it could be cheese, it could be egg and then you have ham with your mustard. So sandwiches like that are just not suitable for here with a lot of fillings (Aditi, p3).

Another commonly mentioned barrier was the size of individual food items. Participants reported that residents were unable to manage large pieces of food. Foods mentioned were the muffins served at morning tea, pieces of vegetable such as pumpkin, pizza, chunks of meat in stews, sausages, and hash browns. Participants cut these items into more manageable sizes for each resident, otherwise they found residents were confused by the large piece and unsure how to tackle it and often just left it on the plate.

Sometimes they bring in sausages. We cut the sausages, if they don't remember how to pick up the fork why would they cut the sausage? (Iryana, p12).

The meat's in great big chunks, big chunky stews. We have to cut it up for a lot of them (Beth, p4).

As a person's ability to use eating utensils diminishes, finger-foods may prolong independence with eating. The use of finger-foods was a popular subject with many participants talking about the benefits. They spoke of residents enjoying meals that they could pick up, such as fish and chips, sausage rolls and mouse traps. However, it was also mentioned that these foods are seen as treat foods which could be part of the attraction.

They still remember to pick and put in their mouth so that's another way, finger-food. ...Make sure the veges are whole. ...they can be picked up. Fish bites, things like that. ...because as their dementia gets further they tend to

don't [not] know what a spoon is for but then somehow they still remember to pick up things and put it in their mouth (Ngairi, p4). ...They love finger-food (Ngairi, p7).

But I like if I can see they have finger-foods because it's easy for them to just pick it up and eat it.fish and chips on a Friday. They love it. They just take the chips and just eat it and fish, but they have big piece of fish. It's good to have those little fish fingers. They enjoy just picking it up and eat it. ...I think finger-food is easy for them to manage, just pick it up and you can see a smile on their face and they think ooh, nice, very nice (Arihi, p2 & 3).

Yes, some of them can say what they want which is a good thing, as long as we can keep that independence going. That's why I like the idea of finger-food when they get into the stage where they can't use knives and forks anymore and they can still feed themselves without having someone sitting there actually shovelling food in their mouth (Beth, p3).

Participants talked a lot about food texture, they noticed residents were unable to chew certain foods and were concerned they might choke on others. Texture of meat was a common concern with residents chewing and chewing, and eventually removing it from their mouth without swallowing. Participants said they would cut the meat into small pieces for those residents who were struggling. Lelei thinks all meals provided to the dementia care unit should be 'soft' meals.

I notice when they eat the meat, they chew and chew and chew. It's like eating chewing gum. ...Some residents, they'll chew and chew. Some of the residents spit it out, because the meat, you know must be too hard for them or too big (Moana, p2).

Sometimes – dementia – it's good for the other facility but dementia, it's good to cut the meat smaller, not big lump of meat. They can't chew it (Arihi, p15).

They should have a soft meal all the time. It doesn't matter how the other people who got their normal teeth, but I reckon the soft one for all of them, that's the meal they always love (Lelei, p10).

One of the two facilities served soup daily at supper time, the other facility did not have soup on the menu. Some days the soup was pureed and other days it was not pureed. Participants commented on problems the residents have managing the chunky soup. They said that when soup arrives and it has not been pureed, they don't serve it, as they have tried in the past and it causes residents to cough. Participants were afraid residents would choke on the lumps. When this happened, they served supper sandwiches with a cup of tea and the soup was thrown out.

...the soup is lumpy. Big chunk of vegetable, it's not good because they will choke on it. This is different to the hospital, dementia. It's good to have blended their soup, pureed soup. ...Sometimes they deliver chunky one so when we look at it we serve cup of tea. We don't serve that soup. ...because when they drink

it you can hear them coughing. ...When we give it to them you can hear them start coughing. That soup is not for dementia (Arihi, p7).

The soup is alright. Soup is good for supper. ...When they don't eat at dinner, they tend to eat at supper. ...sometimes it comes really thick. Sometimes there is ingredients inside which you can barely pour them into the cup, how can we eat them, they need to eat it with a spoon so sometimes we just have to not use that. We have to give a cup of tea. Better to have a cup of tea rather than someone choking (Iryana, p2). ...When it's really thick, there's a lot of ingredients there, it's hard for you to pour it from the thing to the cup so we have to leave it (Iryana, p4).

Teresa and Caroline consider meat with bones to be unsuitable for people with dementia. They explain how they cut chicken meat away from the bones before giving the meat to the residents.

I like taking the chicken off the legs before I give them 'cos I had a resident nearly choke on a chicken bone and it's not nice (Caroline, p7).

They give them chicken legs which are really, really difficult 'cos most of them won't pick it up to eat it so we cut all the meat off the bone, take the bones away and leave them the chicken meat. So that's not really appropriate 'cos even for the ones who that are good dexterity-wise, they still struggle with

getting the meat off it. They've gone past wanting to pick it up and get their fingers dirty (Teresa, p11).

4.3 “It’s about the environment”

Cognitive and functional impairment associated with dementia increase the individuals vulnerability to environmental influences (Briller et al., 2001). *“It’s about the Environment”* is the second and final main-theme to be discussed. This theme incorporates factors relating to the dining environment, such as; background music, table settings, and interactions with other residents, visitors, and staff, including encouragement and assistance from caregivers. These findings are presented under the sub-themes of *Surroundings, Social, and Support*.

4.3.1 Surroundings

...we have music sometimes. We have it low pitch. ...It makes them relax. ...It can be positive but it depends what kind of music of course. Some of the TV can distract, we like to have the TV off (Caroline, p.12).

The first sub-theme of *“It’s about the Environment”* is, *Surroundings*. This sub-theme incorporates factors relating to the surroundings of the dining room or the dining environment, such as; background music, and table settings.

Some participants felt having music playing in the dining room was a distraction leading to confusion and ultimately to residents not eating well. Participants talked about the need to communicate with other staff members and with residents during

mealtimes, and the addition of extra 'noise' i.e. music further complicates the environment and means staff need to speak louder to be heard which may be interpreted as yelling, causing residents to become distracted and even distressed.

Music playing, I think it's not a good idea for them because we have to think about – these are confused residents. They will get distracted very quickly so – this is my opinion, I don't know if I'm right or not but I think, because sometimes the music will distract them. They will not eat. They can't concentrate. That's the thing, they can't concentrate because these people, they have a disease, Alzheimer's. So they will forget and get confused and they can get distracted very easily too so what we need to do is the background music, I think it's not good for them so that they can concentrate on their meal and they know when we tell them "this is your food, lunch time, you need to pick the spoon and eat", they will eat without any background music without any distraction (Devi, p.3).

