

# **Maintaining my relative's personhood: A mixed method design**

**By**

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for the Degree of Doctor of Philosophy***

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## **Abstract**

**Background:** Tom Kitwood's theory of dementia care centres on the concept that personhood is maintained and promoted through person centred care, and when personhood is maintained the person is more likely to experience well-being. Nursing has adopted Kitwood's theory across most specialities, particularly dementia care, and it is now a major part of the education curriculum, policies and guidelines. Family caregivers are increasingly seen on acute hospital wards providing direct care mostly helping their relative in regard to eating and drinking. The assumption is that a family caregiver would instinctively practice person centred care, yet in reality relatives do not always implement the model as defined by Kitwood. This study was developed to explore the transferability of person-centred care in a family context.

**Aim:** The aim of this study was to measure and explore the applicability and acceptability of Kitwood's theory of person-centred care to family caregivers when their relatives with moderate/advanced dementia refuse to eat.

**Methods:** The study focused on mealtimes. A mixed method convergent parallel methodology was utilised using a combination of the Beliefs about Caregiving questionnaire, Dementia Care Mapping, cognitive function, calorie intake, semi-structured interviews and participatory observations. Thirty-one dyads enrolled in phase 1 (quantitative phase) 18 of those completing phase 2 (qualitative phase). The quantitative data were analysed using appropriate statistical analysis, while the qualitative data were analysed using analytic induction methodology. Both sets of data were integrated to facilitate a deeper understanding of how transferable Kitwood's theory of person centre care is to family caregivers.

**Findings:** Patient-centered care, as depicted by Kitwood, is replicated in the care given by the majority, but not all, family caregivers in this study. The results from this study demonstrate that person-centered care delivered by family caregivers was associated with higher levels of patient well-being and calorie intake. However, the family caregiver's attachment style affects their person-centered decision making. These findings identify the need for further research replicating the quantitative methodology with a larger sample size to see if these findings can be re-produced with a greater level of confidence.

**Contribution to knowledge:** For those family caregivers who do not adopt a person-centred approach to the care of the family member with dementia, good dementia care may necessitate health care professionals choosing between conflicting responsibilities, values and the bioethical principles of autonomy, justice, and non-maleficence. Conceptualising care through a model of

person centeredness may not provide healthcare professionals with a relevant framework when family caregivers play such a pivotal role. Should further research findings support the proposition that a patient's tendency towards well-being and eating more is dependent on the delivery of person-centred care, family and professional caregivers would need to know, if they are concerned about calorie intake, they should focus on the person's well-being through the delivery of person-centred care.

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YNWA.

# Chapter 1 Introduction

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This thesis focuses on the applicability and acceptability of Tom Kitwood's theory of person-centred care to family caregivers when their relative with moderate/severe dementia stops eating. An introduction to Kitwood's theory of person-centred care and its application to practice is presented in this chapter. The Mental Capacity Act (2005) is reviewed in the context of people with dementia not eating and the impact this has had on professional decision making. The chapter concludes with an introduction to each of the following chapters.

## 1.0 Background

### 1.1.1 Personhood

Partly as a result of Kitwood's work, the focus of care for people with dementia has changed from task-driven to maintaining personhood; from a medical model to a psychosocial model (Epp, 2003; McCormak, 2004; Broker, 2007). The concept that personhood is maintained in dementia through interactions between the carer and the person with dementia was first developed by Tom Kitwood and made widely available in his book, "Dementia Reconstructed, the person comes first" in 1997. Here Kitwood (1997a) describes how person-centred care, a theoretical framework for the delivery of care, places the person at the centre of that care.

Through observational case studies, Kitwood (1997b) was able to demonstrate a style of relationship between carer and cared for, which diminishes personhood as seen when the person with dementia is, for example, marginalised, intimidated, or outpaced. Kitwood referred to this style as a "malignant social psychology", (1997a Pg. 45). He goes on to assert that this style of relationship leads to a diminishing of the person's abilities resulting in ill-being. In contrast, Kitwood (1997a Pg. 45) states nurturing relationships maintain personhood through behaviours of inclusion and enabling, enhancing well-being and the person's abilities.

There are five domains in Kitwood's theory of person-centred care; comfort, attachment, inclusion, occupation and identity (Kitwood, 1997a Pg. 81). These are considered to be needs but, unlike other needs theories are not seen as hierarchical but as a cluster; each overlapping one another providing an all-encompassing need for love. According to Kitwood (1997a Pg. 81), one theme cross-cutting all five domains necessary in maintaining personhood is, respecting the communication implicit in the observed behaviours of the individual with dementia, even if those communications appear contradictory to accepted standards of care such as maintaining adequate

nutritional intake. Focusing on the interaction between the professional carer and the person with dementia Kitwood recognised that the personhood of the individual with dementia rises out of these interactions and this is reflected in his definition of personhood, “It (personhood) is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being” (Kitwood, 1997a Pg. 9).

However, applying this theory of person-centeredness, which promotes personhood can in some circumstances result in an inadequate nutritional intake for instance, should the person’s behaviour indicate a rejection of food and this behaviour is accepted by the carer and is ongoing there is a real risk of malnutrition. Yet a contrasting approach involving a more direct approach to achieve an adequate nutritional intake, including in extreme situations holding down the persons hands or forcing the spoon into their mouth may result in diminishing personhood as a result of a loss of agency and dignity; an example of Kitwood’s “malignant social psychology” (Kitwood, 1997a Pg. 45).

Despite being well received by nursing as a model of care, particularly in the field of dementia and its inclusion in many current policy documents (NICE Guidelines, 2018; Care Act, 2014; National Dementia Strategy, 2009) Kitwood’s theories, as reviewed in chapter 2, have a weak evidence base. Kitwood’s ideas were derived from observations in care home settings and were reported in the literature as case studies (Kitwood, 1990b, 1997a Pg. 58) with limited methodology detail creating some caution in terms of trustworthiness. Furthermore, in developing his theories of person-centeredness Kitwood focused primarily on the interactions between professional or paid carers and on the person’s maintenance of personhood as opposed to family caregivers.

Modern dementia education supports Kitwood’s overall aim of dementia care as the maintenance of personhood through person-centred care, (Health Education England, 2015). Indeed, in clinical areas where training levels are high, it seems from the researcher’s experiences and the literature (Pavlish et al. 2014) there are times when moral disagreements between nurses and family caregivers regarding the priority of care and treatment of the person occur. Moral disagreements occur when patients, family caregivers or health care professionals feel, “their goal related to care, and outcomes are being thwarted by the incompatible goals of others” (Edelstein et al. 2009), for example, the maintenance of personhood over an adequate nutritional intake. The disagreements may result from an increase in public expectations, greater religious and cultural diversity in our society, a greater emphasis on patient rights or to limited resources (Morris & Dracup, 2008;

Schlairet, 2009) leading to a rise in tension resulting in emotional outbursts, arguments, or defensive behaviour; all resulting in a decline in communication.

Nurses bring to clinical practice their own moral identities of what they believe it is to be a ‘good nurse’. This will be based on their personal beliefs, values, cultural, religious upbringing, education level and the culture of their clinical environment. However, in the UK there is also a legal and ethical framework upon which nurses base their identity; the Professional Code of Conduct (NMC, 2008), the Human Rights Act (1998), the Mental Health Act (1983) and the Mental Capacity Act (2005), see section 1.1.4.

Since Kitwood’s publications in the ‘90s few studies have explored the meaning of personhood from the perspective of the family caregiver, how this affects their delivery of care and the effect this has on their relatives’ personhood. In one of the few studies involving family caregivers, Smebye & Kirkevold (2013) demonstrated relationships based on close emotional bonds sustained the personhood of the person with dementia, while those family caregivers who were reluctant participants in the role presented a threat to their personhood. However, the results of this qualitative study were based exclusively on the themes derived from semi-structured interviews with family caregivers and as a result have some limitations with regards to how their feelings were echoed in terms of how they delivered care. Secondly, the perspective of the person with dementia was not sought, either through interview or observation, ignoring the affect the caregiver has on their personhood. This would seem an important point given Kitwood’s definition of personhood states it is “bestowed” by another upon the person. Shim et al. (2013) interviewed eleven caregivers to explore the meaning of caregiving and concluded the caregivers in their study held altruistic values and believed they had a choice with regards to the attitude they took and a choice to take satisfaction from their role. However, how this meaning of care was translated into care delivery and the effect this had on the personhood of the person with dementia is not explored. Burgener and Twigg’s (2002) quantitative study demonstrated how closer relationships between the caregiver and their relative resulted in improved well-being and problem-solving abilities on the part of the person with dementia, perhaps providing some support for Kentwood’s theory that when well-being is maintained the person’s function is preserved (Kitwood, 1992; 1997a Pg. 61). Well-being was measured by Burgener and Twigg (2002) using a unique combination of The Cornell Scale for Depression in Dementia (Alexopoulos et al. 1999) and the Psychological Well-Being in Cognitively Impaired Persons score (Burgener et al. 2005) which were completed at baseline, 12 month and 18-month intervals during the study by the care recipient

supported by the researcher. There are limitations with this methodology as it may have been difficult for the person with dementia to complete the questionnaires in terms of firstly, recalling their feelings and secondly conveying abstract thoughts about relationships, bringing into question the reliability of these results. There remains a gap in the knowledge regarding how applicable and acceptable Kitwood's theories of person-centred care to family caregivers and the impact this has on the behaviour of their relatives.

### **1.1.2 Dementia and difficulties with eating**

Dementia is a progressive neurodegenerative disease defined as a group of syndromes characterised by a progressive decline in cognition which, with increasing severity, leads to the eventual inability to perform most activities of living, ultimately leading to death. Baring a medical intervention that can prevent or cure Alzheimer's type dementia and the other types of dementia the number of people living and dying with the disease is set to increase (Alzheimer's Society, 2014). It is therefore vital that while we wait for science to find the answers to prevent and cure this, work needs to continue to understand the effects of dementia in order to develop effective ways of sustaining those who have the diagnosis and their carers'.

Dementia affects people in different ways depending on the type of dementia, how long the person has been living with the disease, the areas of the brain most affected and the person's life history and personality. However, changes in peoples' pattern of eating is very common (Lin et al. 2010; Dunne, 2010; Liu et al. 2015).

As the condition progresses the reduced intake of food and fluid appears to be complex and multi-factorial (Aselage et al. 2011). Piguet et al. (2011) describe the pathological changes to specific areas of the brain that result in people with dementia experiencing a number of difficulties leading to reduced consumption of food, this is discussed in detail in section 3.3.

Some people with dementia may forget the voluntary steps of eating and drinking referred to as apraxia or may not be able to recognise the objects involved in eating for example cutlery, plates or even the food itself, this is known as agnosia, (Amella, 2002, 2004; Aselage et al. 2011). There may be a physical reason for the decline, for example, unrecognised or poorly treated pain or depression (Dunne, 2010).

The environment may be causing a disturbance or distraction (Amella, 2008; Whear et al, 2014). Being unable to organise their behaviour to obtain food or lacking the motivation to eat are other common issues which are non-volitional and part of the dying process (Amella, 2008). However,

the response may be intentional. As the person is unable to verbalise their feelings due to the progression of the disease; loss of language, reasoning skills or insight, it can be difficult to differentiate causal factors of poor eating behaviour and therefore it is difficult to find a solution (Aselage, 2011).

### **1.1.3 Mental Capacity Act 2005**

It is everyone's human right to have access to food and drink that is both nutritionally adequate and culturally acceptable. When a person with advanced dementia stops eating there are three things to consider, autonomy, proxy decision-making and best interest decisions.

Under the law, autonomy stresses that each person knows what is best for them and it is recognised that people have a right to choose what health care they do not want even when that decision impacts on their length of life. When a person with dementia stops eating it brings into question whether they can choose this course of action; if they lose capacity do they also lose their autonomy and should someone else, therefore, make this decision?

The choice to eat is not usually a medical decision but one that falls within activities of living, should the person lack capacity then the decision is made by a proxy decision maker's; family, friend or an appointed Independent Mental Capacity Advocate (IMCA) under the guidance of the Mental Capacity Act (2005).

The Mental Capacity Act (MCA) (2005) has changed how decisions are made for some people with dementia. The terms of the Act affect everyone involved in caring for someone with dementia either as a formal or informal carer if at any point the person loses the capacity to make particular decisions or to take a particular action for themselves.

The Act sets out a single clear test for assessing whether a person lacks the capacity to make a particular decision at a particular time. It is important to remember that no one is "incapable" simply as a result of a particular medical condition or diagnosis, their age, appearance or any condition or aspect of a person's behaviour.

The Act is supported by a Code of Practice which provides guidance to anyone who is working with and/or caring for people over the age of 16 who lack the capacity to make specific decisions. The Act is underpinned by five key principles:

- *A presumption of capacity.* Every adult has the right to make his or her own decisions and must be assumed to have the capacity to do so unless it is proved otherwise.

- *Individuals being supported to make their own decisions.* A person must be given all practicable help before anyone treats them as not being able to make their own decisions.
- *Unwise decisions.* Just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.
- *Best Interest.* An act is done, or decision made under the Act for or on behalf of a person who lacks capacity must be done in their best interests.
- *Least restrictive option.* Anything done for, or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedom.

A best interest decision; made when the person is deemed to lack capacity to make a particular decision at the time the decision needs to be made is made using the following checklist:

1. Avoid making assumptions about someone's best interests merely on the basis of the person's age, appearance, condition or behaviour.
2. Consider all relevant circumstances: these are circumstances of which the decision maker is aware and those which it is reasonable to regard as relevant.
3. Regaining capacity: can the decision be put off until the person regains capacity?
4. Permit and encourage participation: this may involve finding the appropriate means of communication and/or using other people to help the person participate in the decision-making process.
5. Special considerations for life-sustaining treatment: the person making the best interests decision must not be motivated by the desire to bring about a person's death.
6. Consider the person's wishes, feelings, beliefs and values – especially any written statements they made when they had capacity.
7. Demonstrate that you have carefully assessed any conflicting evidence or views.
8. Provide clear, objective reasons as to why you believe your action to be in the person's best interests.
9. Take into account the views of other people, including:
  - family and informal carers
  - anyone with an interest in the person's welfare
  - anyone who has been appointed to act on the person's behalf.
10. Take into account the views of any IMCA or any attorney appointed by the person or deputy appointed by the Court of Protection.
11. Consider whether there is a less restrictive alternative or intervention.

A new court, the Court of Protection, a new Office of the Public Guardian and a new Independent Mental Capacity Advocate service were established as part of the Act. The Independent Mental Capacity Advocate service employs Independent Mental Capacity Advocates (IMCAs). An IMCA is someone appointed to support a person who lacks capacity as they have no-one to speak on their behalf, for example, a family member or friend. The IMCA makes representations about the

person's wishes, feelings, beliefs and values, at the same time as bringing to the attention of the decision-maker all factors that are relevant to the decision.

People may have different views on the concept of choice and best interest decisions depending on their interpretation of the MCA. For some, if a person chooses to drink more alcohol than the recommended daily amount that is their individual choice and a person's right, providing they do not as a result of too much alcohol break the law, for example, causing a public disturbance.

Others however, may argue that guidance on choice is needed where the choice can have a negative impact on their health.

To restrict a person with dementia the choice and freedom to drink more alcohol than recommended in ways that other members of society are not restricted could seem unfair. Yet to "allow" someone to become intoxicated and at risk of harm or injury, or ill-health and in some cases put their lives at risk when they are unable to consider the consequences of their actions might seem even more unfair.

The same can apply when people with dementia stop eating. The professional's interpretation and application of dementia care as promoted by Kitwood, may lead some to use Kitwood's care principles as a way of interpreting behaviour and conclude that the person is making a decision communicated through the behaviour displayed. In this interpretation of Kitwood's principles maintaining personhood and well-being is in the patient's best interest and overrules other best interest decisions such as adequate nutrition, which may be in contrast to the views of the family caregiver.

Consequently, when a patient without capacity refuses to eat or eat very little despite all of the reasonable best efforts of the nurse, ensuring other external factors are not negatively impacting on their choice for example, the psychosocial environment or health problems, the nurse withdraws, respecting the patient's implied wishes and their personhood. At the same time accepting, with reluctance the person is not having a sufficient nutritional intake.

Family caregivers may however dispute this prioritisation, arguing it is in the person's best interests to do everything possible to ensure their nutritional intake is enough, including the use of threats or oral force-feeding. This then brings into question the possible burden imposed on the person who is not eating through the actions of others and the impact this may have on their well-being which according to Kitwood (1997) would lead to the diminishing of personhood. This can

result in a tension between family caregivers and nurses regarding the priority of care and treatment of patients, particularly for the more vulnerable patients such as those with advanced dementia.

In nursing practice there seems to be a repugnance associated with any forms of threats or force-feeding, indeed such action from any carer could lead to a safeguarding alert being raised with social services, an investigation into the circumstance and possible legal action taken. In this example, the Mental Capacity Act (2005) may have given rise to a theoretical and philosophical prioritisation of personhood over life-sustaining nutrition. There is a paucity of empirically rigorous studies that have determined whether the application of Kitwood's theories improve nutritional intake (chapter 3 provides a review of nutrition interventions studies). Despite this, the literature, education, organisational policies and law underline the importance of maintaining personhood and person-centred care practices.

As the nursing profession strives to develop its own scientific body of evidence on which to base practice, family care continues to be based on historical family relationships. If nurses and families are to work together for the good of the patient we need a clear understanding of the meaning of care for family caregivers, how they maintain personhood and how the nurse can maintain their relationship with them and with the patient.

## **1.2 Purpose**

The purpose of this study was to measure and explore how applicable and acceptable Kitwood's theory of person-centred care is to family caregivers, specifically at mealtimes when the patient is not eating. Quantitative data (demographics and surveys) and qualitative data (participatory observations and interviews) were used to explore the family caregiver's meaning of person-centred care, the impact this has on their mealtime behaviour and the patient's well-being in the acute hospital setting.

In this thesis, personhood has been used interchangeably with well-being to describe a sense of the person feeling respected and valued as a unique human being and used ill-being to describe the absence of personhood. Person-centred care will be used to refer to a framework on which to base nursing care that maintains personhood.

## **1.3 Introduction to the thesis**

This next section provides a brief summary of each chapter; it serves as an introduction to the contents and purpose of each chapter individually and for the thesis as a whole.

## **Chapter 2: A review of Tom Kitwood's theory of dementia**

This chapter provides a critical review of Tom Kitwood's theory of dementia and dementia care and highlights the impact his theories have on dementia care and consideration of areas for further research.

## **Chapter 3: Review of existing literature – Interventions to support nutrition in people with dementia.**

In this chapter, a systematic literature review of the current evidence of how best to support the nutrition needs of people living with dementia is presented.

## **Chapter 4: Methods Research Methodology and Design**

The pragmatic worldview adopted in this thesis is discussed along with the theoretical framework and methodological foundations. A mixed methodology and analytic induction are introduced and justified.

## **Chapter 5: Data collection**

This chapter describes the data collection tools and methods and participant selection. The phase 1 hypothesis are presented detailing how the data were analysed. A detailed description and justification for the qualitative data collection tools are also provided. The chapter concluded with a discussion around the study strengths and weaknesses. The demographic data are also shown here.

## **Chapter 6: Results**

Here the findings from phase 1 and 2 are presented separately followed by the integrated findings. Case examples are used to provide detail and clarity to the findings.

## **Chapter 7: Discussion**

In chapter 7 the difficulties inherent in Kitwood's theory of person-centred care are discussed in relation to the current health and social milieu.

## **Chapter 8: Conclusion**

The final chapter details the study's contribution to the discussions of transferability of Kitwood's theory of dementia and dementia care. The implications of the study's results for practice are discussed in relation to the current health care climate, with further research recommended in this area.

# Chapter 2 Literature Review

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## 2.0 Introduction

This chapter critically reviews Tom Kitwood's work on dementia and dementia care with a focus on his reconsideration of dementia, well and ill-being and the meaning of personhood. It is important to note that Kitwood wrote extensively about dementia in the 10 years he devoted to the subject and the topics covered do overlap. Therefore, to aid the reader an outline of each subject is presented separately, in the context of eating problems providing insight into how Kitwood's thinking developed over time, this is followed by a critical review of each subject separately; noting that some of the criticisms of each subject overlap too.

Tom Kitwood was arguably one of the most influential writers on dementia and dementia care in the past 30 years (Adams, 1996; Dewing, 2008; Baldwin & Capstick, 2007, Pg.67; Hughes, 2014). His ideas and theories have shaped policy development, education and service delivery internationally. As Kitwood's theories suggest, our beliefs, values, experiences and reflections make us who we are and influence how we view the world; for this reason, a short biography of his life and work are presented in Appendix 1.

## 2.1 Approach used to select literature

In recent years we have witnessed an increase in both political and social interest in the lives of people living with dementia. This has stemmed from the increasing numbers of people living with the disease, the cost to the national purse in meeting their care needs and a number of high profile cases of inadequate care provided to those in hospitals, examples of which include; The Patient Association (2009), Mid Staffordshire NHS Foundation Trust Inquire (2010), Parliamentary and Health Service Ombudsman (2011), care homes (CQC 2013a) and their own homes (CQC 2013) by those paid to provide care. One consequence of this interest has been the drive to increase dementia training for all health care staff with a particular focus on nursing (Health Education England, 2015). The emphasis of this training is based on Tom Kitwood's theory of dementia and dementia care; a psychosocial model, grounded on the maintenance of personhood through person-centred care. As a result, the aim of care for people with dementia has changed from one of promoting orientation to reality to one of maintaining their well-being. However, as outlined in the previous chapter nurses who have adopted this philosophy of care are experiencing tension with family caregivers when their beliefs about the priorities of care are conflicting.

The aim of this literature review was to critically examine Kitwood's theories, explore how they were developed over time, to critically evaluate the basis of his theories and identify areas which need further investigation. Subsequent work by others who have tried to provide further evidence for Kitwood's theories will not be reviewed here but are used in part to support arguments throughout the chapter.

Kitwood wrote extensively on dementia in numerous books and journals most of which are difficult to access. For this reason, Kitwood's original articles which appear in full text in Baldwin & Capsick (2007) were analysed along with his most popular book, "Dementia reconsidered: the person comes first" (1997a).

To select the relevant literature for a critique of Kitwood's theory of dementia and dementia care health-related databases, CINAHL, Medline, PsycInfo, BNI, and HMIC, were searched using the search terms, personhood AND critique, personhood AND review, dementia AND Alzheimer's. All searches covered the time period January 1985 to 2015 from the start of Kitwood's published work on dementia to the present day. A total of 45 papers and 3 books were identified and the abstracts read. Of the 48 abstracts read a total of 4 papers and 1 book were selected as these provide a critical review of at least one of Kitwood's sub-theories; the dialectics of dementia, well and ill-being or personhood and had been subjected to peer review. Articles were included or excluded based on the following criteria.

#### Inclusion criteria

A critical review of one of Kitwood's sub-theories

Peer review journal

#### Exclusion criteria

Implementation of interventions only

Discussions of personhood without a critique of Kitwood's theories

A further paper was included which was recommended by an expert nurse in the field of older peoples nursing that was not found in the literature search. This identified possible limitations in searching electronic databases using keywords. Some general nursing texts are also used to demonstrate key points throughout the review.

## **2.2 Kitwood's alternative theory of dementia**

Kitwood's first publications (1989, 1990) on dementia began by challenging what he saw as the dominance of the research and practice of dementia care by the biomedical model. Kitwood

argued that dementia should be viewed as a dialectic between personal, social and neurology factors moving discussions towards a psychosocial model of dementia. Before developing his own theory of dementia, he critiqued the ‘standard paradigm’ as he referred to it with three overlapping arguments; the limitations of neurological research, the medicalisation of Alzheimer’s disease and the problems of diagnostic imprecision.

### **2.2.1 Neurological research**

Kitwood (1989) argued that neurological research failed to fully explain why some people develop the signs and symptoms of dementia with little neurological pathology on their brain scans, while others had no signs or symptoms of dementia yet have high degrees of neurological damage on their brain scan. Kitwood (1998) also highlighted how psychological factors were being excluded from explanations for the development and progression of dementia stating that it was irrational to simply ignore these factors without proper empirical evidence, particularly given neurological research had not been able to fully explain the changes from, ‘normal to demented functioning’. Furthermore, Kitwood raised the question of how pseudodementia and ramentia can be explained without considering psychological factors. He goes on to claim that the neurological theory was being adapted ad hoc to accommodate evidence that does not fit neatly into it. For example, the neurological explanation of the catastrophic decline in Alzheimer’s dementia, referring to a dramatic decline after a life-changing event, states that the dementia must have already been much worse than expected. Kitwood states, “....it is implausible to suggest that massive Alzheimer-type degeneration of grey matter can occur over the space of 3-6 months” (Kitwood, 1989).

For Kitwood the dominance of the ‘standard paradigm’ of dementia excluded other approaches, inhibiting the development of new knowledge and new ways of delivering dementia care. Secondly, he felt the standard paradigm excluded the person with dementia, only the dementia was seen (Kitwood, 1993). Thirdly, it led to a ‘pervasive’ and pessimistic view of dementia resulting in statements such as “the living dead” (Kitwood, 1996).

### **2.2.2 Medicalization of Alzheimer’s disease**

Kitwood’s second area of criticism of the ‘standard paradigm’ was the medicalisation of Alzheimer’s disease which was sometimes referred to as Alzheimerization. In *Dementia Reconsidered* (1997a Pg. 44) he writes how Alzheimer’s had become a household word as a result of lobbying on the part of the Alzheimer’s movement, which was a partnership of scientists, government representatives and members of the public and media, rather than through the accumulation of new data about dementia. The Alzheimer’s movement had been successful in

replacing the term senile dementia with Alzheimer's dementia as a result of research findings which identified the changes in the brains of the middle-aged woman seen by Alois Alzheimer in his original work were the same as those seen in older people with the same or similar symptoms. As a result, dementia was no longer considered a normal part of the ageing process but caused by a progressive neurological syndrome that should be diagnosed, treated and managed according to medical authority (Baldwin & Capstick, 2007 Pg. 55). It was this medical authority that Kitwood took issue with (1998, 1990a).

The concept of dementia in a predominately biomedical paradigm Kitwood believed, legitimised the bases for hopelessness with a link between 'no cure and no hope'. As a result, society was given permission by the medical authorities not to see 'the person' but simply the dementia. This according to Kitwood resulted in the care being delivered by professional caregivers to people with dementia in an intimidating, infantilising, and disempowering manor (Kitwood, 1990a). Kitwood referred to this dehumanising care as a 'malignant social psychology; malignant as it spread from one caregiver to another'.

Kitwood did not apportion blame for the poor standards of care to the individual staff, but to society as a whole and the care systems within which staff were forced to work and people with dementia forced to live in. Unskilled staff working in an environment that is constantly pressured by a highly demanding workload and a lack of resources resulted in staff becoming demoralised; unable to give the care to the standard they wanted. As a result, staff either left the role or, 'retreated into emotional non-involvement as they do not have the resources to deal with people who have dementia', (Kitwood, 1993a), this he says resulted in a 'moral vacuum'. By placing dementia in a psychological context Kitwood places value on the person with dementia. This framework of dementia allows caregivers to see the person as they were before the diagnosis of dementia and helps to link their behaviours to their present situation, and the person remains.

### **2.2.3 Diagnostic imprecision**

Kitwood's issues with diagnostic imprecision stemmed from the limitations of brain imaging at the time, the overriding concern with memory loss with the use of rather blunt psychological tests such as the Mini-Mental State Exam (MMSE) (Folstein et al. 1975) or the Abbreviated Mental Test (AMT) (Jitapunkel et al. 1991), and the lack of attention to confounding factors such as depression. Since 1989 and Kitwood's first publications on the matter there have been great advances in neurological imaging technology. MRI imaging is now commonplace in the diagnosis of dementia and can demonstrate cell loss in 80-90% of people with signs of Alzheimer's disease, and

differentiate between subtypes of dementia in 90% of people presenting with even early signs of the disease (O'Brein, 2015).

#### **2.2.4 Dementia Reconsidered**

Having outlined why he thought the medical model of dementia was inadequate he published in *The dialectics of dementia* (Kitwood, 1990a Pg. 49) his theory of dementia in terms of the interrelationship between psychology and neurology proposing three basic equations; as detailed clearly by Baldwin & Capstick (2007, Pg.11)

- 1) Senile dementia is compounded from the effects of neurological impairment (NI) and of malignant social psychology (SP),
- 2) Neurological impairment in an elderly person attracts to itself a malignant social psychology,
- 3) Malignant social psychology, bearing down on an aged person, whose physiological buffers are already fragile, actually creates neurological impairment.

This theory was further developed in 1993 when Kitwood wrote that not only did the interrelationship of the neurology and psychology affect the development and progression of dementia but also the person's personality (P), biography (Bi) and other health and sensory problems (H), thus:

$$\text{Dementia} = P + Bi + H + SP \text{ (Kitwood, 1993)}$$

This equation has become the basis for person-centred care.

Kitwood's view on personality is interesting to note. He believed that personality is a resource for action rather than a trait which develops as a result of life opportunities and experiences. These actions can be positive, for example, resilience or negative, for example, avoidance. By understanding the person's personality, we will understand how they are reacting to the experiences brought about by their dementia. On biography, Kitwood stated that we cannot understand how dementia impacts upon an individual if we do not know about their biography, in relation to their experience of loss. Physical health is included by Kitwood as factors such as pain, poor hearing or eyesight which impact on how people communicate with the world and those around them. Kitwood emphasised the importance of the uniqueness of these factors of everyone believing they should determine the individual care required to maintain their personhood through person-centred care.

It is important to note at this stage in his development of the theory of dementia, Kitwood did not propose his equation as a framework just for the provision of person-centred care to people with a diagnosis of dementia, rather he saw each factor interacting with each other in a way that could actually create dementia, he states that social factors are dementogenic (Kitwood, 1989, 1990a). However, in his publication, ‘Towards the reconstruction of an organic mental disorder’ (1993), the idea that dementia is caused by social factors is not mentioned and was not mentioned again in any of his further publications. Baldwin & Capstick (2007, Pg. 16) pose whether this was a tactical ploy by Kitwood or if he was less convinced about it himself. A theory suggesting macro-social factors caused dementia was not a popular one as demonstrated by an article in the British Medical Journal (Flicker 1999, cited in Baldwin & Capstick 2007 Pg. 101). Kitwood may have felt that his most pressing concern, that of how people with dementia were viewed and cared for, would be more acceptable to those in practice if he let this point fade.

### **2.2.5 Critique of a psychosocial model of dementia**

The criticisms for Kitwood’s theory of dementia originate from concerns around a lack of supporting evidence for his claims and ideas, being selective and anecdotal in his presentation of evidence and failing to take note of more recent work in neuropsychology for example the development of acetylcholinesterase inhibitors which reduce the rates of cognitive decline in Alzheimer’s type dementia (Flicker, 1999 cited in Baldwin & Capstick 2007 Pg. 102) and neuroimaging techniques. It is a valid argument that Kitwood did not provide an audit trail or robust evidence for his theory at least in the early days. However, it is common for empirical evidence to follow the development of a theory. Indeed, the research undertaken in this thesis developed a theory of how applicable and acceptable person-centred care is to family caregivers which will now be tested empirically to either falsify or evidence that theory. The evidence Kitwood does put forward in support of his theory of the aetiology of dementia was in the form of case studies. Kitwood (1990b) developed psychobiographies of people with dementia through interviews with their relatives in the company of another researcher who took notes. The interviews would last 2 hours and “focus on events or developments that pertain to the vicissitudes of the experiential and adapted selves” (Kitwood, 1990b). Case studies are a popular method of data collection by psychologists and allow for the reporting of descriptive information about a person or specific environment. The strengths of case studies lie in their ability to provide data that is detailed and insightful shedding light on human thinking and behaviours that would be difficult using other methods. However, case studies do have limitations, namely that the results cannot be generalised to a wider population, as the case under study may not be representative of

a wider population. As the data collected are descriptive the interpretation of the data is dependent on the subjective opinion of the investigator leaving room for investigator bias (McLeod, 2008). When interpreting the data, the researcher decides what is important and what is not, leaving out data they feel is not required. Good case studies inform the reader whether the information used is factual or their inference and opinion, providing enough raw data from the interviews for the reader to make their own judgement, something that was sparse in Kitwood's publications.