...they love it, especially the opera music and the old time music. ...[but] It is a distraction at meal times... ...loud music, I always turn the music off. I find they're calmer. ...either on the TV or a DVD or the radio. It's alright if it's very low but if it's loud and you're trying to tell the girls who's meal you've dished up, because I dish the meal up, you've got to yell loud and then they think you're shouting. Noise is quite a bad thing here at lunch times. Any time actually, they don't like loud noise. That can set them off (Beth, p.1).

...it does distract them a lot. ...But we don't make any noise; we don't put the TV on. The radio we can but just quiet. At the same times we do talk, we do tell them stuff. ...No-one's going to eat, it distracts them. It does upset a lot of them, the music. Too much noise is not good here. Too much drama too (Iryana, p.6).

Conversely, Moana and Caroline reported music as potentially a positive thing, assisting residents to relax and thereby helping to create a calm environment. However, Moana's comments are relating to individual people in their own room or in a second lounge area away from the main dining room, they are not general comments about how music affects people in the main dining room. Caroline talks about music in the main dining room.

...she likes her classical music and now I notice that when she likes music, she likes smiling and then you explain to her again "this is your left-over breakfast that was in the dining room, can you finish it?" (Moana, p.1).

They love music. Classical music calms them down. I notice that lady, when you have problems, she sits in the TV room and she sits there and she folds her legs, swings her arms, swings her head side-to-side. She loves music and when the music is on she'll eat and drink (Moana, p.7).

...we have music some times. We have it low pitch. ...It makes them relax. ...It can be positive but it depends what kind of music of course. Some of the TV can distract, we like to have the TV off (Caroline, p.12).

Table settings were also found to influence food intake. Participants described how too many items on the table can distract residents from their meal. A vase of flowers on the dining table was mostly found to be an unnecessary distraction. Reports of flowers getting into the food or being taken and eaten by residents in the past meant the facilities don't usually have a flower vase on the table. However, one participant thought that just one vase and the cutlery and serviettes were acceptable, but any more items were a distraction.

Sometimes we have flowers and sometimes bad things happen to the flowers. They get in the food and things like that. It's pretty plain. We put a table cloth on for lunch and dinner. It kind of signals if they're sitting around and we do that. It's just a sort of visual (Teresa, p.5).

Oh, the flowers, it was there. One lady took the flowers, she ate it so we don't put the flowers. She said she loved it, she like eating flowers so we don't put flowers anymore (Lelei, p.10).

Sometimes flowers, flowers they don't – they'll start eating them anyway and we have to take them away (Caroline, p.13).

They can have just flower vase, we can put flower vase, not too many things, just fork and knife and serviette. One flower vase is alright so that they know this is what needs to be on the table and what we have to do with that. If too many things they think oh, too many things, they can get distracted very quickly (Devi, p.3).

Following on with the table setting theme, Iryana noticed that using coloured or patterned table cloths was a distraction to residents whilst eating. She noticed residents ate more when the plain white table cloth was used. Caroline also agreed that table settings and table cloth colour influenced food intake.

I've noticed when you put the white table cloth they seem to be eating a lot and there's less talking, directing, reassuring and telling them you need to eat. ...White is always the best. The maroon colour, just looking at it – if it gives you a headache, what about them looking at it (Iryana, p.5&6).

...what's on the table is a big factor. Nice coloured table cloths (Caroline, p.12).

4.3.2 Social

If everything's calm and the staff are calm we can get through lunch quite well (Beth, p7).

The social environment of any SDCU is an integral part of the life of people who live there. Dining is the most social of all activities of daily living (Amella, 1999). A positive

social dining environment supports a person with dementia to consume adequate food and fluid at mealtimes (Amella, 1999). However, participants identified a number of social interactions that commonly distracted residents at meal times resulting in an interruption or an end to their eating. Even in the early stages of dementia, individuals may become easily distracted (Curfman, 2005). Common social distractions which emerged in the data were typically some sort of 'noise' or 'friction' in the dining room caused by others being 'loud' or 'over-the-top'. Other residents, visiting family members, or conversations between staff members were identified as possible causes of the distractions. The following excerpts tell of the colourful array of social distractions that can occur at meal times.

...we've got a gentleman at the moment that can't seem to sit still for any length, he's up and down and up and down, that can cause a bit of friction. We've got another lady that keeps calling out "oh my God, I want to go home". Then you've got the staff telling her to "sit down, sit down" (Beth, p7).

...and if the staff are a little bit over the top, like a bit loud. ...sometimes that's not very good if the staff are talking amongst themselves (Beth, p2 & 3).

...she goes around and touches everybody's food and takes things away. ...Oh, they just tell her to bugger off. [or] "Oh, you can have it then". They get angry too and upset. The whole atmosphere is just not good if there's one there that's (Caroline, p.12).

As the excerpt above suggests, these disruptions often caused a chain reaction among residents, where one causes a distraction and 'sets the others off'. This was a common theme with many participants mentioning it.

...as soon as that resident stands up and says I'm going, the whole lot start so of course that interrupts the serving time (Aditi, p.2).

If any of the other residents are a bit upset that can cause a bit of friction (Beth, p.2).

We don't eat quietly. Some of the residents do play up and if one plays up, the others start... Like I say, if one starts making noise it will upset the others and they start making noise (Iryana, p6&7).

Yeah, you get some residents, we have a couple – they didn't come in as a couple but they're a couple, he decides he's going to feed his lady friend and she decides she's going to spoon her food into someone else's plate and then that one spoons it into someone else's plate and it goes right around. So those interruptions, it's challenging, is meal times (Aditi, p.2).

On the other hand, positive social engagements were mentioned by the majority of participants as a key facilitator to residents eating and drinking well. Most participants mentioned this many times in a number of ways including social interactions between residents and positive effects of family visits. The following two excerpts tell of the

positive effect of engaging with other residents at meal times. It appears that seeing others eating and drinking acts as a prompt or cue for a confused individual to start eating. Perhaps they had forgotten why or how to eat, and seeing someone doing it reminded them.

...you're sitting them around a table where you're seeing each other eating, drinking and it sort of gets them going (Ngaire, p.3).

...we try and bring everybody to the table because when they're sitting with everybody they'll drink more, they'll eat more (Devi, p.5).

Family visits can have a positive influence on the resident's dietary intake. Family visits are particularly valuable if the resident is not eating well. Participants mentioned when family visited, residents talk, laugh, and eat. Caroline also mentioned that the influence from family can be greater than the influence from staff.

...when the family comes, they eat – I can feel it sometimes when one person doesn't eat and then the family comes she eats a lot, where they sit and talk to them. I think it's just being part of them. ...It works when they don't eat. I think it encourages them 'cos one lady, when the husband comes he always sits next to her and then you can see she eats. It's not depending on us to tell her what to do. It's really good when the family comes along and encourages, [it] looks[s] like they're eating when they have the families around them (Lelei, p.2).

But some of them, they know their patient has to be fed, they stay, they help to feed. ...It's very good because the patient knows, like the wife or the husband, they know, they will just laugh and eat. It's very good when they come and help like that, help to feed (Maeva, p.4).

They're happy [when their family visit at meal times]. ...One man, [residents name], his wife comes and you see the difference. He just sits. She's allowed to go "eat your dinner" but we can't go "eat your dinner". He wouldn't listen and tell us to bugger off but he wouldn't say that to his wife (Caroline, p.11).

Participants would strive to create a calm dining environment by attempting to minimise distractions. They have developed ways in which to deal with confused or distracted residents at mealtimes. Sometimes this involved settling agitated residents one by one. The importance of minimising distractions was highlighted by Devi with this general comment.

Minimise distraction so that roughly they will have an idea of what you are doing and they can concentrate on that and they can eat (Devi, p.3).

One reported measure to manage agitated or disruptive residents was for a caregiver to accompany them away from the main dining room to a separate lounge area where they could complete their meal; this prevented further disruption to other residents. However, this of course came at a cost as it meant one less staff member in the main dining room.

...we have certain residents where we have to move them from the dining room 'cos it becomes dangerous (Aditi, p.2).

We've got one that gets quite disruptive and I say "come on [residents name], we'll go down the bottom lounge and have lunch there" (Caroline, p.12).

To simply 'let them go' was another technique employed by participants when certain residents became distracted from their meal and wanted to leave the dining room.

...let her go, she'll come back. It's best to do that, it's no good nagging at them 'cos it only makes them worse. You know yourself, if someone kept telling you to sit down you'd turn around and revolt (Beth, p.7).

Once their mood changed, just let them go and let them do what they want to do and there's a time they'll come back to us (Moana, p.1).

Participants had identified which residents get along and which cause a distraction when seated together. They typically seat residents together who they know get along. In this respect seating was strategic to facilitate eating by reducing distractions. Devi spoke about seating residents in the same place each meal time as part of a routine which helped to reduce agitated behaviour and in turn reduce distractions.

Another thing is the right seating. Some of them might get along with others and some might [not] get along (Caroline, p.1).

...we have to make sure they sit with the people they want. Sometimes we put them there and they don't like it, they want to move to another table so we always make sure they sit with the people they like (Lelei, p.1).

...we sit particular people to particular places. Like [if we seat] too noisy ones to some table which are the quiet ones, because they are dementia, they can get distracted very quickly and then if they don't like anything they'll just get up and walk away and they won't eat. So we have to follow the routine, the time, where they sit and with whom they sit is important too.sometimes we have to move them to different table because dementia, they don't know what they're doing sometimes and they get confused very easily. Some people they scream, they keep on talking, talking, talking, so the others, they don't like it (Devi, p.1).

Residents self-feeding ability was another factor considered when deciding who to seat with whom at meal times. By seating together those residents who require more assistance, it helped participants to manage the dining room more effectively. For instance a caregiver may sit between two residents who require assistance eating and help them both, whilst another who only requires encouragement may sit across the table where the caregiver can watch and talk to them providing verbal assistance. This

grouping also allows the residents who manage independently to sit together and not be distracted by the busyness of caregivers assisting others.

I think it's better to keep all the feeders at one table so it doesn't affect the others (Ngaire, p.4).

With different tables, it's just like having different levels of dementia and sitting into one table, that way they're not deteriorating quicker. ...one table is the feeders so that table stays the same. The same people stay on it. When we see them feeding themselves, then we move them onto a table where other feeders are feeding themselves. I've had a man that the girls were feeding him all the time. I said no, that's the one I always put the spoon on top [demonstrates resting a spoon over the thumb and forefinger]. ...I started coming to feed and I found out that no, just give him a taste of the food and lay his spoon. I said it mightn't happen the first time, you could try ten times but it will happen. Now he's feeding himself (Ngaire, p.7).

4.3.3 Support

Yeah, I think sometimes she forgot she's supposed to eat it. But if you sit there and push her to eat it, she will eat it and after that she says thank you. She wants to eat but sometimes it's just the mind, you know (Maeva, p2).

Support is the third sub-theme in the main-theme “*It’s about the Environment*”. This sub-theme incorporates factors relating to care (both physical assistance and verbal encouragement) by caregivers at mealtimes.

By far the most commonly mentioned positive influence, or facilitator at mealtimes was support from caregivers. Although an individual’s need for assistance at mealtimes indicates greater dependence, the assistance provided was primarily focused on increasing or at least maintaining independence with eating. Participants encouraged and supported residents to eat and drink, they provided examples and physical guidance when required. It was apparent that participants had developed methods to promote eating and drinking.

Participants supported resident’s dietary intake by verbally prompting them to eat. This verbal encouragement was found to be a key method used by participants to help confused residents. They would remind, prompt, or encourage residents who have essentially forgotten why or how to eat and drink. This can mean prompting at each stage of the eating process from sitting down at the table to using the cutlery, to chewing and swallowing the food. Devi and Lelei explain how they assist residents in this manner. Arihi also talks of the prompting at each step to encourage residents to eat.

They get so confused. ...so what we have to do is remind them for example, [resident’s name], here is your fork and knife – it’s lunch time now, here is your fork and knife. Hold and maybe put one spoonful in their mouth and remind them this is so they can get started and then eat. By just reminding or telling

them or sometimes we just show them. Do it, just put one in their mouth so that they know what's going on. ... "[resident's name], this is your dinner or lunch, hold the spoon, you need to chew your food and then swallow". Give them time, do not rush them... "Put the spoon in your mouth, chew your food" and then when they finish chewing "swallow your food dear, swallow your food" (Devi, p1&2).

I think the dementia people; they need a lot of attention from the caregiver. Everything is depends on the caregivers so if we encourage them, sometimes it's so hard for them to drink but we keep on encouraging them and they drink. Like eating, they eat a little bit while when we keep on showing them the spoon and try to example [show] them how to put the spoon in their mouth and they will eat. So everything from the Dementia, it's depend from the caregiver. If they don't give them the drink, they won't drink. If they don't give them the food, they won't eat, it's going to be sitting there (Lelei, p15).

Yeah, we have to keep reminding. Everything we have to remind them, everything because sometimes you put the plate, they just sit there and look. They don't know what to do with it so we have to remind them, that's your meal. You put the knife and fork beside. They just sit there and look at it. So "okay then, here, that's the fork, that's the knife" and then I just start putting the fork in the food, "oh, okay". Put in the mouth and mmm, that's nice, they automatically start eating (Arihi, p5).

Devi and Beth highlight the most important thing is allowing residents to set their own pace during meals, to not rush them.

...the most important thing is giving them time, not to rush them because some will just sit there. You can't hurry them. You can't just say "come on, open your mouth". You have to give them time, take it step by step (Devi, p2).