Much of the criticism of all of Kitwood's work stems from his less than robust research methodologies and data reporting, indeed, Adams (1996) and Baldwin & Capstick (2007 Pg. 97) are concerned about the assumption Kitwood makes with regard to whether the family members were ever told about and are able to accurately recall, the events in their relative's life and apply accurate meaning on behalf of their relative. Despite collecting many psychobiographies only one was published, that of Rose (Kitwood, 1990b). Here Kitwood uses the story of Rose as told by her daughter and granddaughter as an example of how psychosocial events of the past impacted on the aetiology of dementia. However, one case study does not prove causation or even association. Publication of further psychobiographies would allow the reader to understand how themes and trends emerged from the data (Hammersley et al. 2007; Silverman, 2011) improving the validity and reliability of his finding. Despite acknowledging these limitations, he does very little to mollify his critics.

Even when Kitwood does provide more data, Adams (1996) casts further doubt on the credibility of the evidence that dementia is psychosocially constructed. In a paper from 1993 (Kitwood, 1993a) the findings from 44 psychobiographies are presented. However, only 27 of their family members highlighted one or more events in their relative's life that could have played a part in the development of dementia as proposed by Kitwood. There is reverberation here from his criticism of the biomedical models' inability to explain why some people developed dementia signs and symptoms with significant brain damage while others did not.

Despite a lack of transparency and supporting data in his publications Kitwood did facilitate a debate about the impact psychosocial factors have on dementia and those living with it. A platform for further studies was generated which have gone on to prove the biomedical theory of dementia to be incomplete and the psychosocial theory to have credibility. A study, by Sampson et al. (2014), showed people with dementia in acute hospitals who had their pain recognised and

managed demonstrated less ‘behaviours that challenge’, behaviours which staff had generally considered to be solely due to the advancing neurological impairment of dementia.

### **2.3 Ill-being and Well-being**

Fundamental to Kitwood’s theory of dementia and dementia care was the belief that, despite failing cognitive ability, personhood remains in terms of feelings, attachment and a sense of identity. Furthermore, he believed, based on his observations using Dementia Care Mapping (Bradford Dementia Group, 1997); an observation tool he developed to measure how personhood is maintained from the perspective of the person with dementia, that, when people with even severe dementia receive good quality care personhood is maintained and the person experiences a relative state of well-being. High-quality care refers to person-centred care that recognises the uniqueness of the individual drawing on their specific personality, biography and beliefs as described in the previous section. Person-centred care is considered by Kitwood to meet the person’s psychological needs ensuring a relative state of well-being exists. Correspondingly, when psychological needs have not been met a relative state of ill-being exists.

Kitwood’s views on well-and ill-being are most comprehensively described in the Dementia Care Mapping manual first published in 1997 (Bradford Dementia Group, 1997) where six states of relative well- and ill-being are identified and allocated a numerical value:

- +5 exceptional well-being
- +3 moderate
- +1 mild well-being
- 1 mild ill-being
- 3 moderate ill-being
- 5 extreme ill-being

Nineteen indicators of appropriate emotional displays of well-being and ill-being are also listed (Box 2.1).

**Box 2.1 Indicators of well-being and ill-being**

Well-being

Assertiveness, or being able to express wishes in an acceptable way  
Bodily relaxation  
Sensitivity to the emotional needs of others  
Humour  
Creative self-expression (such as singing, dancing or painting)  
Taking pleasure in some aspects of daily life  
Helpfulness  
Initiation of social contact  
Affection  
Self-respect (such as being concerned about hygiene, tidiness and appearance)  
Expressing a full range of emotions, both positive and negative  
Acceptance of others who also have dementia

Ill-being

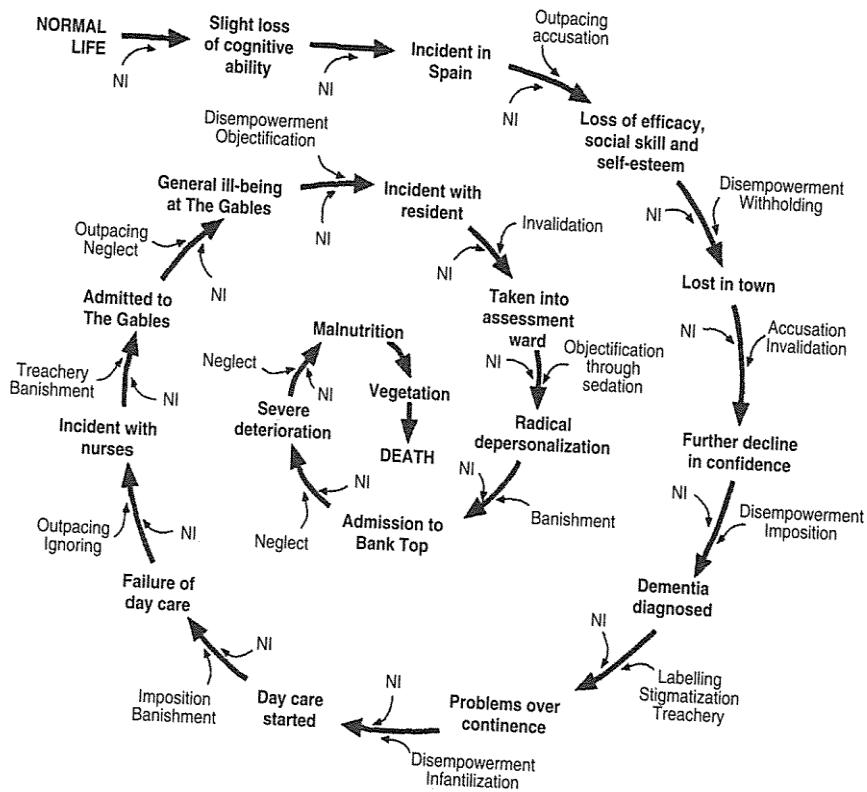
Unattended sadness or grief  
Sustained anger  
Anxiety  
Boredom  
Apathy and withdrawal  
Despair  
Physical discomfort or pain

There are three main points to Kitwood's ideas of well and ill-being (1992, 1997a):

1. Provided the person receives high-quality care that meets their psychological needs they can remain in a relative state of well-being despite advancing dementia.
2. People are not in a state of ill-being as a result of neurological damage alone but due to a combination of other factors including poor quality of care which is described as a "malignant social psychology", countering the biomedical model theory of dementia, that there is nothing that can be done to improve the situation of people with dementia something Kitwood referred to as 'therapeutic nihilism' (Kitwood, 1999).
3. Challenging behaviours seen solely as the result of neurological damage in the biomedical model of dementia should be viewed from the premise that the person is trying to communicate strong emotions of frustration or anger towards their situation in the same way any other person would under the same conditions and are actually signs of human distress.

Kitwood used involutionary spirals (1997a) to explain how the treatment of people with dementia impacted on their ability to function, their well-being and their behaviour (figure 1).

**Fig. 2.1 Involutionary spirals (Kitwood 1997)**



According to Kitwood (1997a), the difficulties experienced by people with dementia could be exacerbated by other factors, mainly the environment, other people, the person's personality and life history and their health including but not exclusively dementia and sensory problems.

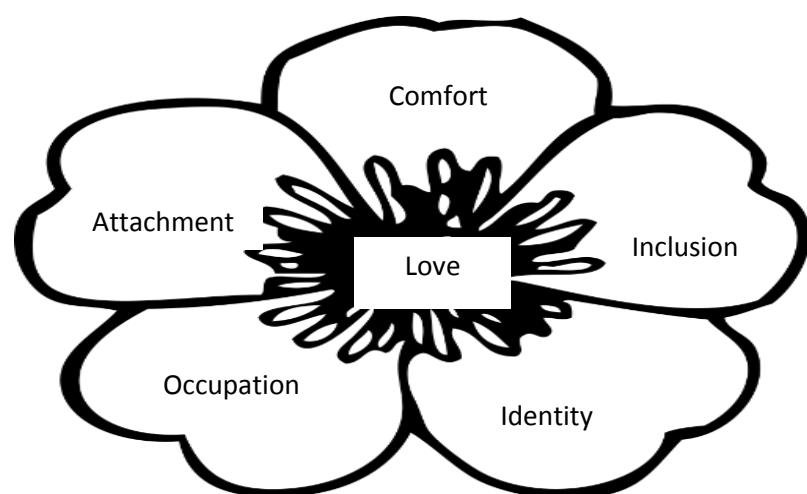
The evidence that people in well-being fair better than those in ill-being is sparse yet having taken the moral high ground it would be impossible to conduct an ethically acceptable study to prove Kitwood's theory either way today. Indeed, the shift in legislation over the past few decades fundamentally endorses upholding personhood (The Mental Capacity Act, 2005; The Care Act, 2016). As a consequence, health and social care decisions are being made based on the quality of life rather than sustaining life; an ethical model verses a medical model. When patients with dementia are admitted to hospital and are found to have a poor nutritional intake without a medical cause, for example, acute illness or depression the assumption is made that the person is on a dying trajectory. Should following a capacity assessment the patient be considered not to have capacity regarding nutritional support a best interest decision will be made with the family. In keeping with the assumption, the person is dying conservative measures would only be recommended by the health care professionals. This would include encouragement, offering food that the person usually likes to eat in a form they can physically manage, little and often with the

appropriate level of help. Any behaviour on the part of the carers that is considered to be more than encouragement for example threats or forcing food would be frowned upon and could lead to concerns around the safety of the patient in terms of aspiration of food and their psychological well-being and result in a safeguarding alert being raised to social services. Yet how acceptable are Kitwood's theories to family caregivers? The discourse in the national press regarding the withholding of food and drink to those placed on the Liverpool Care Pathway may provide some insight into their strength of feelings. Without the evidence should we place personhood above life-sustaining nutrition or should we compromise personhood by being more direct in our approach to nutritional intake while risking the possible negative effect this may have on the patient's well-being?

In his early work when setting out his argument against the biomedical model of dementia and dementia care (as described above) Kitwood (1998) postulated that experiencing ill-being before the diagnosis of dementia actually predisposes a person to dementia. In this paper, Kitwood gives examples from macro and micro social, political and personal life ranging from urban lifestyles to retirement and redundancy as life course events that coupled with neurological damage and the older person's inability to buffer against such events lead to the development of dementia. Around the same time, Kitwood wrote how good quality care that maintained personhood could lead to a state of "rementia" (Kitwood, 1990). By rementia, Kitwood was suggesting there was a therapeutic effect of high-quality care and a reversal of the disease process was possible.

Possibly as a result of the time he spent in care homes observing care while developing DCM (Kitwood and Bredin, 1992), Kitwood's attention moved from the individual experience of well and ill-being to that of the experience of dementia and the skills and values required by professional caregivers. Referred to as positive person-working, now referred to as person-centred care, Kitwood suggested that, by meeting the person's psychological needs personhood will be maintained. In *Dementia Reconsidered* (1997a) he chose a flower with overlapping petals with love at the centre to depict the five needs of people; comfort, attachment, inclusion, occupation, and identity. In one of his final publications, Kitwood (1998) listed 17 ways in which professional carers' can interact with people with dementia in order to meet their psychological needs and promote well-being and 17 ways in which they can have a negative effect promoting a sense of ill-being (Table 2.1). There was no mention of rementia in this paper but rather the more realistic theory of dementia care that is familiar to those working in dementia care today.

**Fig 2.2 Psychological needs model adapted from Dementia Reconsidered (Kitwood, 1997a Pg. 85)**



**Table 2.1 Kitwood's items promoting and damaging personhood (Kitwood, 1997 Pg.46)**

<b>Comfort</b>				
Intimidating	Making a participant fearful Using spoken threats or physical power	1	Warmth	Demonstrating genuine affection, care and concern for the participant
Withholding	Refusing to give asked for attention, or to meet an evident need	2	Holding	Providing safety, security and comfort to the participant
Outpacing	Providing information at a rate too fast for the participant to understand	3	Relaxed pace	Recognising the importance of helping create a relaxed atmosphere
<b>Identity</b>				
Infantilization	Treating the participant in a patronising way as if they were a small child	4	Respect	Treating the participant as and recognising their experience and age
Labelling	Using a label as the main way to describe or relate to someone	5	Acceptance	Entering into a relationship based on an attitude of acceptance
Disparagement	Telling a participant that they are incompetent, useless, worthless	6	Celebration	Recognising, supporting and taking delight in the participants' skill's and achievements
<b>Attachment</b>				
Accusations	Blaming the person for things they have done or not been able to do		Acknowledgement	Recognising the participant as unique and valuing them as an individual
Treachery	Using tricks or deception to distract or manipulate a participant	8	Genuineness	Being honest and open with the participant in a way that is sensitive to their needs and feelings
Invalidation	Failing to acknowledge the reality of the participant	9	Validation	Recognising and supporting the reality of the participant
<b>Occupation</b>				
Disempowerment	Not allowing a participant to use the abilities that they have	10	Empowerment	Assisting the participant to discover and employ abilities and skills
Imposition	Forcing a participant to do something or declining them choice	11	Facilitation	Assessing levels of support required and proving it
Disruption	Interfering with something a participant is doing, breaking their "frame of reference"	12	Enabling	Recognising and encouraging a participant's engagement
Objectification	Treating a participant as if they were a lump of dead matter or an object	13	Collaboration	Treating the participant as a full and equal partner in what is happening
<b>Inclusion</b>				
Stigmatization	Treating a participant as if they were a diseased object or an outcast	14	Recognition	Recognising the participants' uniqueness with an open attitude
Ignoring	Carrying on in the presence of a participant as if they are not there	15	Including	Enabling the participant to be and feel included, physically and psychologically
Banishment	Sending the participant away, excluding them, physically or psychologically	16	Belonging	Proving a sense of acceptance in a particular setting
Mockery	Making fun of a participant, and making jokes at their expense	17	Fun	Using and responding to the use of fun and humour

### **2.3.1 Critique of ill and well-being theory**

Baldwin & Capstick (2007, Pg. 94) raise issue with Kitwood's ill and well-being theory. Firstly, they are concerned with the apparent promotion of "stereotypical ideas that the well-adapted older person should be without passion, desire or legitimate hostility in the face of authority". Baldwin & Capstick (2007, Pg. 96) go on to question the place in Kitwood's theory for the person to be able to express their distress at their situation regardless of how well they are being treated. However, it could be argued that Kitwood's signs of well and ill-being which included "not being easily walked over by others" and "hold their own socially", demonstrating the agency of the person in his theories generally. If the caregivers were to have the critical thinking and complex decision-making skills to understand the interplay between the person's neurological damage, health issues, personality and life history as laid out in Kitwood's equation, they may be able to understand and facilitate such expressions of emotion and also to enable people to pursue risk-taking activities without judgement. This level of dementia care requires investment in professional carers who are highly skilled.

Further criticism of Kitwood's well- and ill-being theory is once again focused around his research methodology and the use of DCM. In a large study, Brighter Future (Kitwood et al. 1995) Kitwood used DCM to observe 224 people with dementia in 77 care settings. While the findings were rather intuitive and not controversial; an increase in well-being was evident when there were high levels of engagement and activity, Baldwin & Capstick (2007, Pg. 102) question the choice of research methodology which was not explained by Kitwood and the construction of the measurements and operational rules of DCM which were not detailed with sufficient clarity for the reader to make a judgement on its validity and reliability.

Further comment on well and ill-being comes from Baldwin & Capstick (Pg. 2007) regarding how a person's outward expression of emotion can be interpreted through observation as behaviour is subjective and open to different interpretation, for example, a lady living at home with dementia receives twice daily care from a home care agency. On this day, the usual homecare worker is on holiday and a different person comes to attend to her washing and dressing needs. The lady refuses to let her help. The homecare worker continues to persuade her to wash; eventually, the lady shouts at the homecare worker and raises her hand to her. Is this lady demonstrating signs of well-being, assertiveness, holding her own, not being walked over, or signs of ill-being, destructive, intense anger? Can we make a judgement on feelings from observation?

Despite these valid criticisms the Bradford Dementia Group have continued to develop DCM over the years and it is now recognised nationally and internationally as a tool to measure the quality of care from the perspective of the person living with dementia in care homes and hospitals (SCIE & NICE, 2006; National Audit Office, 2010), with DCM 8 published in 2005. Like much of Kitwood's work the major problem was its underdevelopment due to his untimely death, as much as to his apparent lack of willingness to publish his data to support his theories.

## **2.4 Kitwood's theory of personhood**

Kitwood's theory of personhood is at the centre of his work on person-centred care. He did not develop his theory in order to simply make a contribution to the discourse on the subject of dementia but to make improvements to the lives of people living with dementia (Kitwood, 1997b). His definition was based on his belief that people with dementia are of moral standing and any definition of personhood was to capture this (Kitwood, 1997a Pg. 9.; 1997b).

Kitwood's definition of personhood (Kitwood, 1997a Pg. 9) states, "It (personhood) is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being".

Personhood according to Kitwood is not solely linked to memory function but is socially constructed; built on relationships with others. Status is bestowed upon a person by others as a right of all humans, their diagnosis of dementia is just one aspect of who they are, they are a person first and this status remains throughout the progression of dementia until death. The underlying philosophy is humanistic which acknowledges the individual as a person who can experience life and interact in relationships (Kitwood, 1970; 1993b; 1994; 1997a; 1997b).

At the time of writing his theory on dementia there was a strong movement from influential ethicists arguing for a capacity and interest-based view of personhood that explicitly denied the personhood of people with dementia, for example, Dan Brock (1993 cited in Baldwin & Capstick, 2007 Pg. 176) wrote:

"I believe that the severely demented, while of course remaining members of the human species, approach more closely the condition of animals than normal humans in their psychological capacities. In some respects, the severely demented are even worse off than animals such as dogs and horses, who have a capacity for integrated and goal-directed behaviour that the severely demented subsequently lack. The dementia that destroys memory in the severely demented

destroys their psychological capacity to forge links across time that establishes a sense of personal identity across time. Hence, they lack personhood."

Kitwood (1997a) draws our attention to his belief that personhood is upheld in the way the person is treated, that it is dynamic and dependent on the situation, for example, the social and physical environment can support or undermine personhood. He went on to say that the deterioration seen in dementia was not just the result of the progression of the dementia but a result of poor care that undermines personhood. He referred to this poor care as a 'malignant social psychology' that existed in relationships which devalued the person for example dehumanised or infantilised. Kitwood's alternative approach to this was positive person working or person-centred care which aims to restore personhood.

In his writings (1970; 1993; 1994; 1997a; 1997b) Kitwood revealed the three main types of discourse that influenced his views of personhood. In "On being a person" (Kitwood, 1997a) he described the discourses of transcendence and the principle that life is sacrosanct, from ethics he takes the principle that persons should always be treated as the end rather than a means to an end and from social psychology, individuals exist within a network of relationships. Kitwood only goes on to develop his ideas about what would make a suitable theory of personhood at a social psychological level, without further discussion of the ethical or spiritual discourse which Baldwin & Capstick (2007 Pg. 180) feel he takes as a given.

In 'Personhood, dementia and dementia care' (1997b) Kitwood develops his psychosocial argument of personhood by bringing together symbolic interactionism and depth psychology processes. The symbolic interactionism process is an aspect of social life in which he argues there are two aspects to being a person, one the "adapted self" and second the "experiential self". The adapted self refers to the socialising aspect and the performance of given roles, for example, mother, worker, while the experiential self refers to relations based on equality, mutual attention and mutual respect.

Within Kitwood's definition of personhood is also the concept of relationship. In "Dementia reconsidered" Kitwood (1997a Pg. 10) states that, "To see personhood in relational terms is I suggest, essential if we are to understand dementia. Even when dementia is so severe an I-Thou form of meeting is not possible". Here Kitwood quotes Buber's theory of being in the world as "I-Thou" or "I-it" (Buber, 1937), where relationships of the I-Thou kind involve intimacy and self-disclosure and respect but can result in anxiety and even suffering but also joy as we engage with

meaning with the person. Relationships based on the I-It can never move beyond the trivial. They imply coldness and detachment and fail to recognise the person. The I-Thou relationship in Kitwood's theory of personhood establishes the idea of a symbiotic relationship between the person with dementia and the carer, with the potential for personhood to be enhanced through their relationship.

#### **2.4.1 Critiques of personhood in dementia**

Kitwood's definition of personhood placed the person at the centre of a care framework that brought them to the forefront of the caring situation at a time when the medical model prevailed, which would seem to be a positive move. However, it has been the subject of much criticism. Nolan et al. (2002), Davis (2004), Baldwin & Clapstick (2007 Pg. 187), Dewing (2008), Smebye & Kirkevold (2012; 2013) all raised concerns regarding Kitwood's apparent focus on people with dementia having personhood bestowed upon them by 'others', placing them in a position of vulnerability and without agency to influence their situation. They also criticise how Kitwood privileges the individual to the exclusion of those around them.

On the point of having personhood bestowed upon them, Smebye & Kirkevold's (2012; 2013) study demonstrated how people with dementia can retain agency; being able to participate in decision making about their health and daily care, indicating people with dementia are not simply influenced by how others interacting with them. In defence of Kitwood, Dewing (2008) points out that Kitwood does stress the moral responsibility of others to protect the vulnerable, but also asks, "what if the "others" do not value the social being and being in relationships with people with dementia, does this not then weaken their position?" Sabat et al. (1999) used case studies to go some way in countering Dewing's argument in their study which demonstrated how people with dementia can maintain their own sense of self and self-esteem enabling them to assert their wishes and make choices even when vulnerable.

Davis (2004) and Smebye & Kirkevold (2013) expressed their concerns for the family caregivers who they argue are further burdened by the need to maintain the personhood of their family member and take responsibility for the anticipated mental decline. While coming to terms with the person receiving a diagnosis of dementia and grieving for the relationship they have lost. Davis (2004) calls for further research into the status of people with dementia and how they are positioned with respect to their family caregivers.

Nolan et al. (2002) also raised concerns that Kitwood's theory of personhood is individualistic, to the exclusion of those providing care, be that family or professional caregivers. Nolan et al. (2003) go on to argue that Kitwood's theory does not appreciate the 'interdependencies and reciprocities' that are explicit in their "relationship-centred" theory. We know from the published narrative of family caregiver's experiences how they gain much from their caring role (Andren et al. 2008; Higeman et al. 2007; Brodaty et al. 2009), demonstrating the mutual benefit of the dyad. While Nolan et al. (2002) accept Kitwood's person-centred care as a framework for respecting personhood they are critical of how it promotes individualism and independence, something McCormak (2001) argues is "untenable" for older people requiring health or social care. We do not exist in social isolation but within networked social relationships, where interconnectedness and partnerships are important (McCormak, 2001). From a person-centred care perspective, should people with dementia refuse to eat, the nurse will respect the person's autonomy, enabling them to make a choice despite failing cognition, in the belief that this action is in their best interests and respecting their personhood. Yet where does this leave the family in the decision-making process?

Rather than promoting individualism and independence Nolan et al. (2002) argue for a framework based on relationships (Senses Framework, Nolan et al. 2001) adapted from the work of Mulrooney (1997). Mulrooney's work identifies when caregivers respect personhood, value interdependence and invest in caregiving as a choice the quality of care is improved. In this model empowering and reciprocal relations are fostered between all those involved, the person, family and friends and all health and social care professional.

Within these relationships, there needs to be an appropriate balance between independence, dependence and interdependence (Rønning, 2002), where the values each person brings to the care situation are clear and used to strengthen a process of negotiation that recognises and values each other's beliefs (McCormak, 2001). Once again in the situation where the person with dementia refuses to eat how does this framework position the patient and all those involved in their care? Would this model change the implied understanding that acting in the person's best interest means maintaining personhood and well-being at all costs and would this be acceptable to family caregivers?

For Dewing (2008) and Baldwin & Clapstick (2007 Pg. 185) while accepting that Kitwood does not develop the theory of 'all others' well they dispute Nolan et al. (2002) criticism, claiming there is a lack of understanding of Kitwood's work and referring to Kitwood's ultimate purpose as being the moral concern of 'others'; all others. It should be noted that in, "On being a person", (Kitwood,

1997b) Kitwood stated, “Individuals exist within a network of relationships” and in Dementia Reconsidered (1997a Pg. 95) he acknowledges the anxiety of the caring role but also the virtues describing the ‘joy’ it can bring. Nevertheless, Dewing (2008) does acknowledge that further work is needed to develop this area.

Taking up this argument, Baldwin & Clapstick (2007 Pg. 182), agree that more work is necessary but feel elaboration of the theory is all that is necessary, not a complete rework, suggesting reviewing personhood as a concept grounded in social interaction and positioning within families. Smebye & Kirkevold (2013) are exponents of the relationship-centred model of care developed by Nolan et al. (2002) and disagree with Brooker’s (2008) claim that Kitwood’s model is inclusive of all others in principle if not specifically spelt out. They argue though that care takes place within the context of relationships, contending, ‘mutuality and reciprocity in interactions’, and are not taken into account in the person-centred care framework.

Hughes (2014 Pg. 18) makes an interesting observation from his conversations with family caregivers about the person with dementia. He reflects that families talk of the person as, not being the same person, for example, “this is not the man I married”, or “this is not my dad”, they do not say they are, “not a person”, something Hughes believes is a very important distinction. What is thought-provoking is if the family caregiver repositions the person with dementia within the family, for example, is no longer a husband, no longer a dad, does the relationship change and if so how do they maintain the person’s personhood?

Perhaps if Kitwood had placed dementia into a political context rather than that of an individual one the care of older people and people with dementia would have seen greater improvement and this argument around the best framework for people with dementia would be unnecessary. As Bartlett and O’Connor (cited in Baldwin & Clapstick, 2007 Pg. 181) point out as a result of Kitwood’s personhood theory being non-political it had limited scope as an agent for political change. By placing dementia in a relational context focusing on the individual and the quality of the care they receive by individuals, Bartlett & O’Connor (2007) argue the responsibility for the person’s well-being lies very much with the individual providing that care. When there are gaps or failings in that care the focus of attention falls on these individuals rather than the socially and politically constructed context in which the care is delivered. Since these observations there has been a change in the political standing of dementia, with the publication of the National Dementia Strategy- Living Well with Dementia (2009) the Prime-ministers Dementia Challenge (2012) the

Alzheimer's Society's Dementia Friends initiative (2013) the Dementia Action Alliance Dementia Friendly Communities projects which includes hospital environment (2013) and a G8 summit (2013) dedicated to dementia as a global issue. These initiatives have started what may be referred to as a notion of citizenship where people with dementia are seen to be a part of their community as a right and not simply bestowed upon them by those who value them and want to be in relationships with them. If it were not for Kitwood's reconsideration of dementia we may not have come this far.

## 2.5 Conclusion

Kitwood's concepts of dementia and dementia care have been readily adopted by nurses, nurse education and health care policy, yet this review raises questions about the academic rigour of his work, in particular, its reliability and validity. Person-centred care as a model on which to base nursing care has proven difficult to implement on a large scale in the modern day which focuses on throughputs and targets. Perhaps with more clarity as to the meaning of personhood and person-centred care its utility in practice would be more obvious to those who are engaged with people with dementia on a daily basis, either professionally or personally, in areas where the biomedical model still prevails.

Person-centred care as proposed by Kitwood (1997a) is based on the relationships developed by professional caregivers with people with dementia in care homes and day centres. He describes how professional caregivers develop therapeutic relationships through learning about the person's life history, personality, health and sensory problems which guide assessment, leading to the creation of person-centred plans of care. This framework should result in good care, well-being, increased ability and the maintenance of personhood, but according to some commentators (Nolan et al. 2002; 2003; 2004; Patterson et al. 2011; Smebye and Kirkevold, 2013) at the expense of excluding family caregivers. Family caregivers in contrast to professional caregivers developed their relationship with the person with dementia over years, with their roles and responsibilities having been established prior to the development of dementia. The care provided by the family caregiver is likely, therefore, to be based on family history and intuition rather than assessment and planning which may have different consequences for the persons' personhood than care given by professional caregivers. There has only been one study to date on this subject (Smebye et al. 2012). In this study, the relationships between persons with dementia, family and professional caregivers in sheltered accommodation and residential homes in Norway were explored. The study reported how close emotional bonds between family caregivers and persons with dementia

and professional relationships between persons with dementia, family and professional caregivers-maintained personhood. Smebye & Kirkevold's (2012) study has increased our understanding of the nature and quality of relationships between people with dementia and family and professional caregivers. Yet we still need to further our understanding of these complex theories of the personal meaning of caring for a family member with dementia and how personhood can be maintained.

It seems from this review there are three areas in Kitwood's theory in need of further development. Firstly, there is the question of accurately interpreting people's behaviour in terms of well and ill-being using Dementia Care Mapping, this is discussed in section 5.9.2.2. Secondly, to know the extent to which people with dementia need personhood bestowed upon them and thirdly, how does a diagnosis of dementia position a person within families and how does this impact on the person's personhood? Both of these areas are discussed in chapter 7.

This study will focus on the family caregiver in the acute hospital and how acceptable and applicable Kitwood's theory of person centred-care is to them when their relative is not eating. This area was chosen as the focus for the study since in clinical practice this is an activity family caregivers engage with, it is a common difficulty experienced by people with dementia and a subject that causes distress for family caregivers, nurses and at times patients themselves.

The following chapter reviews the evidence for interventions at mealtimes with people with dementia in order to determine the evidence base for actions taken by professional and family caregivers when people with dementia stop eating.

# Chapter 3 Review of literature – Interventions to support nutrition in people with dementia.

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## 3.0 Introduction

In this chapter, a systematic literature review of research evidence examining interventions used to support people with dementia to eat is presented. The results of the review were important as they informed the researcher's understanding of best practice in helping people with dementia to eat and provided a base upon which to observe family caregivers in the task. Therefore, throughout the review, the researcher was mindful of the relevance of the interventions to the family caregiver as their actions at mealtimes were the focus of the current study.

The literature review protocol is described below, followed by a description of the characteristics of the included research papers. A critical discussion of the quality of those papers in terms of each intervention is also presented. The chapter concludes with a discussion of the need for more research to investigate interventions based on a person-centred approach where an assessment of the individual's likes, dislikes, habits, strengths and difficulties informs the intervention for each participant recruited to the study. Finally, the aims and objectives of the current study are introduced along with the study propositions.

## 3.1 Background

The reasons for poor nutritional intake in people with dementia are complex and multi-factorial and cause much emotional turmoil for both formal and informal caregivers alike. Many people with dementia experience significant difficulties when eating, in one study 60% of caregivers reported the person they care for having problems (Aselage et al. 2011). These problems were associated with the recognition of food, recognising the feelings of hunger, difficulties using cutlery, getting food to their mouth, chewing and swallowing. Some people with dementia have a preoccupation with food while others refuse to eat at all, hold food in their mouth, turn their head away or spit the food out.

The impact of eating difficulties for people with dementia has been well documented and includes unintentional weight loss (Aselage et al. 2011) malnutrition (Bartali et al. 2006), decline in physical function (Ritchie et al. 2010) poor quality of life (Callahan et al. 2006), and a reduced ability to

fight further medical conditions, for example infection and pressure ulcers (Frias Soriano et al. 2004) and can even result in the person being placed in a care home (Mittelman et al. 2006).

### **3.2 Rationale and objectives**

This literature review was carried out to identify the strength of evidence for interventions in mealtime difficulties for people living with dementia. As well as, identify the gaps in research and possible areas for further research and practice development and to inform the researcher of best practice which would assist when observing family caregivers supporting relatives who are experiencing difficulty.

Previous systematic reviews have been undertaken on mealtime difficulties for people with dementia dating back to 1997 (Watson & Green, 2005) when only a few case studies had been reported. A recent review from Whear et al. (2014) demonstrated moderate evidence for professional educational programmes resulting in people with dementia spending more time eating and reduced mealtime difficulties. However, neither education programmes nor feeding assistance increase food intake. The strength of evidence for the impact of environmental changes on food intake and agitation was reported to be low by Whear (2014), this is confirmed by Bunn et al. (2016) who stated the evidence for environmental interventions including music, family style meals and the availability of snakes showed “promising” results.

As the current study used mealtimes to explore the acceptability and applicability of Kitwood’s theory of person-centred care to family caregivers when their relatives with moderate to severe dementia refuse to eat, it was essential to include and understand any evidence supporting intervention family caregiver could utilise.