We have a few slow people but I prefer to leave them to take their own time 'cos if you start shovelling the food into their mouth, then they get upset. They're best left to their own devices. Just keep an eye on them (Beth, p2).

Lelei agrees with the above comments, and adds to the topic by comparing mealtime care for people with dementia to that for people without dementia.

...we have to remind them about their meal, we have to give them their food, show them the spoon and then you keep on telling them to eat so slow, take their time, don't rush but the normal people [aged care, non-dementia], you just give them their food, they just eat. The dementia, you have to attend them, you have to watch or else they won't eat or they swap it with someone (Lelei, p9).

The following excerpt shows how eating and drinking was not just confined to the dining room or set meal times. Participants also supplied drinks to residents at other times of the day to maximise fluid intake.

...we've got a few that we really have to keep pushing otherwise they wouldn't drink. ...Even when they're walking around the corridors you can take it up to them and tell them to have a couple of mouthfuls (Beth, p8).

Another method used by participants to help residents to eat or drink well is to use the resident's own forgetfulness to work in their favour. Maeva explains this with the example of combating potential dehydration by refilling tea cups often multiple times and leaving it beside the resident. She finds they tend to forget they have just had a cup of tea and will happily drink another one. She also makes the observation that although this is beneficial for hydration status, it may however reduce their appetite for the next meal.

When I see someone's finished, I don't care, sometimes they say no I had enough, I just fill it, just leave it there. I leave it there and sometimes some of them have four cups, three cups. I always just fill it and put it at the front of them. "I already have one". Just leave it there. When they look at it they always drink it. After one, another one. ...But they always say thank you, thank you, thank you. They said "oh, I had enough". I just put it there and walk away. And then turn around, finished. I take it again, fill it again, put it at the front. But it's good for them, it's very good but sometimes maybe they feel full from drinking and when the meal time comes they don't want to eat (Maeva, p10).

As well as verbal assistance, participants often spoke of physically showing and assisting the more dependent residents.

You need to give them a taste and put the spoon across like this [demonstrates resting a spoon across the top of a thumb and forefinger] because you can't get them to grip the spoon straight away, so you just put it across like this and then they'll feel it and then they'll start. If it doesn't happen or it's not going to happen the first time, you'll keep trying until they do (Ngaire, p3).

We just prompt them, help them, feed some people sometimes if that works. Not everybody's open to being fed. There's a whole lot of reasons. I guess their abilities go up and down. Most of them do recognise that they're hungry, so if they're hungry but they don't want to feed themselves, you help (Teresa, p8).

A number of participants at one facility talked about how they use to be allowed to join the residents for meals. This practice was stopped a couple of years ago. Participants did not know why, but thought it was most likely a cost saving measure. Participants thought being able to dine alongside the residents was an important facilitator to residents eating well.

...it's not so much allowed now but we can, if the residents are really agitated that we can have our meal with them and sit at the table and talk to them. ...Yeah. That's one of the main things (Caroline, p2).

As the residents become distracted from a task relatively quickly, bringing them to the dining table too far in advance of the meal being served was found to be a barrier to eating well as the residents lose interest and wander off.

...if the caregivers call them to the table too early, if they put them at the table about quarter to twelve then they've lost them because five minutes at the table and they've gone. The meal doesn't come out until twelve and they just won't stay. They're on the move and they'll just go so then you've got to rush around and hunt them down again and then if the girls start yelling and calling them by name, but rather loudly, then you might as well just leave them and you'll feed them later (Beth, p1).

Caregivers are clearly busy at mealtimes ensuring residents are given adequate support. Mealtimes were seen by some participants as the most challenging time of day. There are many barriers to residents having an adequate oral intake and participants were clearly aware of the role they play in this. Although only one participant directly mentioned the need for patience, it was apparent from the data that a great level of patience was a necessary skill for caregivers to possess.

At meal times, I think that's the hardest time and the busiest time (Lelei, p.1).

This is a special place. You need patience (Iryana, p.6&7).

4.5 Conclusion

The purpose of the present study was to understand factors affecting optimal nutrition and hydration for people living in SDCUs. This chapter has presented the findings following qualitative data analysis from 11 semi-structured interviews with caregivers of people with dementia living in SDCUs. It is apparent from the data, that dietary

intake of people living in SDCUs is influenced by many factors. Also apparent is how inter-related these factors are. Two main factors were found to affect food and fluid intake. The first was environmental factors including those relating to the surroundings of the dining environment, the social aspects to dining, and the support provided by caregivers. The second main factor found to affect dietary intake was individual factors including appetite, whether or not the food appeals, and cognitive and functional abilities.

The following chapter will discuss the research findings in the context of the literature. It includes a discussion of the limitations and strengths of the current study, and makes recommendations for SDCUs and their foodservice providers to optimise nutritional status of the people they cater for.

5.0 Discussion

5.1 Introduction

The purpose of the present study was to understand factors affecting dietary intake for people living in SDCUs, and to provide a range of potential recommendations for foodservice providers in an attempt to ensure optimal nutrition and hydration for this group. The previous chapter presented the findings following analysis of the semi-structured interviews with study participants. This chapter begins with a summary of the study findings. Next is a detailed discussion of the themes identified in the present study in relation to literature on the topic. Recommendations are made for foodservice providers at SDUCs, limitations and strengths of the present study are identified, and recommendations are made for future research on the topic. This chapter ends with a concluding statement.

The present study employed a qualitative descriptive methodology. Data were obtained by semi-structured interviews with eleven caregivers from two SDCUs. Data were analysed using the General Inductive Approach as described by Thomas (2006). Two main-themes and six sub-themes emerged from the data.

5.2 Summary of Findings

It is apparent from the data, that the nutrition and hydration status of people living in SDCUs is influenced by many factors. Also apparent is how inter-related these factors are. The first main-theme identified was *"It's about the Individual"*. This theme incorporated factors relating to the individual which affect their desire for food and

their ability to manage the eating process, as well as their personal likes and dislikes regarding food. The findings were presented under the sub-themes of *Appetite*, *Appeal*, and *Ability*. The second main-theme identified was “*It’s about the environment*”. This theme incorporated factors relating to the dining environment, such as background music, table settings, interactions with other residents, staff and visitors, and support given by caregivers. These findings were presented under the sub-themes of *Surroundings*, *Social*, and *Support*.

As discussed in the literature review, evidence to date suggests a range of inter-related factors may ultimately impact dietary intake, weight loss, malnutrition or dehydration for people with dementia in SDCUs. These factors were identified in the current review as; individual, social, cultural, environmental, and assistance. These influencing factors are guided by the person-centred care philosophy now commonly established in SDCUs. In accordance with the person-centred care philosophy, mealtime interventions should vary depending on the nature of the individual’s abilities or disabilities.

5.3 Discussion of Findings

The first objective that directed the present study was to explore the perceptions of caregivers regarding factors influencing intake of food and fluids for people living in SDCUs.