### **3.3 The function and desire of eating**

Before considering the evidence base for interventions intended to assist people with dementia with eating difficulties it was necessary to examine the role of the brain in appetite and eating and the effects dementia has on this.

The brain is made up of many different parts; the brain stem, cerebellum, the right and left cerebral hemispheres which comprise of four lobes and the limbic system. Each has a different function working together via a communication system of nerve fibres, cells and neurotransmitters.

Lack of appetite or anorexia is a common problem in Alzheimer's type dementia more so than other types (White, 1995). This is likely due to damage to the hypothalamus seen in Alzheimer's disease and some of the areas nearby, which takes place in the early stages of the disease (Dickson, 2001). It is the hypothalamus; part of the limbic system that responds to circulating hormones and signals of reduced energy levels and calories prompting the feeling of hunger (Amella, 2004). The motivation to feed that hunger is regulated by the hippocampus; responsible for short and long-term memory and the amygdala; responsible for emotional memories. When we are hungry, the hippocampus responds by remembering what the feeling means, how and where to obtain food, for example, remembering where the biscuit tin is kept. Our desire to eat is not only controlled by the need for calories and energy levels; there is an emotional desire too. The amygdala drives those emotions; if over time we learn that nice food provides rewards concerning feeling pleasure it is the amygdala that drives us to eat pudding despite having eaten our dinner and no longer feeling hungry.

Damage to the hippocampus may result in a loss of the memories that provide the cues to eat so feeling hungry is no longer associated with a need to eat. Damage to the amygdala affects the person's memory for the pleasures or rewards of eating; as a result, people with dementia will not eat just because the food on offer looks and tastes nice. This damage culminates in people with dementia not feeling hungry and not wanting to eat despite being offered their favourite.

The physical ability to feed one's self is one of the last activities of daily living people with dementia require help with (Aselage, 2009). The frontal lobes are responsible for learning a new skill, once mastered this new skill is stored in the basal ganglia, the motor cortex and cerebellum. These procedural memories are retained in dementia until the late stages of the disease. However, while the procedure of eating is not lost, difficulties do occur due to problems with certain aspects of the task; for example, moving a fork up to the mouth, general clumsiness known as apraxia, due to damage to the left parietal lobe. This difficulty may be further compounded by damage to the right parietal lobe resulting in difficulty recognising objects in three dimensions, where objects are in relation to other objects and where they are in connection to one's self.

People with dementia may also experience difficulty recognising objects if there is damage to the temporal lobes or the hippocampus. The temporal lobes store general knowledge, known as semantic memory. The left temporal lobe and the hippocampus deal with remembering facts, figures, names, the meaning of words and names of objects and have a significant role to play in

understanding speech and talking. The right lobe is more concerned with visual memories and is key to the recognition of familiar objects and faces. Damage to the temporal lobes, in particular, the right lobe causes eating problems as the individual can no longer remember what a knife and fork are for or what specific foods are (Gillette-Guyonnet, 2000).

The motor cortex, an area at the back of the frontal cortex, is responsible for planning movement and the control of specific muscle groups, if damaged the person may express a desire to eat but experience difficulty bringing the fork up to their mouth.

A principal role of the frontal lobe is maintaining attention, setting goals, problem-solving and starting and finishing tasks. The damage caused by dementia may lead people with dementia to forget why they are sitting at the dining table, so they stand up and walk away mid-way through a meal. Damage to the frontal lobes can also cause difficulties with repetitive actions and equally tiredness or a lack of interest.

As the disease progresses the difficulties experienced by the person with dementia become more complex, and commonly nutritional intake declines dramatically.

### **3.4 Aim**

This literature review was carried out to identify evidence for interventions that can be made to mealtimes to help people with dementia who have difficulties with eating and possible areas for further research and practice development.

### **3.5 Methods**

This systematic literature review was carried out using the guidance from the NHS Centre for Review and Dissemination and is reported in line with the PRISMA statement (Centre for Reviews and Dissemination, 2008).

### **3.5 Search strategy**

Searches of 4 electronic databases; Medline (OVID) CINAHL (EBSCOhost), PsychINFO (OVID), BNI from 2004 to October 2018 took place; reference lists included articles were also searched. This time period was chosen for the search as very few intervention studies had been published prior to 2004 (Liu et al. 2015). The search terms included; dementia, Alzheimer's, feeding, eating, mealtime(s), oral intake, nutrition, environment, culture, family caregiver, informal carer, intervention, experiment and quasi-experiment. All articles were written in English, and reviews were not included.

To ensure all relevant studies were included while keeping the search in focus the PICOTS framework (Guyatt, 2008) was used to address the search question and establish inclusion and exclusion criteria.

### **3.5.1 Population of interest**

Studies were included where interventions were implemented with people diagnosed with dementia, living in any setting either institutional or community dwelling.

### **3.5.2 Interventions of interest**

Quantitative studies in which interventions were intending to improve the mealtime experience, the environment, and assistance were included. Educational programmes explicitly aimed at enhancing mealtimes were also included.

Studies investigating interventions with people with dysphagia or those studies examining sip feeds, supplements or fortified foods or enteral feeding were excluded. Studies aimed at improving end of life/palliative care rather than nutritional intake were also excluded.

### **3.5.3 Comparator**

Comparative studies where a baseline or control could be measured against the study data, for example, randomised control trials, before and after studies or time series methods were included in this review. Single case studies were excluded.

### **3.5.4 Outcome of interest**

Only studies with the following outcome measures were included:

- Weight gain/stability
- Calorie intake gain/stability
- Independent eating
- Reduction in behaviours that cause mealtime difficulties for example refusal, spitting out food, walking away or time spent eating.

### **3.5.5 Timing**

Duration of following up was not limited.

### **3.5.6 Setting**

No settings were excluded of example, in home, care homes, day centres and hospitals were all included.

### **3.5.7 Study selection**

Two reviewers selected studies based on the eligibility criteria following three steps:

- 1) Screening by title and abstract
- 2) Assessing full text for eligibility for inclusion
- 3) Reviewing full text for quantitative content

Where it was unclear from the study abstract as to its eligibility for inclusion in the review the full text was retrieved and read thoroughly before a decision was made.

Neither reviewer was blinded to the authors of the studies, the institutions or publication journal. Each reviewer assessed the studies independently, and disagreements were discussed and resolved.

### **3.5.8 Quality Appraisal**

The quality of the individual studies were assessed separately by the same two reviewers using the Quality Assessment Tool for Quantitative Studies (QATQS) (National Collaborating Centre for Methods and Tools, 2008). A full copy of the tool is seen in Appendix 2 with a copy of the supporting dictionary used to promote reliability (Appendix 3). This assessment tool was chosen as it was relatively quick (3-60 minutes each paper) and straightforward to us, it was found by Thomas et al. (2004) to have acceptable validity properties and test re-test reliability. This tool was used by Lin et al. (2012) in a similar systematic review and importantly is recommended by Cochrane for systematic intervention reviews

([https://ph.cochrane.org/sites/ph.cochrane.org/files/public/uploads/Unit\\_Eight.pdf](https://ph.cochrane.org/sites/ph.cochrane.org/files/public/uploads/Unit_Eight.pdf) accessed June 2015).

The QATQS assesses eight components of a study, grading the first six components as strong, moderate or weak, with an overall result for quality being determined. Where discrepancy arose between the two reviewers, discussion took place to achieve agreement.

The Grading of Recommendations, Assessment, Development and Evaluation (GRADE) Working Group criteria (Atkins et al. 2004; Guyatt et al. 2008) was used to assess the strength of the evidence for each primary outcome where 2 or more studies tested the same intervention. GRADE provides a structured, transparent protocol for systematic reviews and is flexible regarding evidence upgrading or downgrading (Dijkers, 2013). In particular, GRADE focuses on the values and preferences of those who will experience the intervention making it particularly appropriate for this review.

Using GRADE the baseline evidence, as determined by the study design i.e. randomised control trial, observation study (Appendix 4) was assessed and graded, this assessment was then refined

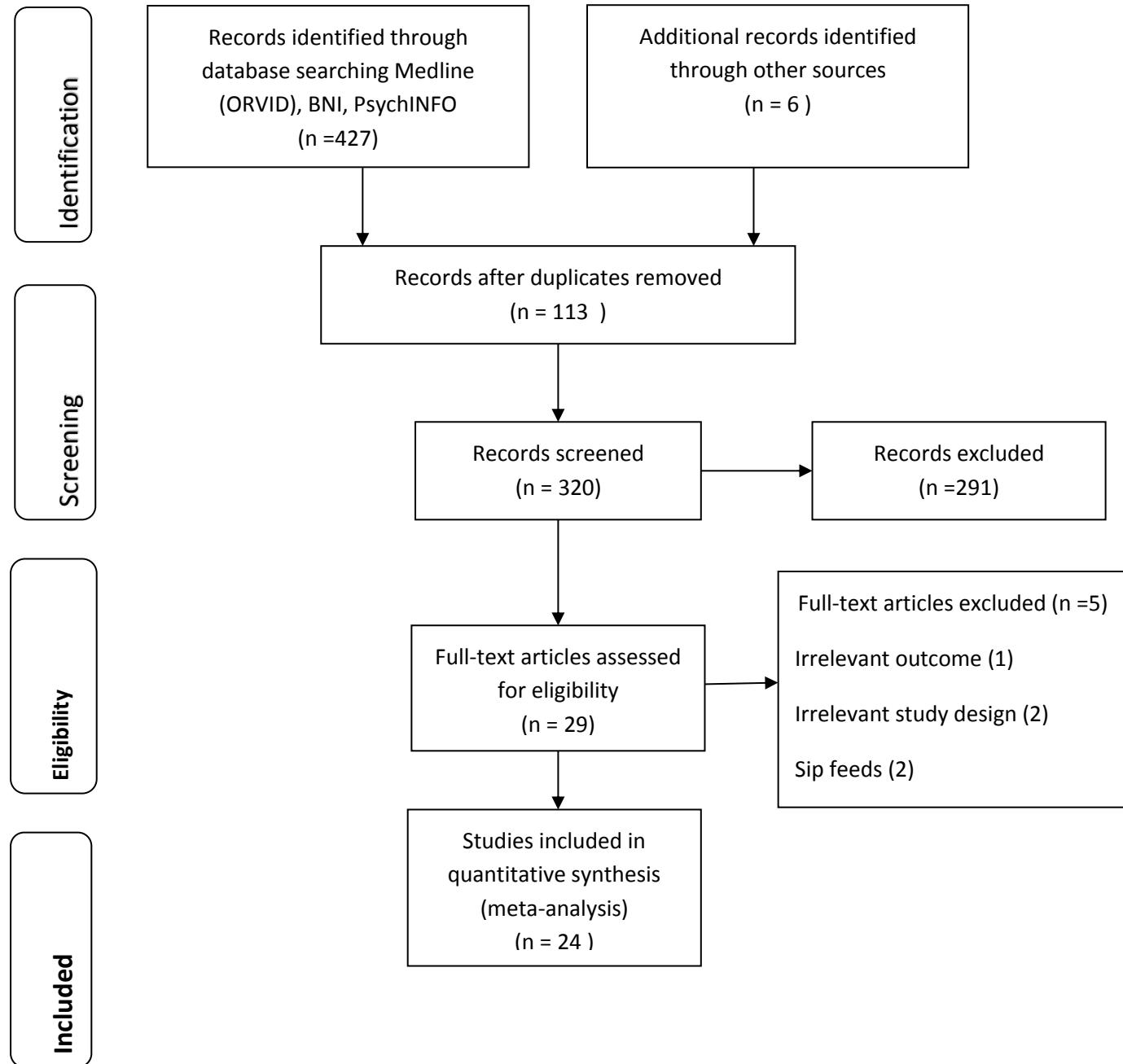
depending on the answers to the questions in Appendix 5 where the grade would be dropped by 1 level for example, from high to moderate if the answer to a question in GRADE was positive. Once again where there was a discrepancy between reviewers, discussions were held to achieve agreement. Final strength definitions are presented in Appendix 6.

### **3.6 Results**

The literature search revealed 427 articles, plus six from the reference list of other articles found giving a total of 433. One hundred and thirteen duplicates were removed leaving 320 to be screened through title and abstract reading. Following screening, 291 articles were excluded leaving 29 full-text articles which were read. A further five were excluded, leaving 24 articles for the final quantitative analysis (flow diagram 3.1)



### 3.1Diagram PRISMA 2009 Flow



### **3.6.1 Data synthesis**

Studies were grouped according to the intervention used in the study, these comprised of four main themes, education, music, environment, exercise, feeding assistance and mixed intervention strategies.

### **3.6.2 Study characterises and quality**

The characteristics and strength of the 24 studies are set out in Appendix 7. Of the 24 studies included in the quality analysis ten papers reported on educational interventions, four music, three environmental changes which included changes to service delivery coloured plates and cutlery and an aquarium in the dining area. Two studies introduced a physical intervention the first an exercise programme before lunch service, the second back and limb massage. Three studies focused on assistance with eating and two studies combined a number of interventions. There were seven randomised clinical trials (RCT), seven clinical controlled trials four cohort studies and five interrupted times series designs.

### **3.6.3 Educational interventions**

Of the ten education studies identified in this literature search, five were RCTs, three clinical controlled trials and two cohort studies. A total of 1,283 people with dementia were enrolled, ranging from 946 in one study (Salva, 2011) to three in another (Beattie, 2004).

Five studies involving an educational intervention were directed at professional care staff; 4 working in long-term specialist dementia units (Chang & Lin, 2005; Suominen, 2007; Mamhidir et al. 2007; Batchelor-Murphy et al. 2015) and 1 in a medical ambulatory medical centre, is the only study to include family caregivers (Salva et al. 2011). The programmes ranged from 3-hours of classroom teaching (Chang & Lin, 2005) to 1-week of classroom teaching plus three months of clinical practice supervision (Mamhidir et al. 2007). Only one programme did not involve face-to-face sessions (Batchelor-Murphy, 2015) this was a feasibility study of a web-based programme. Four papers two from Lin et al. (2010, 2011) and two from Wu et al. (2014a, 2014) presented studies examining the outcomes of a combination of Montessori activities, errorless learning and space retrieval learning on people living with dementia in a care home setting.

The studies from Lin et al. (2010; 2011) and Wu et al. (2014a; 2014) were strong educational studies. Five studies were evaluated as being of moderate quality (Salva et al. 2011; Chang & Lin, 2005; Mamhidir et al. 2007; Suominen et al. 2007; Batchelor-Murphy et al. 2015). One study did not control for the confounders seen in the differences of the baseline data (Chang & Lin, 2005). A cohort study using systematic reinforcement of, “sitting at the table” behaviour (Beattie et al.

2004) was considered a weak study. The studies all used convenience sampling strategies which could have resulted in selection bias. The level of blinding was not discussed in the moderate and weak studies, and the sample sizes were on the whole small ranging from n=3 (Beattie et al. 2004) to n=946 (Salva et al. 2011).

All but one study (Salva et al. 2011) reported some positive outcomes which included time spent sitting with study participants (Chang & Lin, 2005), increased food/calorie consumption (Batchelor-Murphy, 2015; Suominen et al. 2007). However, these studies did not report positive changes in BMI or nutritional status. Encouragingly, there was a positive response from the professional caregivers regarding reported improvements in knowledge (Chang & Lin, 2005) and attitudes towards people with dementia (Batchelor-Murphy, 2015).

#### **3.6.4 Music**

Four studies investigated the effect music had on food/calorie intake and included a total of 76 people. One study used live music before the lunchtime meals involving the participants in singing along (McHugh et al. 2012). While others played recorded music during mealtimes (Thomas & Smith, 2009; Richeson & Neil, 2004; Ho et al. 2011).

The study from Thomas & Smith (2009) was of moderate quality, those from Richeson & Neil (2004), Ho et al. (2011) and McHugh et al. (2012) were weak. Convenience sampling was again used and may have resulted in selection bias, the sample sizes were small, and confounders were not adjusted. There was a large amount of missing data in the McHugh et al. (2012) study.

Only those playing music during the mealtime demonstrated a positive impact on food intake. The study involved the participants taking an active part in the music sessions (McHugh et al. 2012). Ho et al. (2011) played researcher composed music during mealtimes and were able to demonstrate a statistically and clinically significant reduction in mealtime agitation at four-time intervals which continued for two weeks post-intervention. While there was a lack of comparator in this study, repeated assessments at four-time intervals as discussed by the authors, helped to overcome this limitation in part.

#### **3.6.5 Environmental interventions**

Three studies in this review examined the effect of environmental changes on the eating behaviours of residents in long stay accommodation and included a total of 149 participants ranging from nine to 70. Edwards et al. (2013) and Desai et al. (2007) conducted cohort studies in which a home-like food service replaced a tray service, and an aquarium was placed in the dining

area respectively. Both studies demonstrated statistically significant improvements in food intake following the interventions. The third study by Dunne et al. (2004) demonstrated an improvement in both food and fluid intake from a change in colour of tableware from white to high contrast red and blue. All three studies were of moderate quality with the issues of blinding being left unexplained.

### **3.6.6 Physical interventions**

Rolland et al. (2007) introduced an exercise programme into a long-term care home of people who were ambulant living with dementia. This RCT was a strong study, blinding was described, the tool to measure outcomes were valid and reliable, the sample size was calculated, and analysis was based on an intention to treat. However, there were no significant improvements seen in the outcome measures perhaps due to the poor concordance rates of the participants with the programme (25%). In contrast, the study from Rodrigues-Mansilla et al. (2013) was a weak study that yielded good results from ear acupuncture and light massage. Unfortunately, this RCT did not use valid and reliable outcome measurement tools, and the blinding of assessors was not discussed.

### **3.767 Assistance with Eating**

Simmons (2004 & 2008) lead two studies on eating assistance in long-term care units. Both showed positive outcomes for people with dementia regarding increased calories and the amount of food consumed and the amount of time spent receiving help to eat. One is of moderate quality due to a lack of blinding with trained research assistance providing the feeding assistance and collecting the data (2004). The second study (2008) is of strong quality. Batchelor-Murphy et al. (2017) conducted a CCT randomising 30 care home residents to receive eating assistance with one of three sequences of hand-feeding, direct hand (DH) over hand (OH) underhand (UH). The participants in this study were a convenience sample, there was no control group or pre and post outcome measures taken. The trained assistants who provided the feeding assistance also collected the data which included rating video recordings of the mealtimes. Confounders for the >87% female Caucasian population were not made all of which gave this study a weak rating.

### **3.6.8 Mixed interventions**

Wong et al. (2008) conducted a study of moderate quality using an interrupted time series design study to investigate the effect of volunteers or the encouragement of grazing or the use of music in the dining room on calorie intake and weight gain compared to usual care. Blinding to the research outcomes was problematic in this study. Charras and Fremontier (2010) conducted a

strong study testing a combination of staff education and enhanced environment care homes, plus a controlled study of the nutritional outcomes of staff eating their meals with the residents.

### **3.6.9 Summary**

Overall seven studies were strong, 11 moderate and five weak in quality. The main threats to the studies quality were weak design, lack of blinding with only Lin et al. (2010, 2011) describing blinding during data collection. The majority of the studies used convenience sampling strategies. This lack of randomisation or control group may have resulted in selection bias. Sample sizes were also small with 16 of the 23 studies having a sample size of less than 50. Confounding bias was possible in some studies due to a lack of controlling for baseline differences (Chang and Lin, 2005) a carryover effect (Simmons and Schnelle, 2004) and possible mitigating factors (Desai et al. 2007). Only three studies put forward a theory-base for their intervention (Suominen et al. 2007; Hicks-More, 2005; Richeson and Neil, 2004).

## **3.7 Strength of evidence**

The strength of evidence was determined for interventions where papers shared interventions and outcome measures (Appendix 8) using GRADE as described above in section 3.6.8. Three outcome measures, food intake, eating time and eating difficulty were reported across the literature reviewed. Food intake was measured as calorie intake, nutritional value, the weight of food left or observed food left, i.e. 50%. Eating time was measured from the researchers stated start and finish time while eating difficulty was measured using The Edinburgh Feeding Evaluation in Dementia Feeding Scale (Watson & Green, 2005).

The strength of evidence for interventions to improve food intake is low due to weak study designs and inconsistency of results. The evidence for environmental change and music to enhance food intake is also sparse.

Interventions to improve eating time and eating difficulties have moderate strength of evidence due to a lack of consistent results across the studies. The results of this review are consistent with those of similar reviews from, Herke et al. (2018), Lin et al. (2014, 2015), Whear (2014), Keller and Slavghter (2016) and Bunn et al. (2016).

### **3.7.1 Summary of evidence**

There is some evidence training, and education can lead to an improvement in eating time for people with dementia in long-term care facilities and may ease some eating difficulties. Currently,

there is no evidence that environmental changes, music before or during mealtimes, or assistance to eat will improve behaviour disturbances, i.e. refusing to eat.

This review highlights the need for further robust studies to determine the best ways to support people with dementia and their carers both family and professional to eat. However, it is important to note Watson's (2008) observations about the challenges of conducting robust research in this area. Watson (2008) alerts us to the difficulties of deciding on which outcome measures are best suited to answering specific questions, (body weight, calories, the percentage of food consumed) and also the difficulties ensuring participants are blinded to the intervention. It must be considered likely that spending more time with participants, either people with dementia or staff, regardless of the intervention, would have a confounding effect on the outcome, therefore delivering robust research in this area is difficult. In the studies reviewed here both the staff and residents/patients received a co-intervention in terms of additional time and attention simply by being a participant in a study, something known to be a premium in dementia care (Alzheimer's Society, 2016).

**Table 3. 1 Overall study characterises and quality**

NA's = nursing assistants, PWD People with dementia, CCT controlled clinical trial, RCT randomised clinical trial, I = intervention, C = control, NA = not applicable, MNA = Mini Nutrition Assessment, EdFED = The Edinburgh Feeding Evaluation in Dementia Feeding Scale (Watson et al. 2001a, 2001b)

Author, year, location	Study design	Sample & Setting	Intervention	Comparator	Duration	Outcomes	Study quality
<b>Training/education</b>	<b>(n= 10)</b>						
Beattie et al. 2004, USA	CCT	1 male & 2 female PWD in 2 specialist long term dementia units	Systematic reinforcement of sitting-at-table behaviour, Heron Six-category Intervention Analysis	Self-control	6 weeks	<ul style="list-style-type: none"> <li>• Less table leaving</li> <li>• Increased food consumption</li> <li>• Increased body weight</li> </ul>	Week
Chang & Lin 2005, Taiwan	CCT	67 NA's in 2 specialist long term dementia units for >6 months (I=31 all-female, C=36, 94.4% female)	Feeding skills training programme for NA's which included 3-hours of class room teaching and 1-hour of hands-on training	NA's without training	Not available	<ul style="list-style-type: none"> <li>• NA – Increase knowledge</li> <li>• Positive attitude &amp; behaviour</li> <li>• PWD – increased sitting time</li> <li>• Increased feeding difficulties (EdFED)</li> <li>• No increase in food intake</li> </ul>	Moderate
Mamhidir et al. 2007, Sweden	CCT	Staff from a long term dementia specialist unit PWD 18=I, 15=C	Staff education in Erikson theory of the 8 stages of man. 1 week classroom based 3 months intensive support programme in clinical practice	Control group	3 months	<ul style="list-style-type: none"> <li>• Increase in weight correlated to increase in intellectual function</li> <li>• No relationship between weight gain, motor function and appetite</li> </ul>	Moderate

Suominen et al. 2007, Finland	Cohort	23 nurses & 5 food service personnel in 5 nursing homes  21 PWD in 1 ward (mean age 85 yrs. Range 62-95 yrs. All female)	Nutritional education programme for staff six 2-3 hour sessions, with lectures, group discussions, homework & personal feedback.	Self-control	6 month	<ul style="list-style-type: none"> <li>• Increase in energy. Protein, folic acid and calcium intake</li> <li>• No increase in BMI</li> <li>• No increase in MNA</li> </ul>	Moderate
Lin et al 2010, Taiwan	RCT	85 PWD from 3 long term specialist dementia unit (Mean age 81.18 ± 6.37 yrs.)	Spaced retrieval (SR) Montessori-based activities, (MBA) 35-40 minute sessions three times per week	Routine activity	8-weeks	<ul style="list-style-type: none"> <li>• Reduced feeding difficulty scores in SR &amp; MBA groups</li> <li>• Increased need for physical &amp; verbal assistance in MBA group</li> <li>• Improved MNA in SR group</li> <li>• Reduced MNA in MBA group</li> <li>• No increase in BMI</li> </ul>	Strong
Lin et al 2011, Taiwan	RCT	29 PWD in 2 special care units located in 1 long term dementia units (mean age 82.90 ± 5.96, range 68-95 yrs; males =58.6%)	Montessori sessions for 30 minutes 3-days per week, with a 2 week washout period prior to cross-over	Routine activity	8-weeks	<ul style="list-style-type: none"> <li>• Difference between I&amp;C</li> <li>• Sig increase in ability to eat</li> <li>• Sig increase in ability to self-feeding frequency</li> <li>• Sig increase in self-feeding time</li> <li>• No difference in eating time</li> <li>• No difference in assisted feeding</li> </ul>	Strong

						<ul style="list-style-type: none"> <li>• No increase in BMI or MNA</li> <li>•</li> </ul>	
Salva et al. 2011, Spain	RCT	946 ambulant people with mild/moderate Alzheimer's disease living at home with a family caregiver selected from medical centres I = 448 C=498 (mean age 79.0 +7.3)	Personalised information about Alzheimer's and nutrition provided Caregivers received 4 teaching sessions about nutrition Healthcare professionals (NUTRIALZ)	Routine care	12 months	<ul style="list-style-type: none"> <li>• No effect on functional decline</li> <li>• No effect on BMI, MNA, ADLs</li> </ul>	Moderate
Wu et al. 2014, Taiwan	RCT	PWD in one of 4 long term dementia specialist units I=32 C=31	Spaced retrieval & errorless learning 24 training sessions of 35-40 minutes spaced over 8 weeks	Spaced retrieval only training	8 weeks	<ul style="list-style-type: none"> <li>• Increase in food intake</li> <li>• No difference in cognitive status</li> </ul>	Strong
Wu et al. 2014a Taiwan	RCT	PWD in long term care 3 groups Group 1C= 27 Group 2 I=29 Group 3 I=43 (Mean age 82.8 SD 6.1)	Group 2 Spaced retrieval & Montessori Group 3 individualised spaced retrieval & Montessori	Routine activities	8 weeks/6 months	<ul style="list-style-type: none"> <li>• EdFED reduced eating difficulties in groups 2&gt;3</li> <li>• EdFED increased eating amount groups 2&gt;3</li> <li>• EdFED increase in weight groups 2&gt;3</li> </ul>	Strong
Batchelor-Murphy et al. 2015, USA	CCT	Nursing home staff I=17 C=18 who worked 7am -3pm PWD 5 in I & C	Web-based training module providing evidenced based information on mealtime difficulties	Standard training	8 weeks	<ul style="list-style-type: none"> <li>• Increase staff knowledge</li> <li>• Increased self-efficacy</li> <li>• No improvement in feeding skills</li> </ul>	Moderate

						<ul style="list-style-type: none"> <li>• Increase in feeding assistance and food consumed</li> <li>• Increase in feeding difficulties in both groups</li> </ul>	
Music N=4	Study design	Sample & setting	Intervention	Comparator	Duration (I/total)	• Outcomes	Quality
Richeson & Neil, 2004 Canada	Interrupted time series	27 PWN in specialist dementia and rehab unit	Therapeutic music during mealtimes	No music	2 weeks /4 weeks	<ul style="list-style-type: none"> <li>• Increase in food intake</li> <li>• Reduction in agitation and aggression</li> </ul>	Week
Thomas & Smith, 2009 USA	Interrupted Time series Crossover	12 PWD from a 14 bedded unit within a 70 bedded unit 11 females	Music playing during mealtimes	No music	4 weeks / 8 weeks	<ul style="list-style-type: none"> <li>• Increase of 20% in calorie intake</li> <li>• Average weekly calorie intake increased during each week</li> </ul>	Moderate
Ho et al. 2011 Taiwan	Cohort study	22 residents hospital based nursing home beds	Soothing music during mealtimes twice pre day 7 day per week	None	4 weeks/6 weeks	<ul style="list-style-type: none"> <li>• Significant decline in agitation at each time interval with a cumulative effect during 1-4 week and short term longer effect at 5-6 weeks</li> </ul>	Week
McHugh et al. 2012, USA	CCT	15 PWD in a long term care facility I=8 C=7	Vocal re-creative music therapy singing pre composed music with live music accompaniment under direction 4 days a	Self-control		<ul style="list-style-type: none"> <li>• No significant difference in nutritional intake</li> </ul>	Week

			week for 30 minutes for prior to lunch				
Environment change N=3	Study design	Sample & setting	Intervention	Comparator	Duration (I/total)	• Outcomes	Quality
Edwards & Alan, 2013, USA	Cohort	70 PWD in long term care facility (mean age 82.2 range 59-99) 18 male	Aquarium in dining area	Self-control	10 weeks	• Increase in daily food consumption	Moderate
Desai et al. 2007 Canada	Cohort	49 PWD in a nursing home I=26C=23	Food delivery as bulk in a more homelike environment	Tray service delivery in traditional institutional environment	9-12 months	• Increase in energy, protein and carbohydrate intake • No increase in fat intake	Moderate
Dunne et al. 2004 USA	Interrupted time series	7 males with dementia in a long term unit Mean age 82.7 yrs range 72-89	Initial I: high contact with red tableware	White tableware	10d/30d	• Increase in food and fluid intake • Decline post intervention	Moderate
	Interrupted time series	Different 9 males from same unit (83.1 yrs)	High contact blue Low contact red Low contact blue	White tableware	30d/70d	• Increase in food and fluid intake during high blue contact • No increase during low contact with red or blue	
Physical activity N=2	Study design	Sample & setting	Intervention	Comparator	Duration	• Outcomes	Quality
Rolland et al. 2007 France	RCT	134 nursing home PWD from 5 care homes 67=I 67=C	1 hour collective exercise programme twice a week, walking, strengths, balance, flexibility	Routine medical care	12 months	• Reduction in functional decline • Increase in 6-meter walking speed	Strong

						<ul style="list-style-type: none"> <li>• No difference in weight or MNA scores</li> </ul>	
Rodriguez – Mansilla et al. 2013 Spain	RCT	120 PWD living in a residential home. Massage group=40 Ear acupuncture=40 Control=40	Massage by physiotherapist to back and lower limbs Monday to Friday for 20 minutes or ear acupuncture	No therapy	5 months	<ul style="list-style-type: none"> <li>• Improvements in behaviour, sleeping, eating, participation in ADLs</li> </ul>	Week
<b>Feeding assistance N=2</b> Author, year, location	Study design	Sample & setting	Intervention	Comparator	Duration	Outcomes	Quality
Simmons & Schnelle, 2004, USA	Interrupted Time series	134 PWD in 3 nursing homes 11% males  68 of original 134 PWD who did not increase their intake with 1:1 assistance went on to 2 <sup>nd</sup> phase	Individual assistance with 3 meals per day with verbal or physical prompts as necessary  Individual assistance with 3 meals per day plus delivery and choice of snacks	Self-control  Self-control	2 days  2 days	<ul style="list-style-type: none"> <li>• Increase in total calories, in oral intake &amp; assistance time</li> <li>• Increase in total calories</li> <li>• Decrease in staff time compared to mealtimes</li> </ul>	Strong
Simmons et al. 2008 USA	CCT	76 PWD high risk of malnutrition in 4 specialist units C=34 I=35	Assistance with 2 meals per day 5 days a week or snacks delivered between meals	Self-control	24 weeks	<ul style="list-style-type: none"> <li>• Increase in time spent in activity</li> <li>• Increase in calorie intake</li> </ul>	Moderate

						<ul style="list-style-type: none"> <li>• Increase in calorie intake compared to prescribed oral supplements</li> <li>• Reduced staff time compared to meal time assistance</li> <li>• 24 week crossover Increase in calorie intake and BMI or</li> <li>• both groups in each intervention</li> <li>• Average staff time required in snack service was less</li> </ul>	
Batchelor-Murphy et al. 2017 USA	CCT	30 care home residents across 11 care homes Randomised to 3 sequences of handfeeding techniques DH-direct hand OH-over hand UH-under hand	Research Assistants provided feeding assistance for 18 video-recorded meals per resident (N=540 meals). Residents were assisted with one designated technique for 6 consecutive meals, changing technique every 2 days	None	6 days	<ul style="list-style-type: none"> <li>• Time spent eating</li> <li>• Percentage of food eaten greater with DH &amp; UH than OH</li> <li>• Feeding behaviour (EdFED) improved with DH &amp; OH</li> </ul>	Week
<b>Mixed intervention N=2</b> Author, year, location	Study design	Sample & setting	Intervention	Comparator	Duration	<ul style="list-style-type: none"> <li>• Outcomes</li> </ul>	Quality
Wong et al. 2008, New Zealand	Interrupted Time series	Total of 98 PWD in short stay unit enrolled in one of 4 phased	P1 observation P2 encourage grazing P3 volunteers to help with eating	Self –control	36 weeks	<ul style="list-style-type: none"> <li>• P1 BMI fell</li> </ul>	Moderate

		<p>intervention arms of the study.</p> <p>P1=23, 12 males</p> <p>P2=40, 17 males</p> <p>P3 n=7, 5 males</p> <p>P4 n=28, 16 males</p>	<p>P4 soft music playing in the dining room during mealtimes</p>			<ul style="list-style-type: none"> <li>• Increase in BMI, calorie intake during P2-4</li> <li>• No increase in mid arm circumference or MNA</li> </ul>	
Charras & Fremontier, 2010, France	CCT	<p>Staff from 1 specialist long term dementia unit</p> <p>18 PWD C=10 I=8</p>	<p>Staff sharing mealtimes with residents developed from an idea during nutritional training programme which included supervised practice, environmental design and changes to table linen</p>	Self-control	6 months	<ul style="list-style-type: none"> <li>• Increase in weight in I group</li> </ul>	Strong

**Table 3.2 Strength of evidence**

Interventions	Baseline evidence	Study design	Sparse evidence	Acceptable quality	Consistency of results	Directness	Reporting bias	Total subjects	Strength of evidence
<b>Food intake</b> Training/education <i>Chang and Lin, '05</i> <i>Suominen et al. '07</i> <i>Wu et al. '14</i>	Moderate	No (-1)	No	Yes	No (-1)	Direct	No	120	Low
Environmental <i>Dunne et al. '04, Desai et al. '07</i> <i>Edwards &amp; Alan, 2013</i>	Moderate	No (-1)	Yes (-1)	Yes	Yes	Direct	No	137	Low
Music <i>Thomas &amp; Smith, '09</i> <i>Richeson &amp; Neil, '04</i>	Low	No (-1)	Yes (-1)	No (-1)	Yes	Direct	No	54	Insufficient
Feeding assistance <i>Simmons &amp; Schelle, '04, Simmons et al. '08, Batchelor-Murphy et al. '16</i>	Moderate	Yes	Yes (-1)	Yes	Yes	Direct	No	210	Low
<b>Eating time</b> Training/education <i>Chang &amp; Lin, '05, Lin et al. '10, Lin et al. '11</i>	High	Yes	No	Yes	No (-1)	Direct	No	161	Moderate
<b>Eating difficulty</b> Training/education <i>Chang &amp; Lin, '05, Lin et al. '10, Lin et al. '11</i> <i>Wu et al. '14a</i>	High	Yes	No	Yes	No (-1)	Direct	No	260	Moderate

### **3.8 Discussion**

The strongest evidence and that with the most promising outcomes comes from the Taiwan researches investigations of the impact of spaced retrieval therapy, errorless learning and Montessori based activities (Lin, 2010, 2011; Wan, 2014; Wan, 2014a).