5.3.1 Individual factors affecting nutritional status

Participants believed food and fluid intake was commonly affected by factors specific to the individual. These factors were driven by a lack of appetite, food presented lacking appeal to the individual, or a decreased cognitive or functional state resulting in the individual having reduced ability to manage mealtime tasks.

Appetite

Appetite is a determinant of dietary intake (Parraga, 1990), and although a reduced appetite is a natural part of ageing (Smith & Greenwood, 2008), studies have shown people with dementia are more likely to have a poor appetite than those without dementia (Wang et al., 2004). Participants identified that residents often had a poor appetite at dinner, but often ate better a couple of hours later at supper. Behavioural difficulties in dementia are associated with reduced energy consumption, especially at dinner (Young & Greenwood, 2001). Some participants believed larger amounts might be consumed at dinner if dinner was provided later in the day. Two key factors were identified as possible causes for this poor appetite. Firstly, it may be due to the individual being full from earlier meals, as meal and snack times were thought to be close together. Secondly, the poor appetite at dinner may be due to sundowning syndrome. According to Young et al. (2001), sundowning syndrome which is often observed in people with dementia in the afternoon or early evening causes people to become disoriented and easily distracted, and is likely to result in reduced food intake at dinner and supper. Possible explanations for sundowning syndrome include fatigue, changes in light, an instinctive search in the evening for familiar surroundings, and hormonal changes (Jacques & Jackson, 2000).

To allow an individual to consume sufficient amounts at each meal to meet their nutrient and energy requirements, meal and snack times should be optimally spaced out during the day to ensure individuals have an appetite for each meal. Additionally, to support optimal nutrition for those people with a low food intake at dinner, sufficient nutritionally adequate foods should be available at supper.

Appeal

Variety, presentation, taste, and smell, were identified in the present study as factors affecting dietary intake. These factors all relate to how appealing food is to the individual. Food must appeal in order for someone to want to eat it.

To increase food appeal by increasing variety of foods and drinks offered, SDCU foodservice providers can ensure they provide a menu cycle of adequate length with sufficient variety not only for main meals, but also for snacks and drinks. Lengyel et al. (2004) suggested increasing variety of foods by including a 'residents choice' meal or by celebrating special occasions with a special meal to increase residents mealtime satisfaction and dietary intake in ARRC. Similarly, special occasions including barbeques, and 'happy hour' were perceived as facilitators to increased dietary intake in the present study.

Stimulating the senses with great looking, tasting, and smelling food can have a positive effect on appetite. Presenting food in an appealing way was considered in the present study an important influence on dietary intake. An interesting observation was made in the present study - presentation of food is important to all groups, but it is

especially important to someone with dementia who may have forgotten what different foods are, what they taste like, and whether or not they like them. Canadian researchers (Keller, Chambers, Niezgoda, & Duizer, 2012) believe if food is visually appealing it is more likely to be perceived positively by staff and the people consuming it. Well-presented food can inspire an individual with dementia to try something that might otherwise have not interested them. To increase appeal, food should be an attractive colour and a plated meal should contain a variety of colours. Food should also be placed carefully on the plate. A special effort should be made with texture modified foods to ensure the best possible presentation. Pureed foods can be difficult to present attractively and particularly difficult to present in a way that makes them visually identifiable or different from one day to the next. Pfeiffer et al. (2005) reported on pureed foods being successfully presented in an ARRC facility, with the use of food moulds.

Taste is of primary importance to influencing dietary intake (Keller et al., 2012). The present study also revealed cooking smells from the occasional barbeque increased residents' appetite. The use of flavour enhancers (such as bouillon cubes and fruit extract), food aromas from aromatherapy, and a mobile food service cart to bring food and aromas into the dining room have been shown to increase food consumption in ARRC (Pfeiffer et al., 2005). Extra flavour may be required for this group of people, who may have smell or taste losses caused by dementia or as a result of normal ageing (Pfeiffer et al., 2005). Participants in the present study reported foods were sometimes lacking taste, particularly salt. People with dementia may have an increased preference for carbohydrate foods, particularly sweet foods (Greenwood et

al., 2005; Mungas et al., 1990; Young & Greenwood, 2001). Participants found if they placed dessert on the table before an individual had finished their main meal, they would often leave the main and eat the dessert. For this reason, desserts were held back until such time as the resident had finished eating their main meal. This preference for sweet or carbohydrate foods may be useful for increasing energy intake for individuals with a poor appetite. However, caution should be exercised to ensure the individual is not at increased risk of inadequate protein intake due to increased carbohydrate consumption (Greenwood et al., 2005).

Ability

Cognitive impairment affects an individual's ability to manage meals independently (Amella et al., 2008), as it affects their ability to remain focused at mealtimes (Chang & Roberts, 2008b) and commonly results in functional feeding difficulties (Manthorpe & Watson, 2003). Lower food intakes are associated with higher levels of functional difficulties in people with dementia in ARRC (Greenwood et al., 2005).

Many people with dementia find managing a knife and fork difficult and are better able to manage self-feeding with just a fork or a spoon. Even so, some food items are more difficult than others to pick-up from the plate and make it to the mouth. Rice and peas when served as single foods can be difficult for people with dementia to manage as they do not stay on the fork easily. Combining these foods within a meal (such as fried rice, savoury mince, or added to a quiche) may be a better option. People with dementia may also have difficulty eating salad for the same reason. In this

situation, coleslaw may be better managed as it sits on the plate neatly and the small particle size and dressing help it to stay on the fork.

People with dementia may be confused by and have difficulty coping with an evening meal on toast, such as baked beans, or mince. Two issues were identified as possible causes for this difficulty. Firstly, confusion as toast is a food associated with breakfast time. Confusion may lead to anxiety and reduced food intake for people with dementia. Secondly, people may have trouble locating and cutting the toast once food is covering it, alternatively when toast is served on the side the two food items are likely to be eaten separately, one after the other or one and not the other. Serving mince in a Shepherd's pie, or baked beans with mashed potato instead of toast for instance may help to reduce this difficulty.

As the ability to use eating utensils diminishes, finger-foods may prolong independence with eating. However, some finger-foods may also be difficult to manage. Sandwiches with too many fillings, particularly lettuce or tomato (and hamburgers for the same reason) may fall apart when picked-up. There appeared to be some discrepancy between reports of the ideal size to serve pieces of main meal food items such as pumpkin and broccoli. Some participants reported having to cut pieces of vegetable (and meat) into smaller pieces for residents to self-feed with their fork. However, other participants reported benefits of vegetables being served in large pieces allowing them to be picked-up by people who prefer finger-food. It appeared the majority of residents were able to manage some degree of self-feeding with utensils, with only a few residents preferring to pick-up main meal items. The solution

may be to provide two sizes of suitable food items, a 'bite' size for utensil use and a finger-food size for those preferring this option.