All three interventions are based on the understanding that procedural memory is relatively well maintained in people with dementia compared to that of semantic memory (Clare & Jones, 2008). In Spaced Retrieval (SR) therapy the instructor makes a statement and performs a task which they ask the person with dementia to repeat. If completed correctly the person with dementia is asked to repeat the task at increasing time intervals (3, 6, 12 minutes). Should they answer incorrectly or are unable to perform the task they are immediately given the correct answer, shown the task again and asked to complete the task at the last proper time interval. Errorless Learning (EL) focuses on the opposite way of learning to trial and error. The instructor demonstrates the procedure and asked the person with dementia to repeat one part of the task at a time providing cues along the way. There is no opportunity to make a mistake, as any error is remembered in favour of the right task. Montessori based activities (MBA) places the information the person needs for the activity in their space with reminders or templates about what they need to do. The whole procedure is broken down into simple steps which are learnt one by one, not moving on to the next step until the first is mastered. All of these interventions have a bio-medical theory base to them, focusing on the areas of the brain that are the least damaged, avoiding a focus on things they can no longer do or cannot re-learn. What is not made clear in these studies is how concordant the participants were with the intervention; how comfortable they were with taking part in the learning activities; was their well-being monitored and if so what did they do if a participant appeared to be in ill-being?

Interestingly, SR, EL and MSB interventions are all what could be described as therapy-based interventions which conform more closely to the medical model in their design and implementation. They are not linked theoretically to issues of personhood or to the interpersonal relationships which emphasizing the construction of personhood as a concept. Under these circumstances, it is not surprising that the evidence is stronger as the hierarchy of evidence used to critique comes from the medical model and is designed to test these types of interventions. Arguably it is less suited to measuring the effectiveness of interventions derived from a moral and philosophical perspective, partly because of the difficulty of setting up the control. Once the case is made that personhood is a morally superior form of care it is then difficult to justify a study where this is denied to the control group.

These interventions may fit well in clinical practice with therapists more so than nurses or family caregivers in part due to the therapeutic nature of the intervention but also as the combination of medical knowledge, and person-centred care is an attractive one. Further research will need to be carried out in different settings with more significant numbers of participants before this intervention can be recommended as the resources required in terms of time commitment and training appears high.

It was noted from the reviewed studies there were no reports of an assessment of the types of eating difficulties people with dementia were experiencing. Without an assessment of the individual's eating difficulties, an intervention plan that meets the person's needs and compensates for their difficulties cannot be made. Without individual assessment, any intervention becomes a one size fits all approach and not person-centred. Some interventions were intuitive and would seem to be reasonable actions to take to encourage most people to eat, for example, providing more assistance from an informed workforce who have time. It is disappointing that before people with dementia get enough time to eat a meal of their choice in a calm, pleasant environment, research evidence is required to confirm it is the right thing to do. Without specific interventions targeted at the individual's difficulty, results from studies reporting on interventions for groups of people are likely to have limited value (Leah, 2016).

The relationship between dementia and eating difficulties is complex, derived from the biological and psychosocial consequences of the disease. According to Kitwood (1993), if we genuinely want to understand how people are reacting to their experience of dementia; why they are not eating, we need to understand their personality and biography, as well as any physical health factors. When we have all the information necessary we can begin to understand the person, compensate for their difficulties with specific interventions, while encouraging the use of their remaining strengths.

Before we can decide on an intervention, we need to understand the nature of the problem from the position of the person with dementia rather than that of the professional/family caregivers. If through careful observation, questioning and reflection we can come to understand the person behind the eating behaviour perhaps we can then understand the intervention needed to support them through their difficulty (Leah, 2016). We could expect the family caregiver to play an important role here. However, we should not take for granted the family caregivers ability to "hold the memories" for their relative with dementia, memory of their likes, dislikes and routines while

at the same time being able to adapt to their ever-diminishing strengths and increasing difficulties to ultimately provide person-centred care. This study demonstrates how family caregivers experience difficulty coming to terms with the loss of “my rock”, making adjustments for some is simply impossible.

The current body of evidence reviewed here provides us with an essential message for family caregivers, that difficult eating behaviours experienced by their relative while distressing to watch are extremely difficult to alleviate and in no way a reflection of their ability to provide care.

### **3.9 Limitations**

The main limitation of this literature review was the diversity of the interventions and outcome measures employed in the studies making interpretation difficult. Retrieval of literature from 2004 and the classification of interventions into six intervention categories may also have contributed to a bias for grading outcomes.

### **3.10 Conclusion**

The publications included in this review focused on either an intervention aimed at improving the person’s well-being, for example providing a more homely environment (Richeson & Neil, 2002; Desai et al. 2007) assistance to eat (Simmons & Schnelle, 2004; Simmons et al. 2005), while others focused on areas of the brain affected by the dementia process; a medical model for example, space retrieval, (Lin et al. 2010, 2011) errorless learning (Wu et al. 2014, 2014a) and Montessori (Lin et al. 2011; Wan, 2014a) or education for staff (Chang & Lin, 2005; Suominen et al. 2007; Mamhidir et al. 2007). Of note, the studies did not include the completion of an assessment of the participant’s needs regarding eating difficulties nor were family caregivers involved except in 1 study (Salva et al. 2011). One could assume that a family caregiver would have a unique insight into their relative’s needs and be able to use this insider information to support their personhood at mealtimes, which if Kitwood’s theory of dementia care is correct would enhance their well-being and result in improved calorie intake. There is currently no evidence to support this.

### **3.11 Study aim**

To measure and explore the applicability and acceptability of Kitwood’s theory of person-centred care to family caregivers when their relatives with moderate/advanced dementia refuse to eat.

### **3.12 Objectives**

The purpose of this study was to measure and explore how applicable, and acceptable Kitwood’s theory of person-centred care is to family caregivers when their relatives with moderate/advanced

dementia refuse to eat. Quantitative data (functional measurements, questionnaires, and structured observations) were used to explore how the family caregiver's beliefs and values of the caregiver role affect their relative's well-being when they refuse to eat. Qualitative data (semi-structured interviews, and participant observations) were used to identify the observed themes (Table 2.1) from Kitwood's theory of personhood that explain the applicability and acceptability of his theory to family caregivers in the acute hospital setting.

### **3.12.1 Starting proposition**

Kitwood's theory of person-centred care is transferable to family caring of relatives with dementia.

### **3.12.2 Quantitative proposition**

Family caregiver's beliefs about their caring role are associated with the patient's well-being when they refuse to eat.

### **3.12.3 Qualitative proposition**

Kitwood's theory of person-centred care can be applied to the family care situation and be used to understand the type of support given by family carers to their relatives with dementia at mealtimes.

### **3.12.4 Mixed method proposition**

How do the qualitative differences between family caregiver behaviours (person-centred and non-person centred) help to explain the measured quantitative differences seen in the patient's well-being and calorie intake, physical and cognitive function scores?

# Chapter 4 Research Methodology and Design

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## 4.0 Introduction

This chapter starts with an explanation of my philosophical position within this study and how a pragmatic worldview informs it. The theoretical framework and methodological foundations are described. The use of a mixed methodology and analytic induction are introduced, and the reasoning behind their choice is justified.

### 4.1 Methodology

#### 4.1.1 Philosophical position

The starting point for this study came from my practice with the aim to improve patient care. This practice-based research is defined by Dickerson (2012) as, “an investigation that is inspired or created from one’s own daily clinical practice.” The intention is to find a solution to a clinical issue. My clinical problem relates to the different actions taken by family caregivers when their relatives in the advanced stages of dementia, refuse to eat and how these actions affect their relative’s behaviour and well-being at mealtimes.

My views of caring for people with dementia come from my nurse education, and my beliefs and values developed over my lifetime. My beliefs about dementia care have been shaped by Tom Kitwood’s theories of personhood and person-centred care along with my experiences in practice.

Adopting Kitwood’s theoretical perspective in practice means a person with dementia who refuses to eat would be supported in ways that promote their well-being by delivering optimal levels of person-centred care. Through person-centred care, in addition to their physical needs, their psychological and spiritual needs can be met and their personhood maintained and enhanced.

The psychological needs identified are:

Comfort – the feeling of trust that comes from others.

Attachment – security and finding familiarity in unusual places.

Inclusion – being involved in the lives of others.

Occupation – being involved in the processes of normal life.

Identity – what distinguishes a person from others and makes them unique.

In a situation in which a person with dementia refuses to eat, Kitwood's theory of person-centred care would expect the carer (mindful that in Kitwood's research the caregivers were professional caregivers) to address any health issues, for example, pain, infection, constipation, delirium. The caregiver would demonstrate warmth towards the person, providing a feeling of safety, security and comfort in a relaxed environment. The person would be recognised as a unique individual and treated as an equal partner in decisions about the care they receive providing a sense of acceptance. The person's life history and personality would be a part of the plan of care to support them to eat, for example providing the type of foods they like, at a time which suits them, providing the amount of physical help acceptable to them. Should the person continue to refuse to eat despite the implementation of Kitwood's person-centred care framework, the caregiver would reluctantly accept their behaviour as communicating their wishes. There is no place for threats, intimidation, imposition or invalidation when patients do not eat in Kitwood's theory. These actions are what Kitwood referred to as "a malignant social psychology", (Kitwood, 1997) which he argues result in the patient being in a state of relative ill-being.

#### **4.1.2 Positionality**

Positionality refers to the researcher's position concerning the research participants and the research setting (Bonner & Tolhurst, 2002). In particular the researcher's own beliefs, values and political opinions as well as their gender, age, educational level. This needs to be explored at the beginning of the inquiry, enabling the researcher to reflect and state their position within the concepts under investigation (Oliver, 2010). The stating of one's positionality has become increasingly important in qualitative research as a way of improving the trustworthiness of the research process and results (Patton, 2002). This level of transparency serves to inform the research study rather than to invalidate it as biased or contaminated by personal perspectives and social or political viewpoints but reflecting an acceptance that all researchers influence the research process (Drake, 2010). As a part of positionality, researchers position themselves as either "insiders" or "outsiders" to their research subject (Bonner & Tolhurst, 2002). Insider researchers investigate groups, organisations or cultures from which they belong, while outsiders, in contrast, study groups, organisations or cultures from which they do not belong. There are advantages and disadvantages to the insider and outsider positions (Bonner & Tolhurst, 2002). As an insider, the researcher has a superior understanding of the group's culture; the ability to interact naturally with the group having previously established a relationship with them. The disadvantages of being an insider are, however, greater familiarity leading to assumptions based on that previous experience and prior knowledge resulting in a loss of objectivity (DeLyser, 2002);

Bonner & Tolhurst, 2002). It can be equally difficult balancing roles of nurse and a researcher where ethical issues can cause dilemmas, for example, observing a nurse who is not responding to a patient in need (DeLyser, 2002; Bonner & Tolhurst, 2002).

In general, qualitative researchers position themselves as insiders, as this corresponds to their beliefs on how knowledge is developed, for example, constructivism, feminism, critical theory, grounded theory (Breen, 2007). These epistemologies view the research process and outcomes as a co-construction between the researcher and the participants, thereby reducing the balance of power that can exist. The participants are considered to be active informants, and importantly the researcher strives to give the participants a voice within the research thereby conducting research “with” as opposed to “on” them (Patton, 2002 pp64). Pugh et al. (2000) suggest it is possible for a researcher to balance their position within the research limiting the disadvantages and maximising the advantages, despite being opposed to underlying epistemological views and therefore remaining objective.

My position within this study was neither as an insider nor an outsider. I did not feel either quite described the position I occupied while undertaking this study, instead I felt my position was in the middle. I am a nurse in the study hospital but not on the research wards, therefore not considered by the ward team to be “one of them”, nor am I a family caregiver and therefore not considered to be “one of them” either. Breen (2007) also describes his position as “in between” in his study of bereaved relatives following road traffic accidents.

I acknowledge I undertook this research as a direct result of my clinical practice where I had on a number of occasions experienced very different reactions from relatives of patients with moderate to advanced dementia who would not eat. Of interest to me were the relatives whose behaviours appeared to be in direct conflict with that of the medical and nursing staff. Some family caregivers would threaten their relative with not revisiting them if they did not eat, while others would shout at them or force the spoon into their mouth. Some relatives expect the nurses to use the same approach which results in the breakdown of their relationships. As a nurse I understood the position the staff were in; as nurses, we do not consider the use of threats or force-feeding to be in the patient’s best interests in line with the theory of person-centred care as described by Kitwood (1997) and would constitute assault in law. I could also see Kitwood’s theory did not seem to reflect the approach taken by all family caregivers.

During the data collection phases of the study, my position as neither an insider nor an outsider proved to have advantages and disadvantages. I chose a convergent parallel mixed method research design to uncover the complexity of how applicable and acceptable Kitwood's theory of person-centred care is to family caregivers. Data was drawn from a survey, interviews with family caregivers and patients and participant and non-participant observations of mealtimes. In researching a hospital ward in which I was very familiar with the culture and routine proved to be an advantage as this afforded me easy access to appropriate participants as the ward sister, nurse specialists and speech therapists were keen to support the study by identifying potential participants. Not having experienced what it is to be a family caregiver or to help a relative to eat when they have been refusing for weeks or months gave me the advantage of being able to put the participants in a position of power as they have the expertise in this situation, not me. It was important for the voice of the family caregiver to be heard. It was important for me to ensure they felt respected for their expertise and given the opportunity to have their say about the strong emotions they experience as a family caregiver and how they view the ideas of choice, respect and dignity when their relative who lacks capacity is not eating.

However, not being a family caregiver could have been a reason why some potential participants declined to enter the study, not just because I was not a family caregiver but perhaps because I am a white British middle-class female in my 50's and a professional caregiver. These characteristics may also have affected the nature of the relationship between myself and those who did participate and how willing they were to share their personal experiences with me. An example of this is seen in one of my reflective diary entries following an early interview with Lucy (pseudonyms are used for all participants) who is of similar age and social background to me. I wrote in my reflective journal;

*"This interview felt much better than the first, perhaps because neither she nor her mother was distressed at mealtimes, so the interview was relaxed this time. I was able to build a rapport with her chatting about how much we liked to buy clothes and about our daughters. Unlike the first interview I felt able to ask more probing questions; still, a work in progress through" (my interview technique)*

I have explained why I feel that I was neither an insider nor an outsider in this study, however, regardless of the position of any qualitative researcher, it is important to remember that any position taken threatens the objectivity of the research and ultimately its trustworthiness.

The greatest threat to the trustworthiness of this study was my position regarding Kitwood's theories (1997). Like most nurses in gerontology, I have been educated on these theories and they provide the basis for the best practice guidelines, protocols and Acts from which I work, dating back to the National Service Framework for Older People (2001) through to NICE and SCIE guidelines (2007) The National Dementia Strategy (2009), and the Mental Capacity Act (2005), The Care Act (2015) and most recently The NHS Long Term Plan (2019). It was not until I conducted the literature review for this study that I realised how little data Kitwood published and how none of his studies were conducted with family caregivers. Perhaps Kitwood's theories feel intuitive to the healthcare professional and are more acceptable to us than the nihilism that existed previously. From my point of view, I practice to the best of my ability Kitwood's theory of person-centred care.

As recommended by Hammersley and Atkinson (2007 Pg. 73) Wint (2011) and Berger (2013) I used reflexivity to explicitly recognise and acknowledge my position and enhance the objectivity of the study, by being alive to my beliefs and values, how they changed during the study and the influence they could have on each element of the research project. Reflexivity accepts the researcher cannot despite best intentions put their assumptions and biases to one side and to produce findings uninfluenced by them (Hammersley & Atkinson, 2007 pp15).

Reflexivity is according to Berger (2013), "a crucial strategy in the process of generating knowledge by means of qualitative research". I engaged in a continual process of internal dialogue and critical self-reflection of my position within the research, recognising how this may affect my actions. Regular discussions with my PhD peer group and supervisors, other healthcare professionals and family caregivers not involved in my working environment or the research, along with the use of a reflective diary were extremely helpful in ensuring I kept my emotions in perspective, and not allow them to cloud my judgement.

As a result of articulating my beliefs I became aware that throughout the study I could judge the family caregivers if they used tricks or threats to encourage their relatives to eat, asking myself, "why are they treating her like this, she is clearly not going to eat, why have this battle every time"? This would threaten the trustworthiness of the study. I tried to put myself in the position of the family caregiver and used my support system to ensure I heard what was being said and did not ignore or over emphasise aspects of the narratives because of my biases.

An example of this is seen in the reflection written in my diary following the first observations and interview with a family caregiver, I wrote, *"This was one of the most uncomfortable things I have ever had to witness"*. Following the interview, I wrote, *"This man is so devoted to his wife, while it feels misguided (his forcing her to eat) I can see he is desperate to keep his wife alive. In between the harsh words and the forced feeding, he strokes her hand and constantly reminds me and her of the person she was, the things they did together, how it used to be. I hear his frustration, but I also hear his love. I can't condemn him or judge him I need to try to understand his behaviour"*. This first piece started to change my position within the theory of Kitwood, not from a nurse's perspective but from how I view family caregivers and to acknowledge how little I understood them or supported them in these situations.

Further on in the study, I wrote in my diary reflections from a day with a patient. I had spent the lunchtime trying to help her to eat, (she ate nothing, and I ended up with the yoghurt in my lap) in the evening her daughter came to help her with supper, and I observed her force the patient to eat 1/3 of her meal by holding her head in a loose headlock.

On the 21<sup>st</sup> March 2017 I wrote, *"So who is right, was I neglectful at lunchtime or was her daughter too forceful at supper time? Is the outcome of good dementia care wellbeing or adequate nutrition? Is it in the person's best interests to be forced to eat if it results in a beneficial nutritional outcome? Who should decide if it's in their best interests? Do we do what the family ask? In the eyes of the law, this is assault, and the nurse could be disciplined or even prosecuted. Times have changed. In times before MCA, best interests and before person-centred care, dignity and respect were the mainstay of all policies, statements guidelines, and Acts nurses insisted patients ate, no newspaper headlines were lambasting the nursing profession for being too educated to provide good essential care, accusing the nursing profession of neglect."*

*Do the means justify the end? Does force feeding feel more acceptable when the force-feeding achieves its desired aim, the person eats?*

*Is it in the person's best interests to force them to eat when they lack capacity? Who makes this judgement?"*

I acknowledge that my beliefs, values and experiences have influenced my understanding of the study topic, I also recognise that this understanding cannot be detached from this research as the research question and methodology have both been influenced by this understanding. As stated

by Robson (2002 Pg. 174) research in the real world is viewed through the researcher's lens and cannot despite all efforts be completely objective. However, I have tried to describe what I found rather than what I thought I was going to see, trying not to let my values and beliefs affect my judgement when selecting participants, asking interview questions and interpreting the data. My efforts to promote rigour in this study are described in 5.5.

#### **4.1.3 Pragmatic philosophical approach**

The four worldviews associated with mixed method research are positivism, constructivism, participatory and pragmatism (Creswell & Plano Clark, 2011 Pg. 41). Each one with similarities but also differences in their beliefs about the nature of reality (ontology), how knowledge is gained, (epistemology), the role of values in research (axiology), the process of research (methodology) and the language of research (rhetoric) (Creswell, 2007; Lincoln & Guba, 2000). These worldviews provide a general philosophical positioning from which a researcher can base their standpoint to guide their research. Positivism is associated with quantitative research in which researchers base their knowledge on cause and effect; establishing the truth, reductionism; involving a focus on specific variables, the observations and measures of these variables and the testing of a hypothesis. Constructivism is associated with qualitative researchers who base their knowledge on the subjective views and experiences of their research participants. These views and experiences are based on social interactions with others, which are then developed into a more comprehensive understanding of the concepts being studied rather than absolute truths. A participatory perspective is more likely to be favoured with qualitative researchers with a drive to influence social change for those in society who experience discrimination or marginalisation, for example, older people, immigrants and people with disability. Pragmatism is, "a philosophy in which the meaning of actions and beliefs is found in their consequences" (Morgan, 2014 Pg. 26). From a pragmatic point of view, all human actions are the result of past experiences and our beliefs are established as a result of the consequences of the actions we have taken. Furthermore, our experiences are situation and context specific, as no same situation with the same meaning can be recreated, there can be no such thing as truth within social science research only warranted beliefs. Warranted beliefs result from repeatedly taken actions in similar situations and experiencing the consequences of those actions. As a result, we learn the likely consequences of acting one way rather than another (Morgan, 2014 Pg. 26). As we can never experience the same situation twice, the action we take is provisional and based on our warranted beliefs about the likely consequences of that action. This can lead to changes in actions over time if the consequences of the action change, therefore over time beliefs can change. Pragmatists also

believe that the actions we take depend on socially shared worldviews. As no two people are the same or have the same experiences, their worlds will not be the same. They may share beliefs to a greater or lesser degree. The degree to which the same people share the same beliefs influences how likely they are to take similar actions and assign similar meaning to the consequences of that action. Research studies based on a pragmatic view focus on experience and how this experience affects actions and how these actions develop beliefs.

This study was interested in the actions taken by family caregivers to maintain their relative's personhood; this involved developing an understanding of how their previous experiences of family life affect their current actions. As nurses working in a hospital setting, we only observe the current actions and are unaware of any past experiences which limit our ability to make sense of the behaviour. Therefore, the best approach for this study was pragmatism as it enables a pluralistic stance of gathering all types of data that best answer the study questions (Creswell & Plano Clark, 2011 Pg. 43). The research question is best answered with the adoption of elements from each worldview to move our understanding forward particularly where the two databases are merged at the data collections, analysis and interpretation stages.

## **4.2 Research design: A mixed method convergent parallel study**

Mixed methods refer to the mixing of quantitative and qualitative data in one study (Morgan, 2014). Fundamentally, mixed methods research includes the use of a combination of quantitative and qualitative methods to enhance the quality of the findings in a way that neither could do alone (Creswell & Plano Clark, 2007 Pg. 45; Teddlie & Tashakkori, 2009; Morgan, 2014 Pg. 57).

### **4.2.1 Reason for mixing methods**

By mixing the strengths of both methods, the inherent weaknesses of each method are compensated for while enhancing each of their strengths. The study of the transferability of person-centred care to family caregivers of patient's with dementia is a complex one and therefore required a comprehensive account of the subject matter inherent in a mixed method design. According to Bryman (2006), the use of quantitative research explains the construct of social life, while qualitative research "provides a sense of process". Both quantitative and qualitative research was considered necessary to answer this study question. Indeed, the application of a mixed methods design demonstrated a link between family caregiver's nurturing scores derived from quantitative data and attachment styles derived from qualitative data and the transferability of the person-centred care framework. This illustrates how the mixed method design enhanced the completeness of the findings. Equally, through the comparison and

integration of the two datasets at the interpretation stage surprise cases were revealed, these may not have come to light with a single research methodology.

#### **4.2.2 Mixed method design**

The most common mixed method designs published in articles are the convergent parallel design, the embedded design, the exploratory sequential design and the explanatory sequential design (Creswell & Plano Clerk, 2011 Pg. 68). These four provide a basic framework to develop a design that best answers the study questions. In the convergent parallel design both quantitative and qualitative methods are used at around the same time; in one phase, to answer the same question while remaining independent. Each study is separate, producing its results that can stand up to scrutiny in their own right. Both the quantitative and qualitative arms of the study have equal priority. The results are mixed at the interpretation stage after independent analysis.

The embedded design is either an initial qualitative or quantitative design with a stand-alone alternative qualitative or quantitative study embedded within it to enhance the overall research. The embedded design is used when the researchers may want to develop an intervention, for example, to support relatives when patients develop delirium. They start with a qualitative study which includes interviews or focus groups to understand what might be a useful intervention which they develop and test out using a quantitative study.

The exploratory sequential design has two phases, starting with the collection and analysis of qualitative data which takes priority over the second phase quantitative phase. The results from the quantitative phase help to explain the qualitative findings. The explanatory sequential design also has two phases; the first is the collection and analysis of quantitative data followed by the collection and analysis of qualitative data with the first phase quantitative data taking priority over the second phase qualitative data. The qualitative results are used to explain the quantitative results. Sequential designs are used when one method can enhance the effectiveness of the other. The outcomes from the first phase inform the second phase of the study whereby the strengths of one method inputs into or follows up on the other method providing depth of understanding of the concepts under investigation. There is considerable flexibility with this design concerning priority.

There are according to Creswell & Plano Clark (2011 Pg. 64) four decisions that need to be made when choosing a mixed method design, the level of interaction, the priority of each phase, the timings of each phase and the process of mixing, these are discussed below.

#### **4.2.3 The level of interaction between the quantitative and qualitative phases**

There are two levels of interaction, independent and interactive signifying when the 2 phases of the study interact. Independent studies do not interact until the overall interpretation stage, while an interactive study can interact at any stage, for example, phase 1 quantitative survey results can be used to determine the questions used in phase 2 qualitative stage of a study. In this current study, the 2 phases remained independent until the data analysis stage with further integration taking place at the interpretation stage.

#### **4.2.4 Priority of the phase**

The priority of each phase of the study needs to be determined; here the researcher needs to decide which of the two methods qualitative or quantitative, are the most important in answering the study question. In this study equal priority was given to both methods to answer the research question.

#### **4.2.5 The timing of the phases**

The timing refers to the timing of an entire phase; the data collection and analysis (Creswell & Plano Clark, 2007 Pg.65). This can be concurrent when both strands of the study occur in one single phase, sequential with two separate phases or multiphase combination timing used in a programme of research. In this current study, the timing was concurrent as the patients would have been discharged by the time all the dyads from phase 1 had been recruited and the data collected and analysed.

#### **4.2.6 Integration of phase 1 and phase 2**

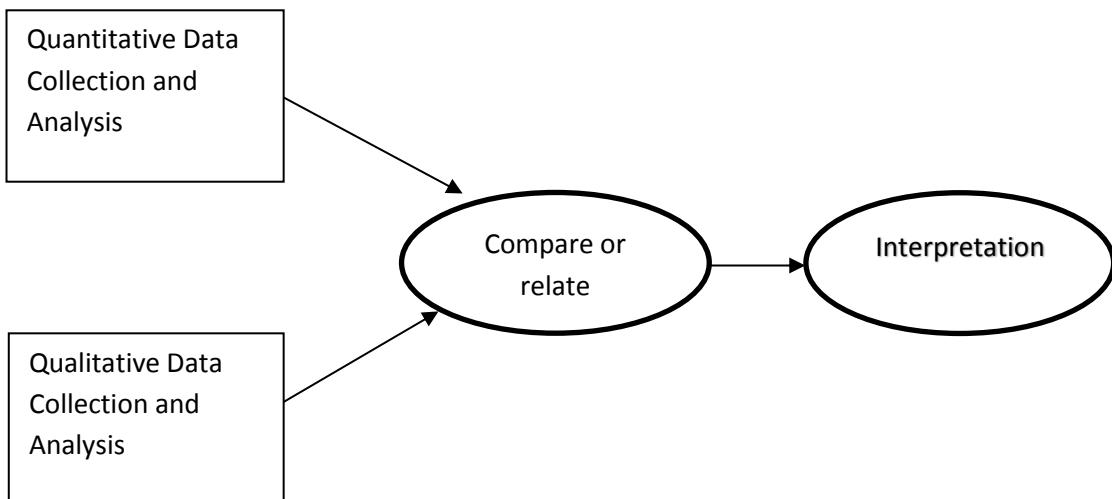
Mixing is the explicit interrelating of the studies quantitative and qualitative phase and is focused on how one method can make use of the results from the other. There are four points at which the phases can mix, interpretation, design, data collection and data analysis. In this current study, the data were mixed during data analysis, where the patient's well-being, calorie intake and cognitive function scores measured in the quantitative phase were compared between the patients receiving person-centered care and those who were not, determined in the qualitative phase. Further mixing of the data took place during the interpretation stage to facilitate conclusions about what has been learnt from drawing the two phases together. This synthesis of the mixed data forms part of the discussion in chapter 7.

The convergent parallel design is best suited to answer the study questions as it matches the study purpose, gives equal value to both sets of data, something considered important in answering the

study questions and ensuring the data was collected in a timely manner reducing the number of participants lost from phase 1.

There are some inherent difficulties with the convergent design most notably when merging the two data sets. Firstly, there is the issue of two different sample sizes demonstrating the distinct purpose of each method, generalisation vs in-depth description respectively (Morgan, 2014 Pg. 72). In this study, there were 31 dyads in the quantitative sample and nine dyads in each of the two groups in the qualitative sample. While this sample size was small as discussed in section 5.9.2.1, it did facilitate the merging of the two data sets. Secondly, the merging of two different types of data in a way that adds to the validity of the study can be a problem. The overall study proposition was written to overcome this.

**Fig 4.1 The Convergent parallel design (From Creswell & Piano Clark 2011 Pg. 69)**



#### 4.2.7 Sampling

Purposeful sampling is the most common sampling strategy employed in qualitative research and was used in this study to ensure the selection of the “right” participants; those who would have the experience of caregiving and be able to articulate its meaning in terms of person-centered care (Patton, 2002). There are a number of purposeful sampling strategies available, typical cases, homogeneity, snowball, theory-based (Patton, 2002). In this study a combination of opportunistic and confirming and disconfirming strategies was used to ensure depth of data, reduce the effect of bias, control for foreseen and unforeseen confounders and maximize efficiency and validity (Morse & Niehaus, 2009; Patton, 2002; Palinkas et al. 2013).

### **4.3 Data collection methods**

The choice of data collection methods to answer the study questions were based on the pragmatic paradigm of inquiry, “what do I want to know and what methods best help me to find the data to answer my question?” (Morgan, 2014). The data collection methods are described and justified below.

**Table 4.1 Data collection methods**

Data collection methods	Patient	Family Caregiver
Demographic data	✓	✓
Calories Food charts	✓	
Cognitive function MoCA©	✓	
Physical function FAST	✓	
Wellbeing Dementia Care Mapping	✓	
Beliefs about Caregiving questionnaire		✓
Semi-structured Interviews	✓	✓
Participant observations	✓	✓

#### **4.3.1 Demographic data**

The use of demographic data collection has a long history in capturing prior behaviour which has been effective in predicting future behaviour (Munford, 1987). Demographic data can be an important variable in research as they may offer an understanding of the individual behaviours (Connelly, 2013). In this study, the demographic data were used to describe similarities and differences between the dyads.

#### **4.3.2 Quantitative Phase 1**

Phase 1 was designed to test the proposition: Family caregiver's beliefs about their caring role affects the patient's well-being when they refuse to eat. To test this proposition, the following questions were answered:

Do patients with dementia who are in well-being have a higher calorie intake?

Do patients with dementia have higher well-being scores when their physical function (FAST) score is high?

Do patients with dementia have higher well-being scores when their cognitive function (MoCA©) score is high?

Do patients with dementia have low well-being scores when their relatives nurturing score is low?

Do patients with dementia have low-well-being scores when their relatives have low monitoring scores?

To test the above proposition, the Beliefs about Caregiving questionnaire (Phillips et al. 1998) and Dementia Care Mapping (Bradford Dementia Group, 1997) scores were collected. Cognitive and physical function were assessed using the Montreal Cognitive Assessment© score (Nasreddine et al. 2005) and Functional Assessment Staging Scale (Reisberg et al. 1988) respectively along with calorie intake taken from Trust standard food charts and calculated by the ward dietician. Patient and family caregiver's demographics were used to provide data used to describe the similarities and differences between the dyads.

#### **4.3.2.1 Montreal Cognitive Assessment© (MOCA)**

The Montreal Cognitive Assessment © (MoCA) (Nasreddine et al. 2005) is a 30-point cognitive test that takes approximately 15-20 minutes to complete and is available in 35 different languages.

Several cognitive domains are measured using the MoCA©:

- **Short term memory** using recall
- **Visuospatial** abilities using a clock drawing test and a three-dimensional cube
- **Executive functions** using an alternation task adapted from the trail-making B task, a phonemic fluency task, and a two-item verbal abstraction task
- **Attention, concentration and working memory** are measured using a sustained attention task, a serial subtraction task and digits forward and backwards
- **Language** is measured using a 3-item conformation naming task, repetition of two syntactically complex sentences
- **Orientation** to time and place
- 1 point is added to the test score if the patients have received less than 12 years of education

The MoCA© detected Mild Cognitive Impairment with 90%-96% sensitivity and specificity of 87% with 95% confidence interval and identified 100% of Alzheimer's dementia with a specificity of 87% in the validation study carried out by Nasreddine et al. in 2005, comparing favourably against the commonly used Mini-Mental State Examination (MMSE) (Folstein et al. 1975). There are still limitations with the MoCA© in that it has only been validated in Alzheimer's type dementia and dementia associated with Parkinson's disease. However, the inclusion of executive function tests does give it an advantage over the MMSE.

A score of 26 or more is considered normal, 22 mild cognitive impairment and 16 suggestive of Alzheimer's disease.

#### **4.3.2.2 Functional Assessment Staging Scale (FAST)**

The Functional Assessment Staging Scale (FAST) (Reisberg et al. 1988) observational scale describes the severity of physical function the person with dementia is experiencing, starting with normality to the most severe dementia. The scores are categorised using established cut-off points, "1" no impairment, "2-5" mild/moderate impairment and "6-7" moderately severe/severe impairment. Stages 6 and 7 are broken down into distinct levels of function, for example, 6a, improperly putting on clothes without assistance or cueing, 6b, unable to bathe properly, 6c, inability to bathe properly.

The FAST scale scores:

1 normal adult; no difficulty

2 normal older adults; subjective complaints of forgetting location of objects

3 early dementia; difficulty in traveling to new locations, decreased organisational capacity

4 mild dementia; decreased ability to perform complex tasks

5 moderate dementia; requires assistance to choose proper clothing to wear

6 moderately severe dementia; broken down into a-e (6a=6.0, 6b=6.2, 6c=6.4, 6d=6.6, 6e=6.8)

7 a-f severe dementia broken down into (7a=7.0, 7b=7.2, 7c=7.4, 7d=7.6, 7e=7.8, 7f=8)

Non-consecutive FAST deficits incur an addition score; if a subset of a stage is missing an additional score of 0.2 is given. Therefore, when assigning a score to a patient the highest level of consecutive ability is identified then additional non-consecutive deficits are noted and added to the initial score. For example, if a patient scores 6a their FAST score = 6.0. If, in addition, they have a non-consecutive deficit of urinary incontinence which scores 6d, the FAST score will be 6.2.

There are limitations to the FAST in that it has only been validated in Alzheimer's disease.

In the same way as the MOCA© the FAST scores were used in this study to describe the similarities and differences between patients and was completed on entry to the study in conjunction with the therapy and nursing teams.

#### **4.3.2.3 Calorie intake**

Calorie intake measured from food charts was the considered to be the best approximation of amount eaten. Patient weight could have been influenced by medical conditions such as heart failure or steroid dosage. There were no processes in place to weight the amount of food left on the plate one the patient

had finished eating, the setting up of a system and embedding this in to practice wold have been impossible given the current workload on the research wards. The food charts were completed well and a dietician calculated the calories eaten making it the most reliable measure.

#### **4.3.2.4 Beliefs about Caregiving Scale**

The Beliefs about Care Giving Scale (BACS) (Phillips et al. 1998) measures family caregiver's beliefs about their approach to duties within their caregiver role. The questionnaire was initially designed to identify family caregivers who were at high risk of providing poor quality care to older community-dwelling people (Phillips et al. 1998). The BACS scale consists of 28- questions on a Likert type scale instrument that has two subscales: nurturing and monitoring. The 12-item nurturing subscale focuses on the caregiver's belief that their role requires subordinating their own needs and interests for those of their relative, while the 16-point monitoring subscale focuses on the family caregiver's belief that they need to control their relative's behaviour. This measure was selected in favour of measures of burden or stress as the researcher had a sense from practice that another variable was influencing the family caregiver's behaviour above and beyond these. The forced-choice Likert format gives four response choices, strongly agree, agree, disagree and strongly disagree. Scoring is such that a, "strongly agree" response is scored 1 point, "agree" 2 points, disagree 3 and the strongly disagree response scores 4 points. Total scores are obtained by summing items within and across subscales.

According to the authors (Phillips et al. 1998), low scores on the nurturing subscale denote a caregiver's emotional enmeshment or over-involvement in their caregiving situation, while monitoring subscale denotes the caregiver's beliefs about how much they control the patient's behaviours. Low scores on the monitoring scale indicate caregiver rigidity and over-involvement, moderate scores on both subscales indicate caregivers wish to provide high-quality care while realising that they will need help in doing so.

Only one study was identified utilising the BACS (Hepburn et al. 2001) in a literature search of electronic databases Medline, CINAHL, PsychINFO, and BNI. The study demonstrated a training programme for caregivers, providing knowledge, skills and care outlook education reduced family caregiver burden and depression rates and a more positive reaction to their relatives' problem behaviour. These outcomes were associated with an increase in nurturing scores.

The reliability of the scale has been established by Hepburn et al. (2001) who reported the standard  $\alpha$  coefficient for reliability for the entire scale to be 0.83, and  $\alpha$  0.87 for nurturing subscale and  $\alpha$  0.86 for the monitoring subscale.

#### **4.3.2.5 Dementia Care Mapping**

Dementia Care Mapping (DCM) is a data collection tool based on a non-participatory observation method, designed by the Bradford Dementia Group (1997). A modified version was used in this study to observe mealtimes from the patient's perspective. To use DCM users must attend a 4-day training course run by the Bradford Dementia Group (BDG) which includes a formal examination. Only on successful completion of the course are the tools available for use. Dementia Care Mapping is used in formal care settings to identify the lived experience of the person receiving care and was designed to measure the quality of the culture of care and care delivery, specifically measuring person-centred care, how personhood is enhanced and the individual's levels of well-being (Brooker, 1998).

The psychometric properties of DCM have been examined in specific research studies which appear on the University of Bradford DCM bibliographic database (accessed November 2015). Studies from Brooker et al. (1998) and Cheoweth & Jeon (2007) demonstrated good face validity of the tool after staff in day hospitals, respite care units and continuing care facilities said they believed DCM would improve the quality of the care delivered. A review of the content validity, referring to the sampling characteristic of the tool including the time spent mapping levels marked variation across the studies on the Bradford University database ranging from 6 hours per day for 4-days (Jarrott & Bruno, 2003; Martin & Younger, 2001) to three 1-hour sessions in 1-day (Sloane et al. 2005). Edition 8 of the Dementia Care Mapping (Brooker and Surr, 2010) manual states 48-time frames of mapping is required to calculate valid individual well-being scores. However, there is no published empirical evidence stating the duration of mapping to achieve valid well-being scores (Cooke, 2012). Equally, there is a lack of consistency in the reporting of the number of people included in the mapping sessions, with some researchers reporting sample size only (Brooker et al. 1998; Chenoweth & Jeon et al. 2001; Martin & Young, 2001; Thornton et al. 2004) while others have reported mapped "50%" of the people in their settings (Ballard et al. 2001; Edelman et al. 2004; Fossey et al. 2002).

Concurrent validity has been reported as weak by Sloane et al. (2005). In their study, Sloane and colleagues compared DCM with quality of life measures reported by paid carers and residents. It seems that despite being aimed at measuring well-being from the person with dementia's point of view, the same biases may still exist as those of proxy measures (Cooke, 2012). The ability of DCM to measure well-being separately from cognition decline (construct validity) has been reported by Thornton et al. (2004), Ballard et al. (2001) Chenoweth & Jeon (2007) and Edelman et al. (2004). Ballard et al. (2001) did find a reduction in Activities of Daily Living was significantly associated

with reduced well-being, and social isolation and Chenoweth & Jeon (2007) reported an association between reduced independence measured using the Functional Assessment Staging tool (Reisberg et al. 1988) and well-being scores. Brooker & Surr (2006) have suggested that all people being mapped should have their dependency level assessed however, this raises the questions as to which measure of function should be used to establish consistency (Cooke, 2012). Importantly, some studies have identified that the external validity of DCM is weak and caution should be taken what generalising study results to a population other than that one from the same setting, i.e. across care home or hospitals (Sloane et al. 2007; Brooker et al. 1998; Edelman et al. 2004). Little has been published describing the internal consistency possible as no other tool measures the same construct (Cooke, 2012). The test-retest reliability of DCM has been shown to be moderate by Fossey et al. (2002) areas that need consideration as the tool is used in the practice development arena to demonstrate change over time in the quality of care and culture. Inter-rater reliability is an important aspect of the DCM tool as it is common to employ more than one mapper in any given project (Cooke, 2012) due to the intensity of the coding system. A .70 agreement between mappers is recommended in clinical practice and .80 in research studies and should be determined before conducting the mapping. In studies with experienced mappers inter-rater reliability levels were consistently high, .70 (Brooker & Surr, 2006) and Innes & Surr (2001), .85 (Edelman et al. 2004). However, in Thornton et al. (2004) a kappa coefficient of .10 was reported for well-being scores of +5 and -47 for +3 well-being scores. It is not clear from the study how experienced the mappers were, however, with the acknowledged complexity of the coding system involved in mapping those undertaking it must maintain their skills and continue to check their inter-rater reliability if the results are to be reliable.

At the end of each five-minute timeframe two types of codes are recorded, 1) Behavioural Category Codes and 2) Mood and Engagement values (Table 4.2) The Behavioural Category Code (BCC) describe 23 different domains of participant behaviour that can occur; these include, for example, reminiscences, walking, a leisure activity. The activity that the patient spends the majority of the 5-minute timeframe in is recorded. The mood and engagement values reflect the patient's relative mood and engagement in the activity, which over the course of a whole map provides a general picture of the person's relative range and level of well or ill-being (WIB). When deciding on the mood and engagement value to be entered for each timeframe both dimensions must be taken into account as summarised in Table 4.2.

**Table 4.2 Summary of Mood and Engagement scores**

Mood	ME Value	Engagement
Very happy, cheerful. Very high positive mood	+5	Very absorbed, deeply engrossed/engaged
Content, happy, relaxed Considerable positive mood	+3	Concentrating but distractible Considerable engagement
Neutral Absence of overt signs of positive or negative mood	+1	Alert and focussed on surroundings. Brief or intermittent engagement
Small signs of negative mood	-1	Withdrawn and out of contact
Considerable signs of negative mood	-3	
Very distressed. Very great signs of negative mood	-5	

A score of either +5, +3, +1, -1, -3, -5 is assigned for each 5-minute timeframe, where +5 is the best mood and engagement a person can achieve (well-being) while -5 (ill-being) is the worst and is a situation that is very difficult to watch without intervention. The mood and engagement scores are then calculated over the mapping period to arrive at an individual WIB score, providing an index of relative well-being for each patient. Patients are considered to be in well-being when their total well score is >1, and ill-being is said to exist if this score is <1.

Dementia Care Mapping also involves observing for any personal enhancers (PE) and personal detractors (PD) which are recorded as narrative descriptions. The personal enhancers in DCM are examples according to Kitwood (1997) of person-centred care that enhances personhood and wellbeing for instance, through meeting the person's need for comfort, identity, attachment, occupation and inclusion with actions that are warm and respectful above what would be expected. Personal detractors in contrast are considered by Kitwood (1997) not to support personhood and are evident through displays of intimidation, ignoring or mockery. The data produced can under DCM rules be presented as a numerical summary table showing the number of times a PE or PD occurred and in which category, i.e. comfort or identity. In this study, however, it was difficult to determine separate instances during the mealtimes as the majority of the activity was an example of personhood being maintained or not. For this reason, the PE and PD underwent qualitative data analysis.

Other tools have been designed and used to measure person-centred care (Noland et al. 2004) however; DCM was chosen for this study as it has been widely used and subject to continued review and development (Cooke, 2012).

## **4.4 Qualitative Phase 2**

Phase 2 of the study was designed to gain a greater depth of understanding of the meaning of care for family caregivers and how this influences the observed nutritional behaviour of their relatives. Participant observation was used as a means of observing the situation in a real setting and how the situation “felt” to the researcher. Semi-structured interviews with the family caregivers were also used to provide an opportunity to listen to their perspective and interpretation of their actions, their relative’s reactions and their warranted beliefs about those actions. The intention was to “interview” patients to hear their voice, gain their perspective on their eating and mealtimes. Unfortunately, the patients recruited to the study were unable to communicate verbally at this level. Therefore, only one patient was “interviewed”.

### **4.4.1 Rational for Participatory observations**

The formal observations carried out using DCM can provide highly reliable and valid data (Brooker, 2006; Woolley et al. 2008) however, there is a risk of losing complexity and completeness when compared with more informal observation (Robson, 2002 Pg. 313). Byrne (2000) acknowledges that participant observation allows the researcher to gain a greater understanding of the situation being studied from the perspective of those involved. Gray (2013) also recognises the importance of the immediacy of the data and how it helps to develop the relationship between the researcher and the participant. It has been well documented that one of the weaknesses of observation is that those being watched behave differently causing concerns around validity (Bernard, 2000 Pg. 334). Observations are also sensitive to bias as they rely on the observer’s perceptions, judgements and interpretations. However, when the researcher is involved in the action as in participant observation, they are less likely to misunderstand the situation, reducing bias (Graneheim et al. 2001). For these reasons, participatory observations of mealtimes were carried out.

### **4.4.2 Rationale for Semi-structured Interviews**

Face-to-face semi-structured interviews were chosen as a second data collection method in phase 2, as this provided an opportunity to verify the researcher interpretations of the behaviours seen during the participatory observations. Interviews allow the researcher the opportunity to engage with participants on a one-to-one basis either face-to-face or via the telephone. Telephone interviews have an advantage when there is a geographical distance between the researcher and participant and when time and resources are limited. However, the interaction via the telephone can be more impersonal in comparison to a face-to-face interview, particularly if they have not met before.

Face-to-face interviews allow for an environment and relationship to be established by the researcher fostering a relaxed atmosphere conducive to obtaining rich data. Furthermore, the face-to-face interview enables the researcher to note the participant's body language and non-verbal cues.

There is a risk with face-to-face interviews of the participant providing responses they think the researcher wants to hear or shows them in a "better" light, rather than being open and honest. This can be mitigated with the assurance of anonymity and confidentiality and the development of an open relationship prior to the interview.

Focus groups were considered and discounted as a data collection method as they are, "used to gain insights into the attitudes of groups" (Clarke and Dawson, 2005 Pg. 77), while this study was concerned with the behaviours of individuals.

The face-to-face interview was chosen over the use of telephone interviews as one form of qualitative data collection in phase 2, as the topic discussed was considered sensitive and complex requiring a personal and supportive interaction. Furthermore, there were no geographic issues as both researcher and participant were in the hospital.

**Table 4.3 Strengths of Methods used in the study**

Methods	Strength	Data collection methods used
Quantitative	<p>Quantitative methods Survey Interviewing &amp; Structures non-participatory observation</p> <ul style="list-style-type: none"> <li>• Can test hypotheses across a wide variety of variables. (Deduction)</li> <li>• Uses standardised procedures for questions and answers (Objectivity)</li> <li>• Can apply results to a wider range of people or setting (generality)</li> </ul>	<p>Beliefs about Care Giving Score (Phillips et al. 1998) Dementia Care Mapping – (BDG, 1997) FAST (Reisberg et al. 1988) MoCA© (Nasreddine et al. 2005) Calories</p>
Qualitative	<p>Participant</p> <ul style="list-style-type: none"> <li>• Starts with observations as a basis for generating theory (induction)</li> <li>• Concentrates on the meaning of observations (Subjectivity)</li> <li>• Studies events as they occur in the natural setting (Context)</li> </ul> <p>Qualitative interviewing</p> <ul style="list-style-type: none"> <li>• Allows interview topics to emerge during conversation (Induction)</li> <li>• Listens to others' interpretation and perspectives (Subjectivity)</li> <li>• Can collect depth on a range of factors related to a topic</li> </ul> <p>From Morgan 2014(a) Pg. 51</p>	<p>Observations during mealtimes Semi-structured interviews</p>

## 4.5 Participants

There are numerous definitions of family caregiver. For clarity, the use of the phrase family caregiver in this study refers to people who provide direct or indirect care, for example, organise or oversee the care, for an adult with dementia whom they are connected to biologically, emotionally or legally. In this study, the patient and family caregiver as a couple is referred to as a dyad.

### 4.5.1 Sample size

Qualitative and quantitative research methods have different methods of determining sample size as a result of their differing views of the world. Quantitative methodologists strive to find the "truth" about the world and make generalisations about populations, in this way they use statistical data to ensure an adequate sample size to avoid biases in the data produced. As this

study is primarily a qualitative study, the goal was not to discover absolute truth but to subjectively understand the concept under investigation.

The gold standard for ensuring an adequate sample size in qualitative studies is described concerning data saturation. Data saturation is said to exist at the point at which no new information or themes are observed in the data (Guest et al. 2006).

However, the choice of method for analysing the qualitative data in this study is analytic induction (4.6.2.1), where the exclusion of further surprise cases determines the sample size.

Surprise case analysis is an analytical procedure that refines propositions until they account for all known cases without exception (Robson 2002). The process involves searching for cases or instances within the population under study, which contradicts the current proposition. If no contradictory cases are found after extensive searching, the proposition is considered increasingly credible because no evidence has been found to oppose it. If such evidence is detected, the proposition is modified to accommodate the new data associated with the surprise cases. This process continues until the proposition has been changed to accommodate all surprise cases and no new surprise cases can be found. On completion of this extensive process, the resulting qualitative report is considered credible (Maxwell 2004).

## 4.6 Data Analysis

In a mixed method design, the data set from each phase is analysed using the appropriate principles for each methodology and are described separately below.

### 4.6.1 Phase 1

Quantitative data analysis is deductive in nature meaning it sets out to prove or disprove a hypothesis or to test a theory. It is orientated to find statistical generalisations and truths reflected in the collection of data in terms of numbers. There are established rules that need to be followed which ensure transparency of the findings and allow other researchers to check and replicate the results.

Quantitative analysis of the study data was undertaken at the end of the data collection period and consisted firstly of an overview of the demographic data using numbers and percentages (5.2.1). Normally distributed continuous variables are described using means  $\pm$  SD. Ordinal data will be described using range, mean + standard deviations. Means and approximated SD's are presented and used to compare the similarities between the two groups; patients' in well-being and ill-being and their calorie intake, physical and cognitive function and their family caregiver

nurturing and monitoring scores. This was followed by the use of the most appropriate statistical test to test each hypothesis. (5.4.1).

#### **4.6.2 Phase 2**

Qualitative data analysis in contrast to quantitative data involves making sense of, interpreting and theorising data. It is both an art and a science, and it is undertaken to utilise a variety of procedures that facilitate working backwards and forwards between data and ideas. It is an iterative and reflexive process (Schwandt, 2007).

In this section analytic induction will be reviewed and compared with other forms of qualitative data analysis, and the decision to use analytic induction for the qualitative data analysis in this study will be justified.

##### **4.6.2.1 Analytic Induction**

###### **4.6.2.2 Definition**

Analytic induction “is a strategy for analysing qualitative data based on the assumptions that the researcher should formulate propositions that apply to all instances (or cases) of the problem under analysis. After an initial examination of the data, the inquirer develops a working proposition to explain the data. One example, instance episode, or case in the data corpus is examined to determine whether the hypothesis fits the facts of that instance. If the proposition does not fit the facts, the proposition is revised or the phenomenon to be explained is redefined to exclude that instance. An instance that does not fit the hypothesis is called a surprise or negative case. The intent here is to use surprise instances for continuous refinement of the proposition until all instances can be satisfactorily explained” (Schwandt 2007).

###### **4.6.2.3 Induction and deduction**

Induction is a process whereby the researcher reflects on their data regarding their experiences of the social phenomena under investigation and attempts to formulate explanations, abstract rules, or guiding principles which can be generalised to explain and predict new or similar experiences (Johnson, 2004 Pg165). Where induction starts with a research question, deduction usually begins with a hypothesis/theory which is either proven or disproven using statistical measures when inferring the characteristic of a finite population from data about a sample drawn from it, with specific levels of confidence and probability focusing on causation.

Induction is commonly focused on a new phenomenon or a different perspective of a phenomenon with no obligation to determine causality (Robinson, 1951). There are no specific

rules, but generally, deduction is seen in quantitative studies and induction in qualitative studies. The arguments for an inductive approach to social science centre's firstly on the idea that being inductively grounded in systematic empirical research ensures the theory building and data collection are interlinked (Wiseman, 1978) making it more plausible and accessible (Glaser & Strauss, 1967). Secondly, that deduction is objective, general and external in its frame of reference which is imposed upon the social behaviour or social phenomena to explain it despite the social phenomena under inquiry having a subjective component (Johnson, 2004 Pg. 167). Social science research, Johnson argues, must study the phenomena in terms of its internal elements and function from a posteriori understanding rather than in terms of any existing, priori external scheme (Johnson, 2004, Pg. 167).

#### **4.6.2.4 Background**

Znaniecki (1934) (cited in Robinson, 1951) developed the method of analytic induction in contrast to the enumerative statistical methods of studying relationships with correlations as a method of developing and importantly testing social science theory. Analytic induction differs from deduction in that testing of a theory is neither the beginning nor always the endpoint in the process of scientific research (Hicks, 1994). Znaniecki (1934) maintains that analytic induction is a method of data analysis that a) gives universal statements b) gives exhaustive knowledge relieving the need for further study and c) leads to genuinely causal laws. However, analytic induction as described by Znaniecki (1934) does not according to Robinson (1951) achieve these statements. In his influential critique of Znaniecki's method Robinson starts by acknowledging the strength of reformulating the studies proposition in analytic induction, stating this is something that has long been practised in scientific studies but not necessarily explicitly stated. The strength according to Robinson of reformulating the proposition comes from what Dubs (1930) (cited in Robinson 1951) calls, "the act of discovery", the fact that a proposition is wrong can lead to the development of a more accurate one. This method is contrary to the conventional proposition testing approaches whereby the data fit the proposition. Robinson (1951) also argues that the reformulation of the proposition relies on the analysis of deviant cases which he says is again simply a different way of saying what enumerative induction described as, "looking for new variables correlated with the residuals, so as to include it in a new multivariable analysis" (Robinson, 1951). This reformulation in analytic induction results in the ability of the researcher to "limit the universal", limiting the scope of the final explanatory hypotheses, thereby ensuring causal homogeneity in the cases to be explained. Cressy (1950) (cited in Robinson, 1951) provides an example of this in his study of

people who had been convicted of embezzlement. Here Cressy (1950) excluded those who had taken up their position of trust within the organisation intent on committing embezzlement, while including those who had taken up their position of trust without intent to commit embezzlement. Importantly, Robinson (1951) identified that as described by Znaniecki (1934), analytic induction only seeks to find the conditions necessary for the phenomenon to be proved and not the conditions sufficient for its presence, (necessary = what must be present if the outcome is to occur, sufficient = anything that if present ensures that the outcome will occur, though it need not be present for the outcome to occur). The inclusion of surprise cases according to Robinson, also used in scientific studies, would provide an adequate explanation for the phenomenon as seen in the well-known examples of analytic induction conducted by Lindesmith (1947) and Cressy (1950) (cited in Robinson, 1951). Lindesmith (1947) included in his study of drug addicts', non-drug addicts, confirming that addiction did not occur when the phenomenon was present. Maxwell (2004) argues that analytic thoroughness achieved by eliminating exceptions and revisiting the proposition preclude the need for statistical tests once the surprise cases have been removed despite the small numbers used. However, Robinson (1951) agrees with Katz (1983) in terms of applying additional statistical tests once the analytic induction process has been completed to refine the final phenomena. According to Robinson's critique, the steps of analytic induction are described as:

- The phenomena are specified in the form of a research question and a tentative proposition of the phenomenon.
- Data are then collected and analysed to determine if the proposition fits with the data or not.
- Should the proposition not fit the data, the proposition is reformulated, further data are collected and analysed to determine if the reformulated proposition now fits the data.
- The researcher actively seeks out surprise cases to test the proposition and reformulate it as necessary.
- Further data are then collected looking for deviants to help refine the proposition, and this continues with further refinement of the proposition until the proposition is proven and the theory developed.
- Confidence in the final proposition comes when the number of situations fitting the proposition increases and there are no further surprise cases (Robson, 2002 Pg. 322; Hemmersley & Atkinson, 2007 Pg.186).

There are a number of steps in this outline of analytic induction common to other data analysis methods used in qualitative research as set out below (Miles & Huberman, 1994 Pg. 9)

- Giving codes to the initial set of materials obtained from observations, interview, documentary analysis

- Adding comments, reflections etc. (commonly referred to as “memos”).
- Going through the documents trying to identify similar phrases, patterns, themes, relationship sequences, differences between sub-groups i.e. denial, rejection of family support.
- Taking these patterns and themes out to the field to help focus the next wave of data collection
- Gradually elaborating a small set of generalisations that cover the consistencies you discern in the data.
- Linking these generalisations to a formal body of knowledge in the form of constructs or theories i.e. Kitwood’s (1997) theory of person-centred care and Bowlby’s (1969) attachment theory.

Glaser and Strauss (1967) made a distinction between grounded theory and analytical induction on the grounds that analytic induction is principally interested in testing causal propositions starting with a theory. While grounded theory is concerned with establishing a threshold of, “plausibility to suggest categories, properties and hypothesis about general problems” (Glaser and Strauss, 1967 Pg. 104). To this end, grounded theory is concerned with the saturation of the data which is said to exist at the point at which no new information or themes are observed in the data which may not include all the data collected (Glaser & Strauss, Pg. 104 1967). In contrast, analytic induction focuses on the exclusion of surprise cases and includes the use of all the available information. A second important distinction between GT and AI is that AI enables and promotes the use of previous research/theory to shape data analysis. This is explicitly excluded in GT and in most descriptions of qualitative data analysis. The inclusion of previous theory / findings could be deemed deductive even if the method of analysis is qualitative.

The notion of moving from thick description and emphasizing data to theoretical explanations to discover causation can result in the researcher having to make a dimensional shift in thinking, from the subjective etic position during the data collection and formation of categories phase to that of external objective inquirer (Johnson, Pg. 150 2004). Weick (1995) however, sees this “oscillation” between these different philosophies as essential in helping to make sense of everyday actions people take. Yet the analytic induction presumption that deterministic laws govern social phenomena, is as a concept often rejected by qualitative researchers claiming it denies people the capacity to make decisions to act (Hammersley and Atkinson, 2007 Pg. 188) to learn and change

the way they act as seen in a pragmatic worldview. It can be useful to think about social class as an example. Deductive quantitative research consistently demonstrates how life chances are mediated by social class, qualitative researchers would insist on a subjective element, if someone argues they are not working class despite all objective data contradicting this, who is correct? Can you label someone working class if they say they are not? And vice versa, someone might claim to be working class when objective data suggests otherwise. Qualitative researchers will highlight those who meet the criteria to be described as working class but who do not experience the poor life chances as the exception that discredits quantitative research.

Katz (1983) holds a moderate view, believing that success should not be measured in terms of causation but to the degree to which changes and hypotheses explain the phenomenon with the least number of unexplained surprise cases as possible, which seems very similar to the “plausibility” goal suggested by Glaser and Strauss (1967 Pg. 104).

#### **4.6.2.5 Methodology Rational**

The use of a mixed methodology and analytic induction in this study provided an appropriate way to gather unique data.

The mixed method convergent parallel design facilitated a complete understanding of the topic giving equal value to both sets of data. The quantitative data measured the hard facts; well-being scores, beliefs and values of being a family caregiver, calorie intake and function, while, the qualitative data described dyad behaviours and feelings. According to (Creswell, 2014 Pg. 37), “it allows for multiple pictures of the same problem from several angles”. This was considered important if answers were to be provided that would satisfy the different perspectives on the study topic of both healthcare professionals and family caregivers as witnessed in practice, within a pre-defined legal and evidenced based context.

The ability to test and develop theories with analytic induction was of value in this thesis as the concept of interest was Kitwood’s established theory of person-centred care and its transferability to family caregivers. As discussed in chapter 2 Kitwood’s theory of person-centred care needs further development specifically in terms of family caregivers and their meaning of caregiving. The traditional inductive approaches used in qualitative research, for example Grounded Theory (Glaser and Strauss, 1967) and phenomenology (Matua, 2014) demand the researcher enter the data collection and analysis phase of the study with a head clear from any existing theories of the concepts under study, being led only by the raw data and the researchers “theoretical sensitivity” (Timmermans & Tavory, 2012). This theoretical sensitivity means having a broad understanding of

the concepts under study and those surrounding it but not being influenced by them, thereby freeing the researcher from theoretical bias. In this way, new theories are developed without preconceptions, prejudging the data or making the data fit the existing theory.