Food texture is an important consideration in ARRC, particularly when catering for people with dementia. Participants reported throwing away soup that arrives from the kitchen without having been pureed as they were scared residents would choke on it. 'Mixed' or 'dual' consistency foods (i.e. foods that retain a solid within a liquid base such as minestrone soup) may be difficult for people with poor oral control to safely contain and manipulate within the mouth (Atherton, Bellis-Smith, Cichero, & Suter, 2007). Careful consideration should be given to providing any foods which pose a choking risk to individuals with dysphagia.

5.3.2 Environmental factors affecting nutritional status

Participants believed food and fluid intake was also affected by factors relating to the dining room environment. These factors were either causes of potential distraction from mealtime tasks or potential facilitators to optimal food and fluid intake.

Surroundings

Cognitive and functional impairment associated with dementia increase an individual's vulnerability to environmental influences (Briller et al., 2001). A dining environment that is loud and over stimulating may cause distraction and anxiety in a person with dementia. However, a supportive dining environment can reduce challenging behaviours and increase independence in mealtime activities (Briller et al., 2001; Chaudhury et al., 2013). Consideration should be given to minimising distractions in

dining room including noise and décor. Turning the television off at mealtimes, and the use of plain white table cloths with minimal items on the table may assist in creating a less distracting dining environment.

Some participants also considered background music to be an unnecessary mealtime distraction. Conversely, other participants considered music to be beneficial by helping to relax residents. Although these reports seem conflicting, they are somewhat representative of findings in the literature. Noise may be highly distressing to people with dementia (Chaudhury et al., 2013) and a calmer environment may be created by eliminating unnecessary noise including loud music (Ullrich et al., 2011). However, quiet, relaxing or soothing music may reduce agitated behaviour during mealtimes, and may increase time spent eating (Ragneskog et al., 1996), resulting in an increased energy consumption (D. W. Thomas & Smith, 2009; Wong et al., 2008). Background music at mealtimes may also have the added benefit of improving care by positively affecting staff, causing them to pay increased attention to residents (Ragneskog et al., 1996). The interesting finding by Wong et al. (2008) that background music increased energy intake at lunch and dinner, but decreased energy intake at breakfast, may explain the apparent conflicting findings of the present study. For example, a participant who typically worked morning shifts may have a different perspective of music at mealtimes compared with a participant who typically worked afternoon shifts. Nevertheless, as music tastes are individual, and 'relaxing' or 'soothing' music is largely subjective, difficulty may arise in catering for musical preferences of all residents (Johnson & Taylor, 2011).

Social

Even in the early stages of dementia, individuals may become easily distracted from mealtime tasks (Curfman, 2005). However, a positive social dining environment supports a person with dementia to consume adequate food and fluid at mealtimes (Amella, 1999). Interactions with other residents, visiting family members, and staff were identified in the present study as possible mealtime distractions and as possible opportunities to enhance mealtime experiences.

Agitated behaviour from one resident may disrupt other residents in the SDCU dining room; this can cause a chain-reaction of agitated behaviour. Separating an individual who is agitated from the group by accompanying them to another dining space may help the individual to relax, and may benefit other residents by reducing distractions in the shared dining environment. A suitable alternative dining space should be available for residents, as well as adequate staff to accompany them. Comparatively, benefits from the social context of mealtimes in a shared dining room have been reported in the literature. Invaluable observational cues allowing for mimicking of appropriate eating behaviours are acknowledged (Amella et al., 2008). Furthermore, having meals in a shared dining room has been associated with higher food and fluid intake for people with dementia (Reed et al., 2005). A thoughtful seating arrangement at a shared dining table may increase dietary intake of confused individuals as they gain prompts from other residents. However, care must be taken when deciding the seating arrangement to ensure more independent individuals are not distracted by more dependent individuals.

Frequent visits from family can bring joy to a resident, positively influencing their dining experience. Participants perceived increased food and fluid intake when residents had a family member visit at mealtimes. This finding is supported in the literature; fewer family visits were a significant predictor of low food intake in people with dementia (Lin et al., 2010), and a lack of social support was associated with low fluid intake in ARRC residents (Kayser-Jones et al., 1999). Encouraging visits from family and friends at mealtimes may positively affect nutrition and hydration status of people with dementia. The dining room environment should be managed accordingly to ensure a resident's visitors do not distract other residents during mealtimes.

Foodservice style may also influence social interactions at mealtimes and has been shown in the literature to affect dietary intake in people with dementia. Positive benefits have been found from a bulk food delivery style, and 'family-style' dining interventions compared to a more traditional tray delivery system (Carrier et al., 2007; Desai et al., 2007). However, the present study did not reveal any insights into pros or cons of different foodservice styles. This is not surprising as participants may only have experience of the foodservice system currently in place at each setting.

Support

Assisting individuals to eat is a major task in SDCUs and one that becomes increasingly difficult as the illness progresses (Chang & Roberts, 2008b; Durnbaugh et al., 1996). Assistance or support from caregivers in the form of encouragement, prompting or physical assistance was a strong positive influencing factor to optimal nutrition and hydration status in the present study. Other researchers have had similar findings;

staff monitoring of residents, skilful feeding techniques, and providing adequate time in which to feed residents have been associated with higher food and fluid intake (Reed et al., 2005; Suski & Nielsen, 1989). Similarly, a lack of feeding assistance was an independent risk factor associated with low food intake in people with dementia (Lin et al., 2010).

More specifically, participants in the current study perceived the practice of staff eating at the table with residents as an effective approach to supporting mealtime independence and fostering an overall calm dining environment, ultimately positively influencing dietary intake. This perception is supported by Charras and Frémontier's (2010) finding of significant weight gain in people with dementia living in a SDCU when staff and residents ate together at lunch.

In accordance with the person-centred care philosophy, mealtime support from caregivers should recognise an individual's needs and desires, assessing their level of ability or dependence at that time. Appropriate individual care may involve encouragement or prompting of confused residents. This may be required at each mealtime task, from sitting down at the table, to using the cutlery, to chewing and swallowing the food. Alternatively, or in conjunction with encouragement, more dependent people may require physical assistance at any, or all stages of the eating process. Additionally, caregivers should let the person with dementia set their own pace for eating and drinking. Supply of food and drink may be required outside of set mealtimes; provision for this should be made within the organisational structure of the SDCU and foodservice system.

5.3.3 Researchers thoughts

Individuals with dementia are a heterogeneous group; differences are more complex than the diagnosis of mild, moderate, or severe. Sources of heterogeneity at mealtimes include the six factors identified in the findings as affecting nutrition and hydration status. Due to the diverse range of issues affecting people with dementia, care interventions must be tailored for each individual. This is the basic concept behind the person-centred care philosophy.