There is an inherent limitation with these traditional qualitative methodologies in building a cumulative body of evidence. According to Charmaz (2008), Clarke (2005), Johnson (2004 Pg. 151) and Matua et al (2014) grounded theory, ethnographic fieldwork, and phenomenology have led to a lack of new theories being developed and an increase in the number of studies that are simply describing experiences. Timmermans & Tavory (2012) agree, arguing that by ignoring existing theory, the development of theory is stifled as is the development of a cumulative knowledge base. Hammersley and Atkinson (2007 Pg. 186) state that, “while ethnographic researchers do not have an obligation to engage in systematic theory testing..... it should be said that theories do need testing and that many theoretical models developed in ethnographic research still await such treatment”. Timmermans & Tavory (2012) go on to advocate for an abductive analytic process that involves making preliminary propositions based on existing theories and the data from the current enquiry. Peirce (1934, Pg. 170) (cited in Reichertz, 2009) was one of the first to propose this concept stating the first step in a methodological process of scientific inquiry before either deduction or induction is abduction. Abduction according to Peirce is, “the process of forming an explanatory hypothesis. It is the only logical operation which introduces any new ideas; for induction does nothing but determine a value, and deduction merely involves the necessary consequences of a pure hypothesis” (Peirce, 1934 Pg. 171) (cited in Reichertz, 2009). Therefore, to disregard Kitwood’s well-established theory in this study would amount to missing an opportunity to advance Kitwood and colleagues’ work and to the building of a cumulative professional knowledge base.

There was a threat to the studies validity posed by the potential dominance of the theory over the voice of the participants. There was a risk of the findings being determined by the initial focus of the study, in this case, Kitwood’s theory of person-centered care, which may have impeded the range of experiences bought to light during the research. However, it is the strength of AI in testing the applicability and acceptability of established knowledge to a new situation, with family caregivers, which makes it an appropriate analytic technique for this study.

As discussed in section 4.1.3 this study was based on a pragmatic world view, a view in which methods and theories are chosen that best answer a practical problem. The pragmatic inquirer does not seek absolute truths but warranted beliefs, which result from repeatedly taken actions in

similar situations and experiencing the consequences of those actions (Morgan 2014 Pg. 26) Furthermore, a pragmatic view point contextualises scientific inquiry within a social, historical and political world, and appraises findings in terms of their practical, social and moral value (Giacobbi et al 2005). James in 1907 (cited in Giacobbi et al 2005, Pg. 22) argues, “Theories thus become instruments, not answers to enigmas in which we can rest....Pragmatism unstiffens all our theories, limbers them up and sets each one to work”.

#### **4.6.2.6 Summary of AI**

The use of a mixed method design shaped the study findings as is summarised in Table 4.3. Collecting observational data using Dementia Care Mapping both a quantitative and qualitative tool (BDG 1997) allowed for the separation of the family caregivers in to two groups, person centred (PCC) and non-person centred (NPCC). The creation of the two groups enabled quantitative analysis of the data and the identification of the surprise cases in the NPCC group. Without the use of AI the researcher would not have been sensitised to search for non-confirming cases (surprise cases) and to test the starting proposition.

The underlying theoretical focus on personalised care derived from Kitwood informed the starting proposition for the research and for AI. The starting proposition informed the decision to categorise the sample into two groups and shaped the analysis and interpretation of the qualitative data. This is justified by the pragmatic philosophical perspective justified by the research question. The study findings may have been very different had there not been a starting proposition, and Kitwood’s theory had not been used to divide the family caregivers into two groups as in thematic analysis for example.

The pragmatic philosophical approach to this study in which Kitwood’s theory is tested means the use of analytic induction to analyse the qualitative data was entirely appropriate as the aim was not to develop a new theory but to examine family caregiver’s behaviour through Kitwood’s lens. This methodology provided an innovative way of gathering and analysing unique data.

#### **4.6.3 Integrating during analysis**

As discussed in section 4.2.3 the data from phase 1 and phase 2 were integrated at the analysis phase of the study and consist of comparisons in well-being scores, calorie intake and cognitive function scores between the patients who received person-centred care from their relative and those who did not. Means and approximated SD’s are presented and used to compare the

similarities between the two groups, this was followed by the use of the most appropriate statistic to test each hypothesis. (5.4.3.1).

## **4.7 Recruitment**

In-patient dyads under the care of geriatric consultants were recruited once considered medically stable. Patients with moderate/advanced dementia (FAST score 6+) and their family caregivers were identified by ward sisters, their deputies or clinical nurse specialists as suitable for entry into the study. They made the initial contact with the dyad regarding entry into the study. For those that showed an interest an information leaflet was given to both patient (if appropriate) and family caregiver (Appendix 9 & 10).

### **4.7.1 Inclusion Criteria for participants**

#### **4.7.1.2 Patients Inclusion criteria**

Patients with dementia according to the DSM4 revised criteria (American Psychiatric Association, 1994)

Able to give verbal consent or implied consent

Personal consultee can provide assent

Caregiver connected by blood, legally or emotionally

Patient likely to be on the ward for a minimum of 1 week

#### **4.7.1.3 Patient Exclusion criteria**

Patients who indicate either verbally or non-verbally they do not wish to participate at any time during the study.

Assent cannot be gained from the family caregiver.

The caregiver is not related to the patient by blood or marriage nor emotionally connected.

Patients considered to be reaching the end of their life by the family caregiver or healthcare staff.

Family caregivers who are non-English speaking.

Unlikely to be on the ward for one week.

Family caregiver not consenting to take part in the study.

#### **4.7.1.4. Family Caregiver Inclusion criteria**

Connected to the patient by blood, legally or emotionally

Visits patient for a least one meal per day

Command of English enough to understand the aims and requirements of the study (can take part in observation arm only)

#### **4.7.1.5 Family Caregiver Exclusion criteria**

Caregiver not connected by blood, legally or emotionally

No able to visit for at least one meal a day

Patient not consenting to take part in the study

Non-English speaking

#### **4.7.2 Explanation of exclusion of non-English speaking family caregivers**

Due to the nature of the qualitative strand of the study observation and interview, it was not possible to include patients if they or their family caregiver did not speak English. During observations, it is the dialogue between the dyad that is being observed, recorded and analysed along with their actions.

The use of interpreters for this group of family caregivers would set up bias, as the events observed by the interpreter would “reach” the researcher through the interpreter who would add their meaning to the event witnessed.

Larger print leaflets were available for both patients and family caregivers who needed them, and it was ensured the patients had their glasses and hearing aids to make sure they had the best opportunity of understanding the research aims and what would be involved.

### **4.8 Ethical issues**

Throughout the planning phase of the study ethical issues were addressed to fulfil the requirements of the Research Governance Framework for Health and Social Care (DoH, 2005). The study was registered with the Health Research Authority in July 2015, and the completed forms were submitted to the NRES committee at Queens Square London with the research protocol in September 2015. The researcher and supervisor attended the NRES meeting in September 2015, and the ethical approval was given (Appendix 25).

A completed Trust research registration form was completed and submitted for approval to the Research and Development department of the research hospital with supporting signatures from the lead consultant and manager of the division, the NRES letter and protocol, peer review, approval was confirmed. The approval letter from NRES was also submitted to the university ethics committee, and approval was received.

#### **4.8.1 Dyad consent**

It is acknowledged that the patients will have dementia or delirium superimposed on their dementia and may not be able to give informed consent. Therefore, the procedure for obtaining

informed consent was developed to comply with capacity legislation governing England and Wales (Mental Capacity Act 2005, Sections 30-34)

Patients and family caregivers who were identified as potential participants who fit the inclusion criteria were invited to join the study. Patients and family caregivers were informed of the wards participation in this project which was designed to develop an understanding of how family caregivers support them to eat and drink by the ward sisters, deputies or clinical nurse specialists.

The family caregiver was given an information leaflet, and the patients were also given a simple information sheet if appropriate, informing them of the study (Appendix 9 & 10). This included how their information will be stored, that it will be confidential and anonymised, what to do if they wish to withdraw from the study at any time and how the results will be used. Potential participants were informed that they do not have to decide immediately as they had 24 hours to determine if they want to participate and time to discuss the study further if they wish, with relatives/carer or research staff. Potential participants were also informed that if they decide not to take part that this will not adversely affect their care in any way. Patients who did not agree were not approached further. Both patient and family caregiver needed to consent to participate in the study, should one not have wished to take part then neither were included in the study.

When the patient and family caregiver both agreed to participate in the study the family caregiver was asked to read and sign a consent form (Appendix 12). A brief structured assessment of the patients' capacity to consent based on the criteria outlined in the Mental Capacity Act 2005 was conducted. If the patient could consent a signed informed consent form was obtained (Appendix 13). If they could not consent their next of kin (who may or may not be their family caregiver) was asked to assent for them; they then acted as a "personal consultee" (Appendix 14). However, patients who could not decide to join the study in the legal sense were not excluded from the consent process as this would be an affront to their dignity and personhood. This research project studied the impact of actions of others on the personhood of people with dementia. Therefore, it was essential the study, and the consent process upheld the patient's personhood. If people with dementia are to have their due, every effort should be made to hear their voice. Dewing (2002) argues that current approaches to determining consent rely too heavily on cognitive ability and recommends a model of consent that considers the capacity of people with dementia in situation-specific context, building on their remaining strengths rather than highlighting their weaknesses. In this study, consent was obtained from patients in an ongoing manner based on their verbal

language and also their non-verbal and behaviour cues; continuous consent (Dewing, 2002). The family caregivers were actively involved in this consent process, and their contribution valued because they provided additional insights into the experience and wishes of the patient. If the family caregiver refused to assent to the patient taking part in the consent process or study this was respected and no further attempt to enrol the patient or family took place. In no way did this decision affect the care they received on the ward. Similarly, if a patient lacked capacity demonstrated verbally or non-verbally, or through their behaviour that they do want to take part in the study, this was respected, and they were not included in the study, regardless of the next of kin's wishes.

If the personal consultee was available on the ward, they were approached by the ward sister or her deputy or nurse specialist and given verbal information and the written information sheet about the study. They were encouraged to consider the person's prior wishes or thoughts regarding taking part in research and they would be given 24-hours to consider this. If the consultee agreed I obtained written consent of this.

Where the professional consultee was not the family caregiver, providing day-to-day care, the family caregiver was also asked to consent to be included in the study.

If the personal consultee was not available on the ward (i.e. lives a distance from the hospital or is not able to visit) we contacted them by telephone and explained in detail the nature and purpose of the study. We asked them to consider the person's prior wishes or thoughts regarding taking part in the research.

When this agreement was given, it was documented in the medical notes, and they were sent the study information sheet and the consultee assent form in the post. The person was included in the study from this point of verbal assent. If subsequently, after ten days, the personal consultee had not returned the signed advice form or changed their decision, the person was withdrawn from the study and any data that had been collected was destroyed.

Had the personal consultee not given verbal assent over the telephone, they would not be approached again, and the patient would not be entered into the study.

If a) no friend or next of kin that could act as personal consultee was documented in the clinical notes, or, b) after three attempts at telephone contact over 48 hours, we were unable to contact a

personal consultee, they were not approached again, and the patient was not entered into the study.

If the patient's "personal" consultee indicated at any time during the study that they did not wish to participate, or they did not wish for the patient to participate further, they were immediately withdrawn from the research, and all data that had been collected was destroyed.

This process for obtaining consent has been developed and peer-reviewed by a multidisciplinary team of researchers and clinicians experienced in dementia and by members of the Alzheimer's Society Quality Research in Dementia group (QRD) which is comprised of people with dementia, current and former carers (Scott et al. 2011; DoH, 2008).

#### **4.8.2 Non-study participants.**

The ward has a full complement of healthcare professionals and domestic staff who were all informed of the study and what to expect. An information sheet to reiterate the information was provided and they had the opportunity to ask questions.

Posters were displayed on the wards two weeks before the start of the study and leaflets were given to patients and visitors not involved in the research (Appendix 15 & 16). The information included information about the research and how to contact the researcher if they had any questions or concerns.

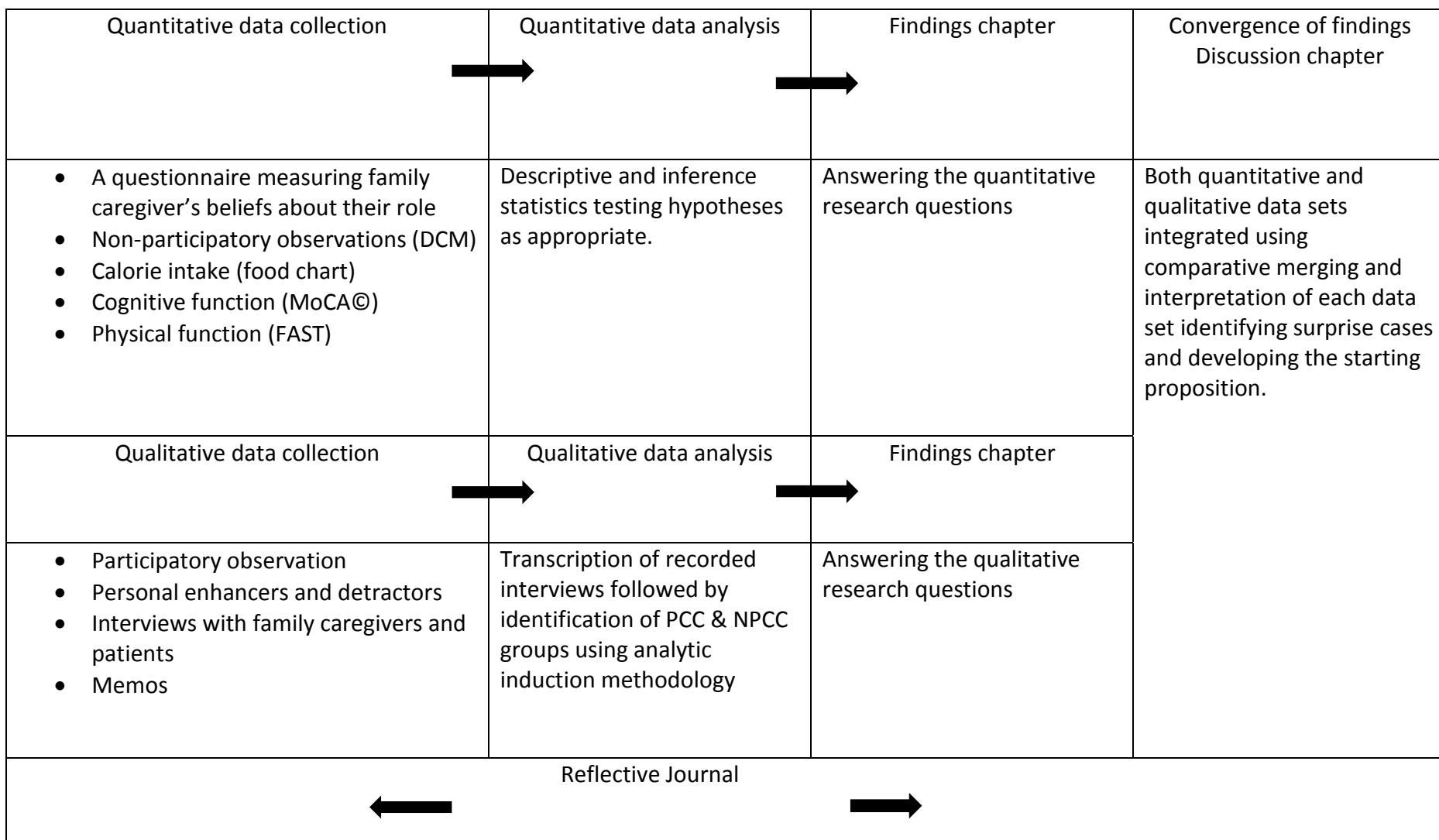


Table 4.4 Summary representation of the convergent parallel mixed methods design

# Chapter 5 Methods

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## 5.0 Introduction

The previous chapter explained the pragmatic approach to this study, justified a mixed method approach and detailed the data collection and analytical methods used in each of the 2 phases.

Chapter 5 goes on to describe how participants were selected for the study, how the data collection tools were used and how that data was analysed. Demographic data are also presented.

In phase 1 the following methods were used:

- Dementia Care Mapping (BDG, 2005) to measure the patient's well-being.
- Beliefs about Caregiving Scale questionnaire (Phillips et al. 1998) measuring family caregivers' tendencies towards nurturing or monitoring.
- Patient's food chart to measure calorie intake.
- Functional Assessment Staging Test (FAST) (Reisberg et al. 1988) a measure of physical function.
- Montreal Cognition Assessment<sup>©</sup> (MoCA) (Nasreddine et al. 2005) a measure of cognitive function.

Thirty-one dyads were recruited to phase 1 of the study. Thirty complete data sets were collected.

A sample of eighteen dyads from phase 1 took part in phase 2 which included:

- Participatory observations
- Interviews with family caregivers and patients
- Observed personal detractor and enhancers from Dementia Care Mapping (BDG, 2005)

Eleven family caregiver interviews were recorded and transcribed verbatim, the remaining six agreed to talk at the bedside as they did not feel they had enough time to spare away from their relative. One patient was able to talk to me, and handwritten notes were taken.

The chapter concludes with a discussion of the limitations of the study design, data collection tools, and findings.

## 5.1 Methods

### 5.1.2 Sampling

A purposeful sampling strategy was used to recruit to the study. Family caregivers were selected to enroll in this study if they provided support for their relative at least one mealtime per day. The use of analytic induction methodology made it necessary not to exclude dyads based on assumptions (Palinkas et al. 2013), whereby an assumption is made that, for example, only dyads with high Beliefs about Caregiving scores would provide relevant information and be recruited to

phase 2. For this reason, all dyads who took part in phase 1 were invited to take part in phase 2. As the study progressed new cases were recruited who would confirm or contradict the emerging themes in keeping with analytic induction methodology (section 4.6.2.1). These surprise cases were used to test out emerging findings, for example, did family caregivers in the person-centered care group involve other family members in the care activities?

Table 5.1 summaries the data collection methods used, and the number of dyads recruited to each phase and Table 5.2 gives an overview of the profiles of dyads recruited to phase 1 and phase 2, which has been anonymised using the letter D with their study recruitment number added, i.e. D1.

## **5.2 Phase 1 Quantitative Data Collection Methods**

Once the participants had agreed to take part in the study and consent/opinion had been gained the following clinical data were collected to determine the participant's characteristics which were used to describe the differences and similarities between them:

- Patient and family caregivers' demographics
- Functional Assessment using the FAST (Reisberg et al. 1988),
- Cognitive assessment using the MoCA© (Nasreddine 2005)
- Average daily calorie intake from a standard food chart calculated by the ward dietician

With this data collected the Beliefs about Care Scale (Phillips et al. 1998) questionnaires were completed by the family caregivers and the Dementia Care Mapping (BDG, 2005) sessions commenced.

### **5.2.1 Beliefs about Caregiving Score**

The nurturing and monitoring scores calculated from the Beliefs about Caregiving Score (BACS) (Philips et al. 1998) and the well-being scores from Dementia Care Mapping (DCM) (BDG, 1997) were used to test the proposition; Family caregiver's beliefs about their caring role affects the patient's well-being when they refuse to eat.

The BACS were scored to produce a nurturing and monitoring score for each family caregiver. The twelve nurturing questions on the 4-point Likert scale produced a score between 12-46, with low scores indicating caregiver enmeshment in their role, while the monitoring questions produced scores between 16 -64, with lower scores indicating less caregiver flexibility. Moderate scores across both nurturing and monitoring scores are considered optimal in terms of quality of care (Philips et al. 1998). See section 4.3.2.4.

Thirty Beliefs about Care Score (Phillips et al. 1998) questionnaires were completed and returned; one family caregiver declined to complete the questionnaire, they did not give a reason, but said, "I know I don't have to complete it". While disappointing from the completeness of data point of view, declining did indicate the participants felt able to refuse and not coerced into taking part.

### **5.2.2 Dementia Care Mapping**

Dementia Care Mapping (BDG, 2005) was used to determine the patient's well-being scores. In this study decisions about the mapping process and data collection were made based on the review of DCM outlined in section 4.3.2.5, how the data collected would answer the research questions and what would work for the dyads in terms of how long and when to map.

To ensure data reliability four mapping sessions in this study were co-mapped by the researcher and a second trained mapper, inter-observer reliability of 80% was achieved after two rounds of mapping and discussions, which is the level demanded by the Bradford Dementia Group (BDG).

The mappings took place in the ward bays as there are no day rooms in the study hospital. Each mapping session involved one dyad and the session commenced once the meal tray was placed in front of the patient and ended once the family caregiver indicated the meal had finished.

Observing one dyad at each mapping session allowing for conversations to be heard and small details of body language to be observed.

Arriving on the ward 10-15 minutes before the meal service allowed for a re-introduction of the researcher to the patient and family caregiver and inform the staff of the mapping session. This also gave the dyad the opportunity to ask any questions or decline to take part if they had changed their mind. The ward staff are well seasoned to mapping as it is used as part of service evaluation and development programmes. Only one dyad was mapped at a time, as when two dyads were enrolled in the study concurrently they were not nursed in the same bay. While more time consuming this did ensure that fine detail could be captured, for example, slight facial expressions from the patients that may have been missed if mapping more dyads.

The aim was to map a minimum of 4 hours (forty-eight 5-minute time frames) of mealtimes per dyad as recommended by the BDG (Brooker & Surr, 2006) to calculate valid individual well-being scores.

$$\text{Percentage time frames spent in each well-being score} = \frac{\text{Total number of time frames in each well-being}}{\text{Total number of time frames}} \times 100$$

Eighteen of the thirty-one participating dyads had forty-eight or more 5-minute time frames recorded, and the remaining thirteen averaged forty-time frames with a range of 23-46. Mapping 4 hours per dyad proved challenging for two reasons, firstly because for some dyads (N=5) mealtimes were quite short requiring a large number of mealtimes to be mapped, and they were discharged before a complete data set could be recorded. Secondly, because the patient (N=4) became unwell, three of the four patients who become unwell died while in the study, reflecting their advanced stage of dementia.

The well-being scores were calculated from the mood and engagement (ME) scores taken during DCM and calculated, (section 5.2.5)

$$\text{Well-being} = \text{Sum of the ME values} \div \text{Total number of time frames}$$

The phase 1 data set was entered into an Excel file. Once the data set was complete, it was reviewed for anomalies and omissions and transferred to IBM SPSS 20.

As part of the DCM session personal enhancers & detractors were also recorded and analysed as part of the qualitative data set.

### **5.2.3 Physical and Cognitive function**

Both the Functional Assessment Staging Scale (FAST) (Reisberg et al. 1988) and the Montreal Cognitive Assessment© (MOCA) was completed by the researcher on enrolment to the study at a time when the patient was considered to have recovered from the acute medical condition necessitating admission to the hospital. In this way, the patient's result was less likely to be influenced by any outstanding levels of delirium, although some degree of delirium was possible in this patient group.

### **5.2.4 Calorie intake**

All patients have a Trust standard food chart completed; from this, the dietitian calculated the patient's calorie intake, this was used to describe the similarities and differences between patients and identify any association between calorie intake and well-being.

## **5.3 Phase 2 Qualitative Data Collection Methods**

In phase 2 of the study four types of qualitative data were collected:

- Participatory observations
- Non-participatory observations from dementia care mapping data (personal enhancers & detractors)

- Memos

### **5.3.1 Participant observations**

The data collected from participatory observations complemented the more structured observational data collected during the DCM. While DCM can provide reliable and valid results as discussed in section 4.3.2.5 (Brooker & Surr, 2006) focusing on the care experience from the patient's perspective, participant observation was also used as an opportunity to observe and talk with the dyads in an attempt to gain some insight into the complexities of the dyads relationship and behaviours.

Before commencing the participatory observations, the researcher attended the ward 10-15 minutes before mealtimes, introduced herself to the staff on duty in the bay in which the patient was allocated. She reminded them why she was there and re-introduced herself to the patient and family caregiver in the study and also those not in the study, so they also understood the researcher's role. The patient and family caregiver were given an opportunity to ask any questions about the study once again and decline to take part should they have changed their mind since completing the consent and opinion forms. The researcher talked with the dyads about their general health and discharge plans to help build relationships and to provide some support to the family caregiver.

The time spent completing participant observations was used in preparing all the patients in the bay for their meal; going to the toilet, sitting out of bed, distributing the meals and providing any additional support the patients in the bay may need without committing to sitting with one patient, but rather staying in proximity to the study dyad. Field notes of the observations were made away from the clinical area on a proforma (Appendix 24) as soon as possible after the observation, to ensure accurate recollection, while avoiding unsettling the patient. The proforma was used to help reduce the likelihood of inconsistent observations and note taking.

Working with the family caregiver created a positive perspective for the patient to ensure they felt comfortable in the company of the researcher. Had the patient shown any signs of distress during the observations the session would have been terminated. At the end of each observation period, the researcher stayed with the patient continuing to show interest in them ending the engagement on a positive note.

### **5.3.2 Semi-structured Interviews**

The semi-structured interviews facilitated the development of an understanding of what had been seen during the observations. During the observations, the researcher's meaning could be

attached to the interactions witnessed, but importantly the interviews provided an opportunity to “check out” these interpretations with the participants to validate any findings. The interviews also gave the family caregiver’s the opportunity to express their concerns, give their perspective on their situation and talk about what was important to them.

A relationship with the dyads had already been established during the observation session by the time the interviews took place, enabling a relaxed and informal atmosphere. The interview topic guide (Appendix 24) consisted of an open introduction question which was descriptive, broad and general, “Can you tell me about a typical mealtime for you and your mum when you are at home”? This was followed by probing questions for example, “That’s interesting can you tell me how that felt for you?” to obtain more in-depth responses to the questions and increase the richness of the data.

Field notes were written up immediately following the interviews with observations detailing the process and initial impressions of the data. The tapes were transcribed by an external company, with a quick turnaround time which gave the opportunity to add the family caregiver gestures that had been recorded in the field notes — these added meaning to the transcript which was helpful during analysis.

The intention was to “interview” patients about their experiences of mealtimes; however all but one lady had minimal verbal communication; therefore, it was only possible to “interview” her.

All 18 dyads recruited to phase 2 were invited to take part in an interview, eleven family caregivers agreed while the remaining six agreeing to talk at the patient’s bedside. The interviews took place in the hospital in a quiet room and lasted approximately 30-40 minutes. The interviews were recorded on audiotape and transcribed verbatim. Handwritten notes were taken during the six bedside interviews.

Interviews were concluded with a “final say” question as this open question can provide an opportunity for the participant to express experiences that are important to them which may have been missed by the researcher and which can provide rich data (Patton, 2002). The most common discussion resulting from this final say question was about how the ward nurses tried to help other patients to eat. At the end of the interviews, the family caregivers were informed the interview was completed, and the tape recorder was turned off. At this point, the researcher did not get up to leave the room but gave the general impression they were not rushing off. This provided an opportunity for the family caregiver to ask any questions about the research or other concerns.

Three family caregivers asked about how dementia progresses. As an experienced nurse and very familiar with these sensitive conversations the researcher was able to have those discussions. These conversations were confidential and not relevant to the current study; therefore, no records were kept of these discussions except in the patient's medical notes as necessary. The interviews conducted at the bedside were conducted as far as possible in the same way. At the end of the session, the family caregivers were informed the interview was over, the researcher put the recorder or pen and paper away to signal this but stayed to ask if there was anything she could do for them, anything they needed.

### **5.3.3 Personal Enhancers and Detractors**

Personal enhancers and detractors are episodes recorded during Dementia Care Mapping when a family caregiver interacts with their relative in a way which has the potential to uphold or undermine their well-being (Brooker & Surr, 2006). During the mapping sessions, any clear episodes of enhancing or detracting behavior were described and clarified according to Kitwood's Person-Centered Care Framework (Table 2.1).

### **5.3.4 Memos**

Memos were used to capture emerging themes, insights and thoughts during the analysis of the interviews. This was also an opportunity to identify assumptions or preconceptions on the part of the researcher. Two types of memos were kept, operational and analytical (Glaser, 1978). The operational memos were notes on the conduction of each stage of the research, for example where limitations existed in the study methodology. The analytic memos were used to record ideas for coding, categories of data, specific questions to ask at interview and different data sources to review. Fresh perspectives emerged, and themes were found, for example, interviewing a close relative of the primary carer of participant D31.

Further content comparative analysis across the interview data and the observational data generated early theories necessitating the recruitment of further participants in search of surprise cases to allow for the refinement of the qualitative proposition. This process continued until no further disconfirming cases were identified.

**Table 5.1 Summary of study propositions, questions and methods**

Starting propositions <b>Quantitative</b>	Research questions	BACS	DCM	Participatory Observations	Personal detractor and enhancers	Interviews	Finding appear in sections
Family caregiver's beliefs about their caring role are associated with their relative's well-being when they refuse to eat.	Do patients with dementia who are in well-being have a greater calorie intake?		X				6.2.1.2
	Do patients with dementia have higher well-being scores when their FAST score is high?		X				6.2.1.3
	Do patients with dementia have higher well-being scores when the MoCA score is high?		X				6.2.1.4
	Do patients with dementia have low well-being scores when their relatives nurturing score is low?	X	X				6.2.1.5
	Do patients with dementia have low-well-being scores when their relatives have low monitoring scores?	X	X				6.2.1.6
<b>Qualitative</b> Kitwood's theory of person-centred care can be applied to the family care situation and be used to understand the type of support given by family carers to their relatives with dementia at mealtimes.	What elements of Kitwood's person-centred framework are observed in the family caregiver's behaviour at mealtimes?			X	X	X	6.3.2
	What are the experiences of family caregivers at mealtimes?			X		X	6.3.3.1

Mixed method	Research question	BACS	DCM	Participant observation	Personal detractor and enhancers	Interviews	Finding appear in sections
	How do the qualitative differences between family caregiver behaviours (person-centred and non-person centred) help to explain the measured quantitative differences seen in the patient's well-being, calorie intake, physical and cognitive function scores?	X	X	X	X	X	6.5

## 5.4 Data analysis

### 5.4.1 Phase 1 Quantitative data analysis – Hypothesis testing

The first-choice methods to test each hypothesis was dependent on the question being asked and how the study data met the assumptions associated with each methodology. Below each hypothesis is discussed in relation to these assumptions.

#### 5.4.1.2 Hypothesise 1

Patients with dementia who are in well-being have a greater calorie intake than those who are in ill-being.

There are a number of different statistical tests that can be used when trying to identify a difference (calorie intake) between two groups, (those in well-being vs those in ill-being). The independent-samples t-test is used when comparing the mean scores between two different groups or conditions when the data is normally distributed, while the Mann-Whitney U Test is used when the data are not normally distributed or when the sample is not randomised (parametric alternative). The independent-samples t-test is the most robust statistical test to test hypothesis 1. However, the assumption of a randomised sample was not met on this occasion therefore the Mann-Whitney U Test was considered the best test.

The Mann-Whitney U Test is used when comparing a difference between two independent groups on a continuous measure, however, unlike the independent – sample t-test which compares means of the two groups the Mann-Whitney U Test compares medians. A number of general assumptions still need to be met regarding the nature of the study data to ensure Mann-Whitney U Test is appropriate these are outlined below:

- Level of measurement
- Observations should be independent

#### Assumptions

1: Level of measurement: The level of measurement for the Mann-Whitney U test assumes the dependent variable is measured using an ordinal or continuous scale. In this study, the dependent variables well-being, calorie intake and cognitive function were measured on a continuous scale.

The independent variable is two independent groups, those receiving person-centred care and those who are not.

2: Independent of observations: Independence of observations implies that each measurement must not be influenced by another measure. There should be no relationship between the two groups or within each group.

#### **5.4.1.3 Hypothesis 2 & 3**

Hypothesis 2) Patients with dementia have higher well-being scores when their physical function (FAST) score is high.

Hypothesis 3) Patients with dementia have higher well-being scores when their cognitive function (MoCA©) score is high.

The choice of test to answer hypothesis 2 & 3 was a correlation analysis. Correlation analysis provides a numerical summary of the direction and the strength of the linear relationship between two variables ( $x, y$ ). The relationship between the two variables can range from -1 to +1 with the sign before the number indicating the direction of the relationship, whereby a positive sign indicates positive correlation; as variable ( $x$ ) increases so does the other negative sign indicates a negative correlation whereby if one variable increases, the other ( $y$ ) decreases. The strength of the relationship is denoted by the numeral whereby -1 or +1 indicates a perfect correlation and a correlation of 0 indicates no relationship between the two variables. When the correlation lies between 0 and 1 Cohen (1988, pp78-81 quoted in Pallant, 2016) suggests the following guideline:

- Small  $r = .10-29$
- Medium  $r = .30-49$
- Large  $r = .50-1.0$

##### **5.4.1.3.1 Hypothesis 2**

There are a number of correlation statistics available that can be used in IBM SPSS depending on the type of data the most robust correlation statistic is either Pearson's or Spearman. The FAST score used to measure physical function collects ordinal data; therefore, the most robust statistic to calculate a correlation between the two variables is Spearman's rho.

The data needs to satisfy a number of assumptions associated with Spearman; these assumptions are listed and discussed in turn.

##### **Assumptions**

1. Level of measurement
2. Related pairs
3. Independence of observations
4. Normality of distribution
5. Outliers
6. Linearity

## 7. Homoscedasticity

1: Level of measurement for the variables used in correlation coefficients is usually continuous, although an exception is made when there is one dichotomous independent variable and one continuous dependent variable. To test hypothesis 2 continuous data from well-being scores and ordinal FAST scores were used.

2: Related pairs; this assumes both sets of data, e.g. well-being and physical function scores were available and were from the same subject. This assumption was met for all 31 participants in the study.

3: Independence of observations implies that each measurement must not be influenced by another measurement, for example when measuring the patient's well-being when they were in the sole company of their family caregiver. Sitting at a dinner table with other patients may have influenced the participant's well-being, violating the assumption of independence.

4: Normality of distribution: Normality of distribution assumes the population from which the study sample was drawn are normally distributed, this is determined by the Shapiro-Wilk. In this study, the dependent variable, well-being, is normally distributed with a Shapiro-Wilk of .491.

5: Outliers are scores that are significantly outside the rest of the scores and can seriously affect the correlation coefficient, especially when the sample size is small. Shapiro-Wilk data are used to reveal any outlier data, of which there were none.

6: Linearity implies the scores from the two variables lie somewhere around a straight line. As described above correlations determine the degree to which a relationship is linear. Spearman's rho, however, is concerned with the measure of the strength and direction of the monotonic association between two variables, a measure less restrictive than linear relationships.  
Scatterplots are produced to determine the relationship between the variables. There was an apparent association identified from the scatterplots.

7: Homoscedasticity refers to the situation in which the variability of a variable is unequal across the range of values of a second variable that predicts it. When checked on a scatterplot the variables created a cone-like shape, as the scatter (or variability) of the dependent variable widens or narrows as the value of the independent variable increases.

#### **5.4.1.3.2 Hypothesis 3:** Patients with dementia have higher well-being scores when their cognitive function (MoCA©) score is high.

The most robust statistical test for hypothesis 3 was Person's correlation. The assumptions are listed and discussed below.

##### Assumptions

1. Level of measurement
2. Related pairs
3. Independence of observations
4. Normality of distribution
5. Outliers
6. Linearity
7. Homoscedasticity

1: Level of measurement for the variables used in correlation coefficients is usually continuous, although an exception is made when there is one dichotomous independent variable and one continuous dependent variable. The data used to test hypothesis 3 well-being and cognitive function are continuous.

2: Related pairs; this assumes both sets of data, e.g. well-being and cognitive function scores were available and were from the same subject. This assumption was met for all 31 participants in the study.

3: Independence of observations implies that each measurement must not be influenced by another measurement, this has been described above.

4: Normality of distribution: Normality of distribution assumes the population from which the study sample was drawn are normally distributed, this is determined by the Shapiro-Wilk. In this study, the dependent variable, well-being, is normally distributed with a Shapiro-Wilk of .491.

5: Outliers are scores that are way outside the rest of the scores and can seriously affect the correlation coefficient, especially when the sample size is small. Shapiro-Wilk data are used to reveal any outlier data, of which there were none.

6: Linearity implies the scores from the two variables lie somewhere around a straight line. As described above correlations determine the degree to which a relationship is linear. While linearity is not an assumption of Pearson's correlation, it would not normally be used if it were already known the two variables are not linear, as other statistical measures would better describe the relationship between the two variables. Therefore, scatterplots are produced to determine the

relationship between the variables. There was an apparent association identified from the scatterplots.

7: Homoscedasticity refers to the situation in which the variability of a variable is unequal across the range of values of a second variable that predicts it. When checked on a scatterplot the variables created a cone-like shape, as the scatter (or variability) of the dependent variable widens or narrows as the value of the independent variable increases.

#### **5.4.1.4 Hypothesis 4 & 5**

Hypothesis 4: Family caregivers monitoring scores predict the level of well-being of the patients with dementia

Hypothesis 5: Family caregivers nurturing scores predict the level of well-being of the patients with dementia

The first-choice method to test hypothesis 4 and 5 was logistic regression. Regression analysis allows to test the relationship between variables, and it allows to test models of prediction (Pallant, 2007). In order to conduct a regression analysis, the correlation analysis was performed first to establish the relationship between variables (well-being and monitoring or nurturing scores). The correlation analysis conducted was the Spearman's correlation due to the monitoring and nurturing data being ordinal.

The relationship between caregivers' monitoring (as measured by the BACS) and patients' well-being was investigated using Spearman's correlation coefficient. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, and homoscedasticity. There was no significant correlation found between the two variables,  $\rho = .043$ ,  $n = 30$ ,  $p = .824$ .

The relationship between caregivers' nurturing (as measured by the BACS) and patients' well-being was investigated using Spearman's correlation coefficient. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, and homoscedasticity.

There was no significant correlation found between the two variables,  $\rho = .332$ ,  $n = 30$ ,  $p = .074$ ; however, the significance score shows a tendency, and perhaps if the sample had been bigger, there would have been a positive, significant relationship between nurturing and well-being.

Therefore, due to the correlation analysis results showing no significant relationship between patients' well-being scores and caregivers' nurturing/monitoring results, there was no basis for conducting regression analysis.

The findings from the quantitative analysis were used as a framework for analysing the qualitative data, as discussed in section 4.2.6.

### **5.4.2 Phase 2 Qualitative data analysis**

Analytic induction was used to analyse the qualitative data with the addition of statistical tests as described in section 4.6.2.1. The qualitative data comprised of:

- Written narratives generated from interviews
- Field notes from participant observations
- Personal enhancers and detractors from dementia care mapping
- Memos

The initial aim was to establish two groups; those family caregivers delivering person-centred care and those who were not, based on Kitwood's framework (1997) described in section 2.4 and presented in Table 2.1. The separation of family caregivers into these two groups also reflects the starting proposition developed to enable the use of analytic induction as the methodology for analyzing the qualitative data.

#### **5.4.2.1 Steering Group**

This analysis was conducted by two members of the study steering group who remained blinded to the phase 1 results to reduce the development of any preconceptions of the family caregiver. The two members independently read and re-read all the anonymised interview transcripts, and participatory observation sheets to consider if the care being delivered was person-centred. Some debate was necessary to achieve agreement on what constituted a mild or severe detractor, for example, family caregiver D6 admitted to "tricking" her mother into eating 21 dried grapes which she had read on the internet improves brain function.

*F6/O: "I always tell her, "its religious mum," they say it's very religious you have to take it, they say take it? Yes, they say take it so take it."*

*Researcher: "And she is happy to take it"*

*F6 "Yes, if you tell her that one of the people that she believes in, you know, tell her to take it and she says ok and takes it"*

The Steering Group members considered this to be an example of trickery; a mild detractor rather than treachery, and therefore person-centred care was being delivered by this family caregiver. After discussion the Steering Group were able to agree on the behaviour of all eighteen dyads.

#### **5.4.2.2 Interviews and Observations**

In the first instance, the interviews were read through to gain a sense of the data, then the data was coded and described thematically against Kitwood's person-centred care framework (Table 2.1) by the researcher and research steering group independently. The same analytic process was used for the data generated from the participatory observations and the personal enhancer and detractor data collected during Dementia Care Mapping. These data increased the depth of understanding of the relationship between the family caregiver and their relative and how they interacted with their other family members and ward staff.

The observed data were compared with interview data and against emerging themes and theories (Charmaz, 2006), for example, the level of involvement different family caregivers had in the direct care of their relative and the personal sacrifice they have made in their own lives to be available to provide care.

Of the eighteen participants nine family caregivers were providing person-centred care, and nine were not. The demographics of the family caregivers in each group are shown below in Table 5.5 which shows the family caregivers in the PCC group to be predominately white British, while the non-PCC group were more diverse concerning ethnicity and religion.

During the data analysis, it became clear a range of existing social theories could provide plausible explanations for the differences and similarities between the two groups' behaviours at mealtime, for example, caregiver burden, grief, anger, attachment style. Therefore, the data was reviewed to test if these theories were evident in this study and if so did they account fully for the behaviours observed or were "surprise" (Agar, 2006) additional dimensions evident. This abductive process is a qualitative approach aimed at generating creative and novel theoretical insights, developing existing theories using robust methodological steps (Timmersman & Tavory, 2012). The findings are discussed in detail in chapter 6.

#### **5.4.2.3 Integrating qualitative data**

Integration of the qualitative data was made possible by comparing the memos written during the analysis of the interview data, and the observations bring the data sets together. These memos provided a link that prompted an evaluation of the family caregivers' relationship with the patient and other family members. This drawing together of the data resulted in the development of the proposition, Kitwood's theory of person-centred can be applied to the family care situation and be used to understand the type of support given by family carers to their relatives with dementia at mealtimes.

### **5.4.3 Integration of quantitative and qualitative data**

#### **5.4.3.1 Hypothesis 6, 7**

Once the quantitative and qualitative data sets were analysed separately, they were integrated to determine how the qualitative differences between family caregiver behaviours (person-centred and non-person centred) help to explain the measured quantitative differences seen in the patient's well-being and calorie intake.

Hypothesis 6 – Patients who receive person-centred care from their family caregiver at mealtimes have higher measures of well-being scores at mealtimes.

Hypothesis 7- Patients who receive person-centred care from their caregivers at mealtimes have a higher calorie intake.

As explained in section 5.4.1.2 there are a number of different statistical tests that can be used when trying to identify a difference between the two groups. The independent-samples t-test is the most robust statistical test to answer these questions; however, the assumption of a randomised sample was not met on this occasion, therefore the Mann-Whitney U Test was considered the best test for hypotheses 6, 7.

The Mann-Whitney U Test is used when comparing a difference between two independent groups on a continuous measure, however, unlike the independent –sample t-test which compares means of the two groups the Mann-Whitney U Test compares medians. A number of general assumptions still need to be met regarding the nature of the study data to ensure the Mann-Whitney U Test is appropriate, this is outlined below:

- Level of measurement
- Observations should be independent

Assumptions

1: Level of measurement: The level of measurement for the Mann-Whitney U test assumes the dependent variable is measured using an ordinal or continuous scale. In this study, the dependent variables well-being, calorie intake and cognitive function were measured on a continuous scale.

The independent variable is two independent groups, those receiving person-centred care and those who are not.

2: Independent of observations: Independence of observations implies that another measure must not influence each measurement. There should be no relationship between the two groups or within each group.

## **5.5 Promoting Rigour**

As discussed in section 4.6.2.5 there are acknowledged concerns with regard to the rigour of analytic induction methodology and steps were taken throughout this study to mitigate these concerns. Auditability; leaving a clear decision trail, is according to Meyrick (2006) key to promoting rigour, therefore the importance of the research topic to practices has been explained (Chapter 1), the literature reviewed (Chapter 2 & 3), and the decisions made regarding the study design, data collection methods and analysis (Chapters 4 & 5) have been clearly set out and justified. Table 5.6 summarises the strategies used to promote rigour, with reference to the chapter sections supporting these points.

**Table 5.2 A summary of strategies to promote rigour**

Criterion	Strategies adopted and chapter section	How strategy promotes rigour
Trustworthy	<p>Credibility</p> <p>Using mixed method convergent parallel design (4.2) Validated collect data tools (4.3)</p> <p>Building rapport with patients and family caregivers (5.6) Wearing uniform (5.6) Participatory observations (4.4.1 &amp; 5.3.1)</p> <p>Purposeful sampling of dyads (5.1.2)</p> <p>Open questions, probing and final say question (4.4.2 &amp; 5.3.2)</p> <p>Field notes taken during observations (5.3.1) Audio-taping of interviews, where not feasible extensive field notes taken (5.3.2)</p> <p>An open question with probes and final “say question” (5.3.2)</p> <p>Steering group used for data analysis (5.4.2.1, 5.4.2, 5.8)</p> <p>Immediately writing up field notes (5.3.1)</p> <p>Researcher’s diary to ensure reflexivity (4.1.2, 5.6)</p>	<p>Structured research design Collection of valid content</p> <p>Promoting natural behaviours Encourage relaxed atmosphere and natural behaviour of dyads and staff</p> <p>Ensure information-rich dyads recruited</p> <p>Ensuring expression of own thoughts</p> <p>Ensure details recorded accurately</p> <p>Increasing acceptance of researcher reducing dyad bias</p> <p>Self-monitoring of researcher beliefs and values</p> <p>Accurate and comprehensive transcripts</p> <p>Identify my position, beliefs and values</p>

## **5.6 Researcher-participant relationship**

By choosing to conduct a study which used qualitative data I was exposed to some ethical challenges, some of which I anticipated and some I did not. Kidd and Finlayson (2006) refer to the anticipated ethical dilemmas of qualitative research navigated safely by bioethical principles as “charted waters”, and those ethical dilemmas that are unforeseen as “uncharted waters”.

At the start of the study I was aware of:

- a) My desire to gain information versus respectful and compassionate questioning
- b) The risk of becoming too close versus being too distant from my participants
- c) The asymmetry of power between myself as the researcher versus the family caregiver resulting in my leading the questioning and the direction of the interviews
- d) The risk of boundaries becoming blurred between conducting research and caring for the participants
- e) Being seen as a therapist, counsellor, nurse rather than researcher
- f) The possibility of seeing family caregiver use verbal threats for example, “if you don’t eat this I’m not visiting you tomorrow”.

I recognised that repeated encounters with the dyads over the course of their time as participants was likely to result in getting to know each other personally at some level, which could potentially affect the research study either by strengthening the data or by blurring the boundaries, running the risk of developing what Gardner (2010) calls “fake relationships”. Haahr et al. (2014) describe a fake relationship as one that is developed by the researcher purely for their gain. In my keenness to gain my data there was a risk of developing this type of relationship. In my reflective diary I acknowledged this, and that I felt I owed the dyads something for giving up their time for me, unchecked, this could be harmful to both the participant and to me (Brinkermann & Kvale, 2005). To avoid this situation, I used my reflective diary and study support group to question my feeling and actions. For example, I discussed a situation where a family caregiver enrolled in the study had expressed a wish for the ward to provide more appropriate bibs at mealtimes which I was prepared to purchase through our charity fund but was unsure if I was trying to court favour. The study support group reminded me that the fund was there for this very reason and this is how I always respond to fairly simple requests from any relative. I purchased the bibs.

My uncharted waters; ethical dilemmas occurring more than I had expected, arose during the observation periods of the study. While I had expected to witness verbal threats by the family caregivers towards their relative I had not expected to see family caregivers physically force their relative to eat.

As a result, on some occasions, I found the mapping and observation sessions very challenging. Two family caregivers used a syringe to feed their relative when they declined to eat, putting the patient at risk of aspiration and in my opinion unwarranted psychological distress. A number of family caregivers would fight with the patient forcing a spoon into their mouth while holding their hands down. During the Dementia Care Mapping sessions, I saw the patient's mood and engagement scores drop in minutes of the meal starting. This was distressing for me and brought me into direct conflict with my role as nurse and researcher. On discussion with the patient's consultant and nurses, this behaviour by the family caregiver appeared to be an established practice for them which despite being witnessed had not been challenged, except to ensure the patients were not at risk of aspiration. A safeguarding alert had not been considered for any of these dyads, yet here was a vulnerable patient at risk of emotional harm from a family caregiver. My concerns with this situation emanated from the principles of the Mental Capacity Act (2005), in particular, the best interests of the patient. By failing to address the situation the ward medical and nursing teams were implying it is in the patient's best interests for family caregivers to use these techniques to increase their food intake. This is in contrast to Kitwood's theories of dementia care which as yet have not been tested with family caregivers.

On reflection, it seemed to me the family caregiver was just as vulnerable as their relative who as a result of their caring role was going through a time of loss and transition. If a safeguarding alert were to have been submitted to adult social services the consequences may have been devastating for both parties, with the patient possibly being placed in a care home, separated from their carer while the family caregiver may have experienced a strong feeling of guilt, anger, resentment or sorrow. Any action on my part had to take into account the needs of the family caregiver as well as the patient, and I had to bear in mind the family caregivers' behaviour was taking place in what appeared at face value to be a loving relationship, not an abusive one. As a result, I reconciled myself with working with the nurses and speech therapists to ensure the patients were not at risk of aspiration and used my research to try to relate to the family caregiver's behaviour rather than to resolve what I saw as a problem.

By adopting a research perspective rather than a professional perspective I tried to remove any taken for granted assumptions from my analysis, for example, I did not make assumptions that the caregiver's behavior was unacceptable as this would have been a judgment. The purpose of research is to remove judgment and study what happens. The core principle of inductive qualitative research sets out to remove all prior judgment from the analysis and to understand the participant's world as they experience it unfettered by societal and professional concerns. By

making my underlying assumptions transparent, I set out to test whether Kitwood's theories make sense in the world of the participants. The participants' views and behaviors were always paramount, not the theory or my professional concerns the focus was very much on the empirical data generated by the study. By emphasizing this aspect to the participants, I gained their trust to engage with the research as described below.

By adopting a research perspective rather than a professional perspective in this way taken for granted assumptions are removed from the analysis, so the assumption that some of the caregiver's behaviours are unacceptable is a judgement. The purpose of research is to remove judgement and study what happens. This goes back to the heart of the methodology debate in which grounded theory, in particular, sets out to remove all prior judgement from the analysis and to understand the participant's world as they experience it, unfettered by societal and professional concerns. This is a core principle of inductive qualitative research and one which must sit at the heart of analysis whatever methodology is used. Despite rejecting grounded theory in favour of analytic induction in this study this principle is not jettisoned, rather the underlying assumptions are made transparent and are tested as to whether they make sense in the world of the participants. The participant's views and behaviours are always paramount, not the theory or professional concerns. It is only by emphasising this aspect that you can win the trust of the participants to engage with the research.

## **5.7 Benefits and risks**

There was a risk in conducting this study that the observations may be seen as intrusive in nature. The patients might have felt uneasy if they thought they were being looked at or studied. I took the time to establish a good relationship with the patients to build a rapport that fostered trust, reducing the power inequalities between me, the patient and the family caregiver. The observation may have led the family caregiver to feel unable to speak without what they say being recorded as part of the study. Working as a member of the ward team in my usual role as consultant nurse helped to reduce the feeling of being watched and fostered a relaxed environment. I was always greeted warmly by the family caregiver, and we would chat about general topics ranging from the local bus route to Brexit. Equally I emphasised their views were of paramount importance and how I wanted to hear their story, their reality of the situation and what strategies they used to support their relative to eat.

During the interviews the family caregiver may have become emotional as the topic of caring for a relative with dementia can be a very sensitive one. I am an experienced nurse used to having

difficult and sensitive conversations with people. Had the family caregiver become distressed I would have stopped the interview and provided the necessary support. By taking part in this study, I hope the family caregivers felt their opinions and experiences were of value, and they were afforded the opportunity to validate their feeling, perhaps even boosting their self-esteem as capable carers. By including people with dementia who are unable to consent legally, I hoped I gave them the opportunity to have their voice heard, with careful observation of their non-verbal communication. Exclusion from participating in the research process would have been an affront to their dignity.

I may have been at risk of being used by the family caregiver as someone who could have afforded them special treatment, for example, faster access to a service. The family caregivers may have used the opportunity to express their dissatisfaction with the care being received by the hospital. At the time of enrolment, it was explained there would be no direct benefits to participants except for an opportunity to express their feelings. Should the participants have felt the need to complain about any aspect of their or their relative's care, I would have brokered the complaints procedure for them but not taken up their concerns formally.

At the beginning of the interviews, it was explained to the family caregiver that the meeting was not to discuss their relative's management plan or care, but they were offered an opportunity to discuss these matters in the usual way. Had this happened I would have stopped the interview and discussed the issues or concerns raised, if any serious issues had come to light I would have signposted them to the most appropriate person or service according to Trust policy.

## **5.8 Potential risk of bias**

In a study such as this where there are many opportunities to engage with the participants there is a risk of bias that I needed to be mindful of. For example, a family caregiver told me she was due to attend hospital for a colonoscopy that week but was going to cancel as she felt she should be with her husband to make sure he was eating. She had cancelled the same appointment last year. The ward sister and I spoke to her at length assuring her we would be there to help her husband, thankfully she attended her appointment and the ward sister, and I helped her husband eat on the two days she was unable to attend. This level of involvement could have raised a threat to the validity of the study findings. However, my actions may have facilitated a trusting relationship with the family caregiver, promoting a more honest insight into her beliefs about her caregiving role. I could have become over-involved in the case and developed a sense of attachment towards the family caregiver. However, I felt it would have been morally wrong not to have provided the

support required to enable this lady to attend to her own health needs. This particular case enabled me to give something back to her and her husband for allowing me into their world at a tough time. By taking on the role of helping her husband to eat, I did gain some insight as to how she must feel trying meal after meal to get her husband to take just a teaspoon of custard.

To maintain a natural position throughout the study, I began the research process by writing a reflexivity piece detailing my beliefs and values about personhood to identify areas of possible bias. Throughout the study, it was important to ensure my professional perspective of the subject did not influence my judgement of the family caregivers' behaviours. The study aimed to explore the acceptability and applicability of Kitwood's framework for family caregivers; therefore, my professional opinion on the rights or wrongs of their behaviour is of little consequence. What is important is how family caregivers view their world in relation to Kitwood's framework. For this reason, the steering group were asked to assist in deciding which family caregivers were providing person-centred care. Blinding to the well-being scores from phase 1 reduced the likelihood that assumptions would be made by the group based on their preconceived ideas of person-centred care. Importantly this also served to guard against my preconceived ideas as I was aware of the phase 1 results.

## **5.9 Chapter Summary**

This chapter provided a detailed explanation of the research design and the methods used to facilitate data collection and analysis that would answer the study question. A detailed explanation of each phase of the mixed methods was provided. Phase 1, the quantitative phase, used Dementia Care Mapping (BDG 1997), a non-participatory observation tool along with the BACS (Philips et al. 1998) validated measures of cognitive and physical function and food charts for calorie intake. Phase 2, the qualitative phase, employed semi-structured interviews and participatory observations. Integral to the discussion in this chapter was consideration for the researcher- participant relationship and the potential risk of bias. The following chapter provides the study findings.

# Chapter 6 Results

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## 6.0 Introduction

Chapter 5 explained how the data was collected and analysed. Chapter 6 first revisits the background to the inquiry and then presents the finding of the quantitative results from the data collected in phase 1. This data demonstrates how the patient's physical and cognitive scores and the family caregiver's beliefs about their nurturing role are associated with the patient's level of well-being. The qualitative data is then presented illustrating how family caregiver attachment style influences their acceptance of and enmeshment in the caregiving role. Those family caregivers who have secure attachment styles were able to distance themselves emotionally while remaining physically close to their relative and appeared more likely to find Kitwood's model of person-centred care acceptable and applicable. The quantitative and qualitative data were mixed during the interpretation stage to facilitate conclusions about what was learnt from drawing the two phases together, this synthesis of the integrated data shows a difference in the well-being scores and calorie intake between patients who received person-centered care from a family caregiver at mealtimes and those who did not.

## 6.1 Background

The propositions for this thesis emanated from a combination of research evidence as discussed in the literature review chapter and clinical practice, where there appeared to be a tension between healthcare professionals and some family caregivers when their relatives with dementia stopped eating. This tension arose when family caregivers resorted to behaviours of intimidation, treachery or imposition as a strategy to support their relative to eat, leaving the healthcare professional in an ethically difficult position. From a healthcare professional's perspective, there are concerns regarding the patient's safety from aspirating food that is forced or given via a syringe, as well as a risk to the patient's psychological well-being. However, healthcare professionals are also mindful of the significant role the family caregiver plays in the patient's life; in many cases providing 24 hours care at a high cost to themselves physically, emotionally and financially. The option of alerting social services of the family caregivers' behaviour is always there through adult safeguards. Yet the concern here is the impact this may have on the family caregiver in terms of guilt, anger and distress and distress to the patient if their relative is no longer allowed to care for them. There could also be irredeemable damage to the health professionals' relationship with the family caregiver. As a result, family caregivers are rarely challenged in these situations or provided

with any support except for a referral to the speech and language therapist in the hope that education on how to safely support their relative with eating will change their strategies to ones considered acceptable to healthcare professionals. Ultimately, despite the family caregiver's behaviour being considered not in the patient's best interests, there is a sense the behaviour is borne out of love and not indicative of an abusive relationship, which seems to render the healthcare professionals unwilling to act, perhaps in need of evidence as to the best course of action.

This study has explored the applicability and acceptability of person-centred care from the family caregiver point of view as a first step to developing interventions that may support them and their relative.

#### **6.1.2 Starting proposition**

Kitwood's theory of person-centred care is transferable to family caregivers of relatives with dementia.

#### **6.1.3 Quantitative proposition**

Family caregiver's beliefs about their caring role are associated with their relative's well-being when they refuse to eat.

#### **6.1.4 Qualitative proposition**

Kitwood's theory of person-centred can be applied to the family care situation and be used to understand the type of support given by family carers to their relatives with dementia at mealtimes.

#### **6.1.5 Mixed method proposition**

How do the qualitative differences between family caregiver behaviours (person-centred and non-person centred) help to explain the measured quantitative differences seen in the patient's well-being, calorie intake, physical and cognitive function scores?

### **6.2 Demographic data**

Thirty-one dyads participated in this study, their demographics are presented in Table 6.2 below. The demographic data, physical and cognitive function scores and calorie intake were collected and collated employing descriptive statistics which are used to describe and compare the dyads enrolled in the study.

The family caregivers in the study were younger (Mean:  $M = 59.28$  years, range 31-82, Standard Deviation:  $SD = 14.94$ ) than their relative (Mean:  $M = 83.74$  years, range 70-96, Standard

Deviation:  $SD = 5.84$ ). Most family caregivers (61%), and patients (58%) were female. Ninety percent of family caregivers were either spouse (29%) or adult children (61%) of the person with dementia. The remaining 10% included one grandson, one nephew, and one son-in-law for simplicity of description these were grouped as “other”. Fifty-five percent of family carers described their relative as white British or British, while 13% described them as Caribbean, 10% as European and 10% as African, 3% were Irish, and a further 3% were South Asian. There was minimal variation in family caregiver and patient ethnicity. Sixty-one per cent of the patients in the study were Christian, with 26% reported to be Muslim, 6% Jewish and 6% atheists. There was also limited variation in religious beliefs except for those with no religious beliefs with 29% of family caregivers reporting to be atheist compared to 6% of patients.

Most patients lived at home with their family caregiver (84%) with 3% living at home alone, 3% living at home with another family member (husband) and 10% were resident in a care home.

Thirteen percent of the adult children used the term “carer” to describe their occupation, where none of the spouse carers used this descriptor.

Eleven of the 18 (61%) female patients were described as a housewife, (35% of the total number of patients). Eleven of the 13 male patients (65%) were described as tradesmen, (23% of the total number of patients). In contrast 39% of family caregivers described themselves as professionals. This was reflected in the educational levels of the participants with 83% of family caregivers holding a minimum of an “O” level qualification, with 61% of the patients holding no qualifications.

Alzheimer’s type dementia was the most common dementia diagnosis (77%) which reflects national prevalence data on types of dementia (Alzheimer’s Research UK website accessed November 2017).

**Table 6.1 Demographic data phase 1**

		Patients N=31	Family caregivers N=31
Age	Range	70-96	31-82
	Mean	83.74	59.28
	SD	5.84	14.94
Gender	Female	58% (18)	61% (19)
	Male	42% (13)	39% (12)
Type of dementia	Alzheimer's	77% (24)	
	Vascular	20% (6)	
	Other	3% (1)	
Ethnicity	White British/British	55% (17)	52% (16)
	Caribbean	13% (4)	10% (3)
	European	10% (3)	16% (5)
	South Asia	10% (3)	10% (3)
	Irish	3% (1)	3% (1)
	African	10% (3)	10% (3)
Religion	Christian	61% (19)	39% (12)
	Muslim	26% (11)	26% (11)
	Jewish	6% (2)	6% (2)
	Atheist	6% (2)	29% (9)
Education	"O"/ "A" level/ Certificate	6% (2)	48% (15)
	1 <sup>st</sup> Degree	3% (1)	13% (4)
	Higher degree	3% (1)	0
	Professional qualification	6% (2)	19% (6)
	Trade qualification	19% (6)	3% (1)
	No qualifications	61% (19)	16% (5)
Occupation	Housewife	35% (11)	0
	Trades person	23% (7)	26% (8)
	Professional	16% (5)	39% (12)
	Manual worker	26% (8)	16% (5)
	Carer		13% (4)
	Retired		3% (1)
	Student		3% (1)
Relationship	Adult child		61% (19)
	Spouse		29% (9)
	Nephew		3% (1)
	Grandson		3% (1)
	Son-in-law		3% (1)

**Table 6.3 provides a profile of the dyads recruited to the study and highlights those recruited to phase 2**

**Table 6.3 Dyad profile – Phase 1**

Code	Patient Gender	Patients Age	Family caregiver	Family Caregiver Age	Data collected phase 1	Recruited to phase 2
D1	M	70	Wife	67	DCM, BACS	N
D2	F	77	Husband	73	DCM, BACS	C, O
D3	F	78	Daughter	65	DCM, BACS	N
D4	F	72	Daughter	33	DCM	N
D5	F	94	Son	63	DCM, BACS	N
D6	F	79	Daughter	36	DCM, BACS	I, O
D7	F	85	Daughter	51	DCM, BACS	I, O
D8	M	86	Wife	80	DCM, BACS	I,O
D9	F	85	Daughter	52	DCM, BACS	N
D10	M	87	Nephew	47	DCM, BACS	N
D11	M	82	Wife	82	DCM, BACS	N
D12	F	88	Daughter	61	DCM, BACS	C, O
D13	M	82	Wife	80	DCM, BACS	I, O
D14	F	87	Son	62	DCM, BACS	C, O
D15	F	83	Son	50	DCM, BACS	N
D16	M	78	Wife	78	DCM, BACS	I, O
D17	M	90	Daughter	64	DCM, BACS	I, O
D18	F	85	Daughter	55	DCM, BACS	C, O
D19	F	80	Son	41	DCM, BACS	N
D20	M	88	Grandson	31	DCM, BACS	I, O
D21	M	88	Daughter	55	DCM, BACS	I, O
D22	F	89	Son	49	DCM, BACS	N
D23	F	88	Son	45	DCM, BACS	I,C
D24	F	87	Son-in-law	52	DCM, BACS	I, O
D25	F	86	Daughter	78	DCM, BACS	N
D26	F	86	Son	53	DCM, BACS	C, O
D27	F	78	Husband	78	DCM, BACS	N
D28	M	83	Wife	82	DCM, BACS	N
D29	M	86	Wife	72	DCM, BACS	I, O
D30	M	80	Daughter	48	DCM, BACS	C, O
D31	F	78	Son	53	DCM, BACS	C, O

DCM = Dementia Care Mapping, BACS = Beliefs about Caregivers Scores, O = Observation, C = interview at bedside, N = not recruited

Table 6.4 provides an overview of the data collection methods and the number of participants who completed each phase

**Table 6.4 Overview of data collection methods and participants.**

	Participants	Sample size
<b>Phase 1 quantitative N=31</b>		
Dementia Care Mapping	Dyads	31
Beliefs about Caregiving	Family caregivers	30
<b>Phase 2 qualitative N=18</b>		
Interviews	Family caregivers	10
Informal interview	Family caregivers Patients	7 1
Participatory observations	Dyads	18

## 6.3 Result

### 6.3.1 Phase 1- Quantitative results

#### 6.3.2 Patient outcome measures

The patient data demonstrates a wide variation in the patient's well-being scores from moderate levels of well-being (+2.4) to low level (-2.9). Similar to the Functional Assessment Staging Tool (FAST) (Reisberg, 1988) used to measure physical and cognitive function the range is wide, however, the Standard Deviation is small reflecting a homogenous group regarding physical function, living with moderately severe levels of dementia and well-being. The Montreal Cognitive Assessment (MoCA©) (Nasreddine, 2005) used to measure the patients' level of cognitive function and the patient's calorie intake also show variation in their scores, however, the Standard Deviation reflects the patient group as a heterogeneous group in terms of cognitive ability and calorie intake. These results can be seen in Table 6.5.