Participants in this study appeared to genuinely care for the people they were employed to care for. This group of caregivers had many valuable and varied insights into the research topic. However, it was observed that caregivers may be constrained under organisational structure; they may not necessarily have an avenue to feedback what they are seeing and thinking.

A hypothetical case

Whilst developing the model to explain the findings, the inter-related and cyclical nature of the identified factors was most apparent. For instance, an individual's reduced cognitive ability may cause them to become easily distracted from eating, this may reduce their food intake thereby worsening their nutritional status, which may cause them to become unwell, which may reduce their functional abilities and affect their appetite. This hypothetical example could continue endlessly; we could say whilst being unwell and having a poor appetite they may be more likely to behave in a manner which is distracting to other residents, and less inclined to engage in the social aspects of mealtimes, thereby receiving less enjoyment and benefit from mealtimes,

further contributing to their reduced intake and declining nutritional status. This example not only highlights the individuals own path but also how one resident can have an effect on other residents. We could change the outcome of this story by providing patient-centred care at the beginning where the individual first becomes distracted. Appropriate assistance at this time may allow the individual to re-focus on their own meal, to consume an adequate amount, thereby, maintaining their nutritional status.

5.5 Recommendations for SDCUs and foodservice providers

The second objective that directed the present study was to provide a range of potential recommendations for foodservice providers in an attempt to ensure optimal nutrition and hydration for people living in SDCUs.

The following recommendations are made to SDCUs and their foodservice providers:

1. Meal and snack times should be optimally spaced out during the day to ensure individuals have an appetite for each meal.
2. Sufficient nutritionally adequate foods should be available at supper, particularly for individuals with a low intake at dinner.
3. Menu cycles should be of adequate length with sufficient variety for main meals, snacks, and drinks.
4. Increase variety of foods by celebrating special occasions with a special meal, introducing occasional events such as barbeques, or a weekly 'happy hour'.

5. Food should be an attractive colour and a plated meal should contain a variety of colours.
6. Care should be taken to place food attractively on the plate. A special effort should be made with texture modified foods to ensure best possible presentation, and that food is visually identifiable or different from one day to the next.
7. Taste and smell of foods should be optimised. Foods may need extra flavour to account for reduced sense of taste in people with dementia. Opportunities to allow cooking aromas to enter the lounge or dining room should be created and utilised.
8. Intake of high-protein foods should be encouraged in individuals with a preference for carbohydrate foods, whilst still acknowledging the value of carbohydrate foods for meeting energy requirements.
9. Foods that are difficult to pick-up with a fork (i.e. peas, rice, and salad) should be combined in a meal with other foods or presented differently whenever possible, making them easier to manage.
10. Meals served on or with toast (i.e. baked beans or savoury mince) may be difficult for people with dementia to manage independently. Consider serving these items with an alternative carbohydrate food such as mashed potato.
11. Sandwiches should hold together when picked-up (fillings such as lettuce or tomato may cause the sandwich to fall apart easily - hamburgers may be unsuitable for the same reason).
12. Consider providing two sizes of suitable food items, a 'bite' size for utensil use and a larger 'finger-food' size for individuals preferring this option.

13. Careful consideration should be given to providing 'mixed' or 'dual' consistency foods (i.e. foods that retain a solid within a liquid base such as minestrone soup) as these foods may pose a choking risk to individuals with dysphagia.
14. Minimise distractions in the dining room during mealtimes, such as, turning off the television, and setting tables with essential items only.
15. Relaxing background music may be beneficial during lunch and dinner. However, consideration should be given to the wishes and behavioural responses of individuals
16. Shared dining rooms should be available and residents should be encouraged to use them. Observational cues from others allow an individual with dementia to mimic appropriate eating behaviours. However, seating arrangements should be such that more independent individuals are not distracted by more dependent individuals.
17. A suitable alternative dining space should be available for residents requiring time away from the group, as well as adequate staff to accompany them.
18. Visits from family and friends at mealtimes should be encouraged. However, the dining room environment should be managed accordingly to ensure a resident's visitors do not distract other residents during mealtimes.
19. Mealtime support from caregivers should recognise an individual's needs and desires, assessing their level of ability or dependence at that time. Interventions involving appropriate encouragement or physical assistance should be provided.
20. Allow the person with dementia to set their own pace for eating and drinking.

21. Nutritious food and drink should be available to residents outside of set mealtimes.

However, before making any drastic changes to the mealtime environment, caregiving approaches, or foodservice provision, additional studies are required to adequately assess the relationship between these factors and dietary intake or nutritional status.

5.6 Limitations and strengths of the present study

Limitations

This study did not seek the perspectives of people with dementia themselves nor did it set out to assess any quantitative measures of factors affecting nutritional status of people with dementia. A limitation of the setting was that both facilities had the same foodservice provider. The sample size (11 participants), although small, was sufficient to reach data saturation. Participation in the study was limited to people employed as caregivers.

Strengths

This is the first study aiming to investigate factors affecting nutrition and hydration status for people living in SDCUs in New Zealand, and to identify potential recommendations for foodservice providers in an attempt to ensure optimal nutrition and hydration for this group. Given that little was known of the research topic, a qualitative approach was most appropriate to illicit the participants perspectives. A strength of the setting was that the two SDCUs involved were operated by two different ARRC organisations. In order to recruit caregivers who had valuable

experience in caring for people with dementia, an inclusion factor for participation was - at least one year in current or similar role caring for people with dementia. Although the time each participant had been employed in this role was not recorded for purposes of this study, the topic came up during conversation with majority of participants having worked in this field for many years.

5.7 Future research

There is a lack of research involving interventions to address poor nutrition or hydration status in older adults living in SDCUs. Furthermore, inadequate research design often including a small sample size means generalizability and validity of many findings has been limited. Using the present study findings as a starting point further research should be carried out to devise effective interventions to address poor nutrition and hydration status of people living in specialised dementia care in New Zealand. Further research may include qualitative or quantitative studies investigating perceptions of other employees such as nurses, nurse managers or dietitians, or those of family members.

5.8 Concluding statement

The present study explored the perceptions of caregivers regarding factors affecting dietary intake of people living in SDCUs. This perspective, currently unreported in New Zealand, adds to our understanding of undernutrition and dehydration in people residing in specialised dementia care.

Factors affecting nutrition and hydration status of people living in SDCUs include individual factors relating to appetite, food appeal, and cognitive and functional ability, as well as the environmental surroundings of the dining room, including the social environment of mealtimes, and support from caregivers. These factors are complex and inter-related, for instance support from caregivers, in the form of verbal encouragement or physical assistance may be required in response to difficulties evoked by other factors such as environmental distractions, or reduced functional ability. Organisations providing specialised dementia care, their staff, and foodservice providers can take a number of steps to ensure optimal nutrition and hydration for the people they care for.