**Table 6.5 Patient outcome measures - Phase 1**

Outcome	Mean/Range	SD
Well-being	0.09/ -2.9 - +2.4	1.55
MoCA	5.55/0-24	7.47
FAST	6.83/4-7.8	0.71
Calories	841.12/1200-200	274.59

### **6.3.3 Calorie intake**

Nineteen family caregivers stated their relative was not eating enough, eight said they were eating, while four were unsure. The patients considered to be eating were on average taking 1000 calories per day, which is below the recommended daily intake of 2,000- 2,400 for men aged 70+ and 1,600 – 2000 for women aged 70+ depending on activity levels according to the Office of Disease Prevention and Health Promotion (2015). Those considered not to be eating enough and those where the family caregiver was unsure, had a calorie intake well below that recommendation. In summary, all patients in the study were eating less than recommended as seen in Table 6.6.

**Table 6.6 calorie intake**

Calorie intake per day	Mean	SD
Eating	1002	272
Not eating	721.38	335.78
Unsure	800	216

### **6.3.4 Family caregiver outcome measures**

#### **6.3.4.1 Beliefs about Caregiving Scores (BACS)**

Table 6.7 presents the quantitative data for the family caregiver's nurturing and monitoring scores which demonstrates heterogeneity. This data and the patient data in Table 6.6 were used to address the quantitative proposition.

**Table 6.7 Family caregiver outcome measures – Phase 1**

Family caregiver		
Nurturing scores (N=30)	Mean/Range	16.57/12-25
	SD	4.12
Monitoring scores (N=30)	Mean/Range	45.60/16-60
	SD	10.01

## **6.4 Phase 1 – Quantitative results**

In this section the quantitative proposition is addressed by testing the following hypothesis:

### **6.4.1 Hypothesis 1 – Patients with dementia who are in well-being have a greater calorie intake than those who are in ill-being.**

A Mann-Whitney U test revealed a significant difference in the calorie intake of patients in well-being ( $Md = 1000, n = 18$ ) and those in ill-being ( $Md = 600, n = 18$ ),  $U = 68.00, z = 2.437, p = .014, r = 0.57$ .

### **6.4.2. Hypothesis 2- Patients with dementia have higher well-being scores when their physical function score is high.**

The relationship between the patient physical function (measures using FAST) and patients' well-being was investigated using Spearman's correlation coefficient. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, and homoscedasticity. There was a significant negative correlation found between the two variables,  $\rho = -.438, n=31, p = .014$

### **6.4.3. Hypothesis 3 – Patients with dementia have higher well-being scores when their cognitive function scores is high.**

The relationship between well-being (as measures DCM) and cognitive function (measured using MoCA© scores) was investigated using Pearson product-moment correlation coefficient. Preliminary analysis was performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity as detailed above. There was a significant correlation between the two variables,  $r=.412, n=31, p < .021$ .

### **6.4.4. Hypothesis 4 – Family caregivers monitoring scores predict the level of well-being of the patients with dementia**

The relationship between caregivers' monitoring (as measured by the BACS) and patients' well-being was investigated using Spearman's correlation coefficient. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, and homoscedasticity. There was no significant correlation found between the two variables,  $\rho = .056, n=30, p = .771$ .

### **6.4.5. Hypothesis 5- Family caregivers nurturing scores predict the level of well-being of the patients with dementia**

The relationship between caregivers' nurturing (as measured by the BACS) and patients' well-being was investigated using Spearman's correlation coefficient. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, and homoscedasticity. There was no significant correlation found between the two variables,  $\rho = .332, n = 30, p = .074$ ;

however, the significance score shows a tendency, and perhaps if the sample had been bigger, there would have been a positive, significant relationship between nurturing and well-being.

#### **6.4.6 Summary**

The results above demonstrate:

- 
- Patients in well-being have a higher calorie intake than patients in ill-being at mealtimes.
- The patient's level of well-being is positively associated with physical function scores.
- The patient's level of well-being is positively associated with cognitive function score.
- The patient's level of well-being is not associated with the family caregivers monitoring score.
- The family caregiver's nurturing score is not associated with the patient's well-being score. However, these results suggest a tendency.

#### **6.4.7 New quantitative proposition:**

The evidence presented above lead to a redrafting of the phase 1 proposition from:

Family caregiver's beliefs about their caring role are associated with their relative's well-being when they refuse to eat.

To

Family caregiver's beliefs about their nurturing role plus the patient's calorie intake, cognitive and physical functioning are associated with the patient's well-being scores.

### **6.5. Phase 2- Qualitative results**

In this section the findings from the interviews, observations and the personal detractors and enhancers from Dementia Care Mapping are presented with the intention of answering the following questions:

- 1) Which elements of Kitwood's person-centred framework are observed in the family caregiver's behaviour at mealtimes?
- 2) What are the experiences of family caregivers at mealtimes?

Eighteen family caregivers and one patient were interviewed. Six of the interviews with family caregivers were by the bedside with notes taken at the time, and greater detail added immediately afterwards. All eighteen dyads took part in participatory observations, and their demographics are presented in Table 6.5.

Nine family caregivers consistently demonstrated person-centred care (PCC) during mealtimes, with nine family caregivers not providing person-centred care (NPCC), when analysed against Kitwood's framework (Table 2.1). The groups' demographics are presented in Table 6.6. Each of the five elements of the framework, comfort, identity, attachment, occupation and inclusion (section 2.3) are discussed in turn. Two themes, acceptance and enmeshment and how these fit with the social theory of attachment style (Bowlby, 1969) is also presented. Both sections include dialogue extracts from interviews and field notes from observations to provide contextual meaning and supporting evidence for these findings.

		Phase 2 Patients	Phase 2 Family Caregivers
N=		18	18
Age	Range	77-90	31-80
	Mean	85.41	57.59
	SD	4.91	13.88
Gender	Female	11	11
	Male	7	7
MoCA	Mean	3.82	
	SD	6.21	
FAST	Mean	7.16	
	SD	0.41	
Calories	Mean	696.47	
	SD	345.61	
Place of residence	Own home with family carer	78% (14)	
	Own home alone	0	
	Own home with family	6% (1)	
	Residential home	17% (3)	
Type of dementia	Alzheimer's	89% (16)	
	Vascular	6% (1)	
	Other	6% (1)	
Ethnicity	White British/ British	50% (9)	55 % (10)
	Caribbean	22% (4)	12% (2)
	European	6% (1)	22% (4)
	South Asia	6% (1)	6% (1)
	Irish	0	0
	African	17% (3)	6% (1)
Religion	Christian	67% (12)	61% (11)
	Muslim	22% (4)	22% (4)
	Jewish	6% (1)	6% (1)
	Atheist	6% (1)	12% (2)
Education	"O"/ "A" level/ Certificate	6% (1)	33% (6)
	1 <sup>st</sup> Degree	6% (1)	33% (6)
	Higher degree	6% (1)	0
	Professional qualification	0	6% (1)
	Trade qualification	6% (1)	0
	No qualifications	78% (14)	27% (5)
Occupation	Housewife	44% (8)	0
	Trades person	28% (5)	27% (5)
	Professional	6% (1)	39% (7)
	Manual worker	22% (4)	12% (2)
	Carer		12% (2)
	Retired		6% 1
	Student		6% (1)
Relationship	Adult child		56% (10)
	Spouse		27% (5)
	Nephew		6% (1)
	Grandson		6% (1)
	Son-in-law		6% (1)

**Table 6.8 Demographic data of participants in phase 2**

**Table 6.9 Phase 2 – Family Caregiver Demographics: person-centred care (PCC) and not person-centred care (NPCC)**

	N=9 Family caregiver PCC	N=9 Family caregiver Non-PCC
Range	31-64	52-73
Mean	55.4	64.7
Female	4	6
Male	5	3
<b>Relationship</b>		
Daughter	4	3
Son	2	1
Wife	1	3
Husband	0	1
Other	2	1
<b>Ethnicity</b>		
White British	3	3
British	2	2
Caribbean	1	1
European	2	2
South Asia	0	1
African	1	0
<b>Religion</b>		
Christian	6	4
Muslim	1	1
Jewish	1	1
Atheist	1	3
<b>Education</b>		
"O" or "A" level or Certificate	2	4
1 <sup>st</sup> Degree	2	3
Higher degree	1	
Professional qualification	1	0
Trade qualification	1	0
No qualifications	2	2
<b>Profession</b>		
Housewife	0	2
Tradesperson	2	3
Professional	4	3
Carer	2	0
Retired	1	1

### **6.5.1 Let the mealtime battles begin**

To provide context to the setting in which the observations took place a summation of mealtime experience is provided below. Codes are used to preserve the anonymity of the participants<sup>1</sup>. All but one of the observations took place in four bedded bays across three wards. The mealmates observed involved the ward hostess serving the patients at their bedside with the patients either sitting in bed or sitting in the chair next to their bed. Lunch and supper comprised of three courses, soup, main meal and dessert, pre-plated as ordered the day before by the patients and family caregivers. If the patient needed a special diet for example, of puree consistency, the consistency would be prescribed by the speech and language therapist, with the choice of food selected by the patient or their family caregiver the day before and served at the same time as the other meals.

The nursing staff did not participate in the mealmates of patients when their family caregivers were present except to ensure they had everything they needed. They focused on the patients without visitors of whom were the clear majority. The policy of protected mealmates was in the most part adhered to with the nursing staff giving their attention to the nutritional needs of their patients. However, often there was a patient who needed other forms of personal care that took priority over food service, and this was at times disturbing for those eating if the patient receiving the care was distressed. This also meant some patients had to wait for the help they needed until the staff were free. Sometimes the family caregivers in the study helped those patients who were left waiting (D7, D17, and D24).

The amount of support each patient required to eat varied from simple prompting to providing full assistance. Throughout each meal, the actual amount of help given by the family caregivers could change, with moments of full feeding interspersed with the patient feeding themselves.

One family caregiver (D20) stayed 24 hours a day with their relative so were on the ward for breakfast, as well as lunch and supper, others stayed for long periods of the day being present for both lunch and supper (D2, D6, D7, D8, D13, D16, D17, D22, D24, D26 and D29). While others (D12, D14, D18, D23, and D31) timed their visits to coincide with mealmates as other commitments allowed.

<sup>1</sup> Participants are referred to by their dyad number, i.e. D1, prefixed by F for family caregiver and P for patient, PCC for person-centred care group, NPCC for non-person-centred care group, NPCC for non-person-centred care group plus two surprise cases. O also prefixed family caregivers and patient references if an observation was made or I if interview data is quoted

When the family caregiver was present before meal service, behaviours that supported their relatives need for comfort was observed.

Observation field notes;

F2 “sat in close to his relative reminiscing about holidays they had spent in Italy.”

F8 “sat close kissing him on the cheek”.

The relatives would be sitting chatting to their relative, bringing them up to date on family matters and issues around the house;

Reflective journal;

“This was a nice time to be an observer, seeing family caregivers and their relatives engaging as relatives rather than family caregivers.”

The more outgoing family caregivers developed relationships with the visitors of other patients and shared stories of their relatives past often with great warmth and pride, (D7, D8, D18, D26, D29) supporting their relatives need of identity. They also gave the visitors updates on their relative's progress, telling them if anything had happened, for example, how they slept and what the nurse did or did not do when they were not there.

Lunch was served at around at 12.30-13.30, supper at 17.30-18.30-; as the mealtime approached family caregivers would start to prepare their relative both physically and psychologically.

Physically, by arranging their bedside table, pouring a drink, making them comfortable. To prepare their relative psychologically the family caregivers would inform their relative it was nearly mealtime, telling them they must be hungry and how important it was for them to eat. Often, they would refer to the need to eat in order for them to get well and go home (D7, D16, D24, D29). These conversations sustained the need for inclusion. However, in the case of D16, this was, in fact, a lie as the patient was to be discharged into a care home, without them knowing, undermining their need for attachment through trickery.

The family caregivers either positioned themselves in front of their relative or at their side, most would sit, but some stood (D8, D12, D14, D18) creating an imposing presence. Two family caregivers (D12 & D18) who came especially for mealtimes were often late.

D18/O “The relative arrived 5-6 minutes after the meal had been served. There was a flurry of activity, saying hello, making apologies for the lateness to the patient, the staff and other relatives while getting the food ready. This created a sense of anxiety as the patient appeared “outpaced.”

F13, F18 and D12 seemed to have clear expectations about how much their relative would eat at each meal and were not leaving until this expectation had been met.

*D12/O “40 minutes go by with D12 still trying to “wake up” her relative, using a syringe of water she had been trying to get her to drink. When her relative buried her head in the pillow D12 shock her head and pulled the pillow away. Her mother opens her eyes. The daughter gets a small banana from her bag and a small spoon and begins scraping the banana with the spoon and giving it to her mother, which she eats with no resistance. The daughter smiles at me, and I smile back. We talk again this time about how as a nurse I would not have spent 40 minutes trying to get a patient to eat not because I didn’t have the time but because I would interpret the behaviour as not wanting to eat and I would respect this. She replied, “I understand this but it’s my mother, I have to keep trying otherwise I can’t rest”. I asked, “Do you feel better now she has eaten the banana?” “Yes, now some water.”*

The continued attempts to get her mother to drink led to a fractious encounter where the family caregiver accused the patient of deliberately being difficult, disregarding her reality, forcing her to drink and once again undermining her need for attachment using intimidation as a means to achieve their expectations. A second daughter D18, would start the meal by setting out the expectations of how much her mother was to eat, yet one mouthful in and the battle began:

*P/18 “No more, no more.”*

*F18/O: “Don’t tell me that, you cannot tell me that, I will decide when you have had enough, you have not had enough”*

*P/18 closes her mouth*

*F18/O: “Open, open. If you don’t eat you will be fed with a tube” holds her hands down and forces the spoon into her mouth.*

The family caregivers had various practical strategies to encourage their relatives to eat. All started with the soup, most pouring it in to a cup if the patient could hold it themselves, promoting empowerment, (F2, F22, F24 and F26) any soup left over was poured over the main

meal using it as a gravy to provide a bit more moisture, making it easier to eat. Patients were never allowed to eat their dessert; first, they were all encouraged to eat the main meal first.

Only one family caregiver (F23) brought food in from home, the rest provided snacks to tempt their relative between meals, but their meals were hospital food.

For most of the family caregivers (F6, F7, F8, F16, F17, F20, F22, F23, F24, and F26) the arrival of the meal was taken in their stride, the mood remained calm as they continued talking with their relative positively, saying how good the food looked or smelt, taking it out the wrappers adding salt and pepper letting them dictate the pace. For others (F2, F12, F13, F14, F18, F29, F30 F31) the arrival of the meal signalled a change in atmosphere, the tone of their voice changed, their body tension changed, a sense of strain come to the fore and as the mealtime continued this strain would for some (F2, F12, F13, F14, F18, F29, F30, F31) increase to outward shows of exasperation toward their relatives situation.

When the patient said, they did not want to eat, or when they told their family caregivers, they had had enough different levels of persistence were seen between the family caregivers. There were those who would just keep repeating in a relaxed manner how important it was to eat (F6, F7, F16, F24). Some would stop, (F17, F20, F24) put the tray to one side for a few minutes and talk with them about something else, watch some television, then start again, perhaps 3 or 4 times per meal. Other forms of persistence included one family caregiver (D8) tirelessly standing over her relative for 45 minutes twice a day for 14 days tapping the spoon of food on his bottom lip while he held his mouth closed creating an imposing scene in which the patient ate three teaspoons of the main course. Other patients were subjected to having the spoon of food pushed into their mouth when they did not want any more. F8 and F13 ate dessert without protest, but not the main meal, yet their relative insisted they ate both and continued to try to push or tap the spoon against their closed mouth.

F13/O: “He needs good food in his belly”, and F8 was very clear a closed mouth was not her relative saying he did not want to eat as “He can’t talk”.

Where anxiety levels were already high refusal to eat or to stop when it was felt not enough had been eaten was met with varying levels of insistence rather than persistence. Four family caregivers (F2, F29, F30, and F31) used a very matter of fact approach, creating an environment where there was no place of disagreement; the food was put into the patient’s mouth with their

protests mostly ignored. Often it felt the patient was being outpaced as more food was put into their mouth despite not having finished the last spoon full. As the meal continued and F2's relative continued to insist she did not want any more food he used verbal threats, as well as putting more food in her already full mouth, telling her he would not visit tomorrow if she did not eat and that she had been bad. Others, F12 and F14, tried to force food into their relative's closed mouth using a syringe, which their relative tried to reject but were held down until their futile resistance ceased.

Where patients were physically able, this insistence created a palpably hostile environment (F12, F13, F14, F15 and F29). Unlike F8, and F31, whose dementia was so advanced they were unable to move their head away or to raise a hand to demonstrate the rejection of the food, F12, F13, F14, F15, and F29 were physically more able to resist the imposition and intimidating behaviour of their relative and demonstrate their disapproval. Their show of disapproval resulted in a physical battle between the dyads, with the patients pushing the spoon away, turning their head into the pillow, covering their face with the bed sheet, shouting, swearing and spitting. In turn, the family caregiver would try to hold their hands down, hold their head still, pull the sheet away, trap their hands under the bedside table.

The nursing staff were clearly uncomfortable witnessing this battle between the patient and family caregiver, yet rather than being outraged at what could easily be considered abusive behaviour, the overriding sense from these scenes was one of forced compassion, born out of a desperate need to hold on to their loved one. Once the mealtime was over calm resumed, the battle cries subsided, and family caregivers returned to their role as relative, chatting once again about everyday events.

## **6.5.2 Which elements of Kitwood's framework are observed in the family caregiver's model of care at mealtimes?**

### **6.5.2.1 Comfort**

Defined as the provision of warmth, closeness and a relaxed pace, comfort was observed by all the family caregivers in the PCC group throughout mealtimes, exhibiting a good rapport with their relative:

*F26/O: At the start of the meal the family caregiver explained to her how she had been up all day and how she needed to eat then, go to bed on a full stomach as the kitchen would be shut then. He gently offered her food on a folk, to begin with, she turned her head away. Staying calm and quietly spoken he repeated the need to eat and then she could go to bed. At times she would be restless in the chair, but he just sat in front of her, talking gently*

*reminding her to swallow when she finally took a mouthful. After an hour she said no more, and he stopped, she had eaten half the meal.*

*F23/I: I've arrived, he's really unhappy in the care home, and I have to settle him. I want him to be really calm before he eats because there's no point if dad is just not being dad, you know, not being calm Dad. He's not going to eat. It's a bit like any of us; if we're all over the place, it's not the best time to eat really. Um, so yeah. He could even be punching out. You just have to weigh him up, and I just found that sometimes, particularly in the summer, um, if it's a really nice day, if I think "oh he's not in the mood to eat", I take him out, he'll be nice and calm. Or sometimes I'll take him down to the chapel if it's raining and bring him back up to his room and he can be a different person. So, it's about doing something else sometimes, to actually get to a position, you know, where you feel that you can, he's happy to eat really, and he's calmer, and he's thinking about food rather than something else.*

While able to provide comfort the PCC family caregivers still experienced anxiety, and in some instances, the family caregiver did not always feel relaxed in the moment:

*F26/I: I get agitated, but I don't let her see that. I try not to [inaudible 10:57]*

*Researcher: What do you think drives your agitation?*

*F26/I: The fact that I want her to get... I want to see her get well and to me, it doesn't appear as though she's thinking along those lines and that's what sets in the agitation for me.*

However, they were able to keep these anxieties hidden ensuring the mealtimes were conducted at an easy-going pace in a pleasant atmosphere:

*F20/PCC/O: A good pace, talking and having fun throughout, checking out if he is ok.*

*Demonstrating the food was not too hot by tasting it. Stopped when he said he had enough, waiting 5 minutes, watched TV then asked if he would like some dinner and then recommencing until he said he was finished.*

*F17/PCC/O: Prepares the food by taking it out of the silver container and plating it up. No fuss, relaxed pace.*

*He is easily distracted looking around the ward, his daughter says, "dad, dad" gently to get his attention*

*The patient drops a chip onto the floor which worries him, "don't worry dad it's gone, it's gone" in a gentle, relaxed tone*

*When he indicated he had had enough, by waving his hand, she stops, plumps up his pillows, waits a minute and starts again with minimal fuss; he continues to eat a little more.*

When the researcher arrived on the ward, 10 minutes before meal service, the atmosphere between all the dyads enrolled in the study was calm and relaxed:

*F2/NPCC/O: Sitting together waiting for lunch, talking gently and holding hands. Both engaged in reminiscing about trips to Italy when they had pasta. Pasta was on the menu for lunch today.*

*F8/NPCC /0: Sits in close wakes him with a kiss on the cheek. "It takes patience and love". (to help people eat) she tells me.*

As the mealtime approached the atmosphere changed from relaxed to anxious for the Non-PCC group:

*F2/O and P2/O: Sitting together waiting for lunch, talking gently and holding hands discussing the food and what to eat next and what they had for breakfast.*

*As Lunch arrives the scene changes:*

*P2/O: On seeing the meal, "I feel sick."*

*F2/O puts food into her mouth.*

*P2/O "Your pushing me too far, you're making me feel sick."*

*F2/O "you always say this why?"*

*P2/O "because you keep pushing me, you're pushing me, if you push me any more I'll push the plate on your head.*

*F2/O continues putting food in her mouth*

*P2/O "I don't want any more, please, don't do this to me, why do you do this to me, why don't you listen? I don't like it; you're forcing me."*

*F2/O "I know, but it's good for you."*

In his desire and anxiety for his wife to eat this family caregiver could not hear his wife's calls for comfort. He did not acknowledge her feelings or demonstrate empathy; his focus was on getting the food into her.

The difficulties people with dementia experience regarding eating as described in section 3.3 can be a source of high anxiety for both the patient and their relative (Ball et al. 2015; Bunn et al. 2016), which can affect their behaviour. In contrast to the NPCC caregivers, the PCC caregivers were able to continue to provide comfort when their relative refused to eat through emotional and physical closeness and maintaining a relaxed atmosphere.

*Researcher: "Can you talk me through a mealtime, how that starts and what you do?*

*F24/I: "Well, it depends on what mood she's in to begin with. If she's in one of those moods where she's not really willing to cooperate or no – I shouldn't say willing to cooperate, where she's probably feeling a bit frustrated at her inability to help herself because she was an active person before. It's a question of trying to coax her. Talk to her and try and get her to understand that whatever I'm doing is for her own benefit, that she needs to eat, she needs to build her strength back up; she needs to drink to keep her body hydrated and to keep her kidneys functioning properly and so on. And after a bit of persuading, she will understand that and begin to [inaudible 01:57]*

Where comfort was not evident, intimidation defined by Kitwood (1997 Pg. 46) as, "making the participant frightened or fearful by using spoken threats or physical power", was often seen. Some of the behaviour observed by the NPCC group started moderately intimidating but soon as the patient tried to be heard the intensity increased, ending with the patient in distress:

*F2/O "One mouthful more"*

*P2/O "Can't we call this done?" (Crying) "I'll be on the floor in a minute you have no idea."*

*F2/O puts a folk full of mash potato into his wife's mouth.*

*F2/O, "do you want the soup back"? I can't give up on you". Puts the soup cup back into her hands and say "just push it down" referring to the soup*

*P2/O "if that makes you happy....give me a chance to breath don't push me."*

*F2/O, "I'm not" pushes cup towards her mouth she takes a sip*

*P2/O, "that's enough now, I like it very much but no more now, say yes so I know."*

*FO/2 "Sinful"*

*P2/O cries out*

Some mealtime interactions began in a highly intimidating fashion, perhaps reflecting the family caregiver's anticipation of their relative's refusal to eat. Here the refusal to eat and the "fight" that ensued was foreseen by the family caregiver who took steps to control the situation from the start:

*F18/O: The meal arrived, and the family caregiver placed it in on the table in front of her relative and used the table to keep her hands trapped under it so she could not use them to push her or the food away as she had done last evening. Putting the food in her mother's mouth, she said, "Swallow then milk, swallow then milk", adding, "Don't grab" as her mother turned her head away and tried to take the spoon, having released her hand from under the table. The patient shouted "No, no" and the battle commenced. This scene continued for 10 minutes until the family caregiver grabbed her relative and held her in a headlock while tried to force the spoon into her mouth. (Researcher intervened).*

*F12/O lets her relative know she is there saying "mummy, mummy" then tries to turn her over so she can "give her something". The patient keeps her eyes shut and turns her head away from the family caregiver who takes a 20ml syringe of water and tries to put it into her mouth, but the patient keeps her mouth tightly closed. This behaviour continues for 5 minutes, with the patient moving her head trying to avoid the syringe, pulling the bed sheet over her head for protection. Then the family caregiver put the heel of her hand on the patient's forehead to hold her head still (researcher intervened).*

Four patients (P12, P14, P18, P29) who experienced intimidation were in some way able to "hold their own". They were able to make attempts at defending themselves from the physical force of their relative either by shouting back:

*P14/O “No, no, go away go away, I hate you, you cow. I don’t want it, ##### off”. Family caregiver continues to hold down the patient’s hands and put a syringe of cold tea to her closed mouth.*

Alternatively, by pushing them away:

*F12/O held her relative’s hands down as they “fought”, with the patient trying to pull the sheets over her face and buried her face in the pillow to stop the family caregiver pushing the syringe into her mouth.*

In contrast, F2 tried to talk to her husband to get him to stop intimidating her; she did not fight or shout instead she attempted to explain how he was making her feel. She did not raise her voice, but pleaded with him to stop, like the other patients who tried their best to communicate their wishes this family caregiver did not hear her and he did not stop:

*P2/O “I’ve had enough for one day”. Family caregiver pours soup into a cup and hands it to her, she takes it and takes a sip “I can’t do any more (starts to cry)*

*F2/O “tea, toast?*

*P2/O “are you pushing me now; do I have a choice?”*

*F2/O puts soup into her mouth.*

*P2/O “I don’t want to argue I love you.”*

Five other patients (P8, P13, P29, P30, P31) who experienced this level of intimidation were not observed holding their own. These five patients had very advanced dementia (Fast score 7.2-7.8), and as a result were unable to move their head away, push the cup away or call out, the only means of communicating their objection was to keep his mouth shut.

*F13/O, forces the spoon into his mouth, “take, take, take, take, take fish take, take, take good, good, good, good (repeats his name three times) (Forces the spoon into his mouth) “Buba eat, eat”.*

*P13/O keeps his mouth shut*

*F13/O “Try Ensure, he likes Ensure” He takes the Ensure with ease*

*F13/O forces water into his mouth, MrO13 coughs and pushed the cup away.*

*F13/O, “He hits me at home (when I try to feed him), so I have to hold his hands”. Holding his hands down under the bed sheet she forces the spoon into his mouth, most drops on his chest as he moves his head away, she cleans it up.*

In summary, both sets of family caregivers demonstrated their concern and anxiety about their relative’s eating behaviours, yet the PCC group were able to keep these emotions in check and continue to behave in a manner that met their relative’s need for comfort. In contrast, those in the

non-PCC were unable to control their strong emotions which manifested as intimidation, resulting in a battle of wills with both patient and family caregiver in a state of relative ill-being.

#### 6.5.2.2 Identity

Identity within Kitwood's framework (1997) recognises that despite the advancements of dementia the core uniqueness of the person remains intact and includes a sense of respect, acceptance and celebration from caregivers.

During the interviews with family caregivers those in the PCC talked about the persons' identity, respecting their feelings and wondering why they were not eating. They were able to relate to their relative having a sense of continuity with the past; whom they used to be, how they used to respond before the onset of dementia and acknowledged their current behaviour as not dissimilar from that before the onset of dementia:

*F24/I: It becomes a bit frustrating to me because I know that she needs to eat, but at the same time, I try to understand why she's not eating. I would say, you know "what was your night like?" for example if it's at breakfast time. And I would know straight away that if she didn't have a very good night's rest, then that will have an impact on whether or not she'll want to eat.*

*F21/I: But you know, sometimes if he doesn't want to eat he just doesn't want to eat. You're not going to make him; my dad's really determined, you know. He knows whether he wants to eat or not. You can say what you want to him but at the end of the day, no. If he doesn't want to eat, he doesn't want to eat.*

*D17/I: "I noticed she's (nursing assistant) quite forceful, and I don't like – that's what I didn't like. He had his mouth shut, and she was trying to force the spoon in. It was so bad I had to say to her, "Look he doesn't want anymore, you know?" That's what I don't like. I don't think it's their fault, I know he should eat but if he really doesn't want it or it could be that he doesn't like it or that it tastes funny, we don't taste the food, you know? But you know, he wasn't taking it in, and I don't like [inaudible 07.13] I don't like that. I thought, you know, stop if he doesn't want it. You know he has good days and bad days, you know don't try and force him like that, that's what I was thinking."*

*F6/I: "Well if she doesn't eat, I just leave her, I can't just force her".*

However, those in the NPCC group failed to acknowledge their relative's identity in the interviews and were observed to fail to respect their identity in the form of denying choice:

*Researcher: By closing his lips to the food is he making a choice not to eat?*

*F8/O, "Choice, what choice?"*

*Researcher: "Does he have a choice?"*

F8/O, "look at him, how can he choose?"

Researcher: "by closing his mouth."

F8/O: "He has no choice."

Researcher: *Do you think he is trying to tell us something when he keeps his mouth shut?*"

F13/O "No, nothing, he can't speak."

Researcher: *"Do you think your mother is saying something by refusing to eat?"*

F31/O "No my mother would not refuse to eat, she would not choose to die."

One daughter in the NPCC acknowledged her mother's behaviour as communicating her wish not to eat and considered why this might be:

F12/O: *"Maybe she is fed up with this life, she is distressed by this (feeding her), she does not recognise us or talk to us, it's no life, but she may take it if I try".*

Nevertheless, she continued to try to get her mother to take water from a syringe forced into her mouth:

F12/O *held the patient's hands down and they "fought", with the patient trying to pull the sheets over her face and bury her face in the pillow.*

Kitwood terms this behaviour invalidation, "failing to acknowledge the subjective reality of the person's experience and especially what they are feeling" (Kitwood, 1997 Pg. 47), thereby creating an emotional distance that diminishes trust.

To summarise, family caregivers in the PCC group recognised and respected their relative as "self", despite their failing cognitive ability and were able to support their need for identity. For the non-PCC group, it appears their relative's failing cognitive ability signals a fading of the persons "self", resulting in behaviour that denies them the choice, undermines their need for identity and leaves their relative exposed to behaviours of invalidation.

#### **6.5.2.3 Attachment**

Attachment refers to the bonding or connection with others, providing a relationship that affords security and trust which includes validating their reality, being sensitive to their needs and valuing them as a unique individual (Brooker & Surr, 2010).

Here we see how a relative in the PCC group acknowledged her husband's reality:

F16/I: *"The other evening I went in there, and he said "all the angels are talking to me", and I said, "oh that's kind of them, that's nice to have angels talk to you".*

The statement did not faze her and she did not try to correct him or make fun of him, she accepted what he had said and demonstrated respect.

There were dyads in the PCCC group in which a unique relationship existed; where only that one relative from the whole family could provide the necessary care and support:

*F23/O needed to go to the bathroom before lunch but would not go with the nurse. Her son arrived shortly after the several attempts.*

*S23/O: Talking to mum about getting up and walking and how important it was for her to stay active, she smiles and touches his face. Then he takes her hand, and they walk to the bathroom.*

*Researcher: "I see your son helps you to eat, can the nurse help you to eat as well?"*

*F23/I: "Oh no my son helps me" (to eat)*

*Researcher: "Can a nurse help you?"*

*F23/I: "I don't know them, but I know my son."*

*F/21/I "Dad does not eat if I