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7.0 Appendices

Appendix A: Ethics Approval Letter



Appendix B: Participant Information Sheet

Understanding facilitators and barriers to optimal nutrition and hydration for individuals living in dementia care units

INFORMATION SHEET

Individual Interview

We would like to invite you to take part in this study which aims to investigate things that help and prevent ideal food and fluid intake for people living in dementia care units.

Please read this information sheet carefully before deciding whether or not to participate.

Researcher introduction

Debra Nell is a dietetics student in the Institute of Food Nutrition and Human Health at Massey University and is conducting this research as part of her Master of Science in Nutrition and Dietetics. Kathryn Beck is a New Zealand Registered Dietitian and tutor in the Institute of Food Nutrition and Human Health at Massey University. Dr Stephen Neville is a registered nurse and a senior lecturer in the School of Health and Social Services at Massey University.

Why is this research important?

Many factors affect the food and fluid intake of people with dementia. This is of particular concern, as reduced food and fluid intake can lead to poor nutrition and dehydration. As caregivers are often involved with residents at meal times they are likely to have a good understanding of the different factors affecting the intake of people with dementia. This study involves conducting interviews with caregivers to understand their thoughts regarding things that help and prevent ideal food and fluid intake for people living in dementia care units. Findings from the interviews will be used to develop recommendations for foodservice providers to ensure the best food and fluid opportunities are provided to this at risk group.

Who are we looking for?

We are looking for 10-12 caregivers to take part in this study. You should be aged 18 or over, have worked in your current role caring for dementia residents for at least one year, and be involved with residents at meal times.

You will be given a \$30 petrol or supermarket voucher for your time.

What is going to happen?

Taking part in this study involves attending one interview session with the researcher. During this session you will be asked to sign a consent form after having read this information sheet. The researcher will ask for your thoughts about factors related to food and fluid intake of the dementia patients you care for. The interview will be audio-taped and will take approximately 1 hour. The interview will be held at your work place and will be arranged at a time that suits you, your employer and the researcher.

What will happen to the information you provide?

All information collected during this study will be confidential and will be used only for the purposes of this project. To protect your privacy your real name will not be used anywhere. Instead we will use an anonymous ID code to label any information relating to you. Access to any information that links your personal details to the ID code will be stored in a locked filing cabinet at Massey University and restricted to members of the research team.

Findings from the interviews will be written up as part of the main researcher's Master of Science Nutrition and Dietetics thesis project. A set of recommendations based on the findings will be produced for use in dementia care facilities. Results of this project may be published or presented at conferences or seminars. No individual will be able to be identified.

At the end of this study the list of participants and their study identification code will be disposed of. Any raw data on which the results of the project depend will be retained in secure storage for 5 years, after which it will be destroyed.

A summary of the project findings will be available to all study participants. All participants will be sent this information via email or a personal letter.

What are the benefits and risks of taking part in this study?

- You will receive a brief report summarising the main findings of the project via mail or email.
- You will be given a \$30 petrol or supermarket voucher for your time in taking part in this research.
- The principal benefit of taking part in this study is that you will contribute to a study and our understanding of barriers to optimal nutrition and hydration for individuals living in dementia care units.
- It is not envisaged that there will be any discomforts or risks to the participants as a result of participation.
- If you have any specific requirements including cultural requirements or concerns about the project, or about being a participant, please contact a member of the research team to discuss.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study at any time, up until 30th May 2013;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- ask for the recorder to be turned off at any time during the interview;
- be given access to a summary of the project findings when it is concluded

Project Contacts

If you have any further questions or concerns about the project, either now or in the future, please contact:

Researcher	Supervisor	Supervisor
Debra Nell, BSc, Nutrition and Dietetics student	Kathryn Beck, MSc, NZRD	Dr Stephen Neville, RN, PhD, FCNA (NZ)
Institute of Food Nutrition and Human Health, Massey University	Institute of Food Nutrition and Human Health, Massey University	School of Health and Social Services, Massey University
Email debra_nell@yahoo.co.uk	Email k.l.beck@massey.ac.nz	Email S.J.Neville@massey.ac.nz
Phone (021) 1818730	Phone (09) 443 9649	Phone (09) 4439386

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 12/099. If you have any concerns about the conduct of this research, please contact Dr Ralph Bathurst, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43404, email humanethicsnorth@massey.ac.nz.

Appendix C: Participant Consent Form

Understanding barriers to optimal nutrition and hydration for individuals living in dementia care units

PARTICIPANT CONSENT FORM Individual interview

This consent form will be held for a period of five (5) years

I have read the information sheet and have had the details of the study explained to me. I have had time to consider whether to take part. I have been given appropriate contact details to obtain further information and to discuss the study. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports of this study. I understand that a requirement of participation in this study is that my interview with the researcher will be audio-taped. I understand that taking part in this study is voluntary and that I may withdraw from the study up until one day after the interview.

Please circle the applicable choice for the statement below:

I wish/do not wish to have sent to me a summary of the study findings.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: Date:

Full name:
(Printed)

Appendix D: Interview Schedule of Questions

Understanding facilitators and barriers to optimal nutrition and hydration for individuals living in dementia care units

Interview Schedule

The following questions (1-9) will be used by the researcher as a guide during the semi-structured interviews with caregivers. Points below each question are not intended to be used as questions necessarily rather they may be used as prompts for further discussion if required.

- 1) Can you please tell me about what happens here at meal times?

Barriers

- 2) What things stop residents from eating well?
 - Distractions during meal times, timing of meals, presentation / texture / temperature of foods, residents not recognising certain foods or not knowing what to do with the food, residents forgetting how to use cutlery correctly.
- 3) Which foods or meals do you feel residents regularly do not eat well? Why do you think this might be?
- 4) What things stop residents from being well hydrated?
 - Availability of drinks, availability of drinks they like, simply forgetting to drink / not recognising feeling of thirst.

Facilitators

- 5) What things help residents to eat well?
 - Calming / homely atmosphere, adequate assistance, good presentation of meals / texture / temperature of foods, suitable snacks available between meals.
 - Please expand on each factor you mentioned.
- 6) Which foods or meals do you feel residents regularly eat well?
 - Why do you think this might be?

- 7) What things help residents to drink enough?
 - Availability of drinks, availability of drinks they like, frequent reminders from staff.
 - What types of drinks do residents generally prefer?
- 8) If you could redesign the meal service here, what would you do differently to encourage residents to eat well?

Conclusion

- 9) Is there anything we haven't talked about that you think could help to improve your patient's food and drink intake?

Appendix E: Transcriber Confidentiality Agreement

Understanding barriers to optimal nutrition and hydration for individuals living in dementia care units

TRANSCRIBER'S CONFIDENTIALITY AGREEMENT

I (Full name – printed) agree to transcribe the tapes provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any records of them, other than those required for the project.

Signature: Date: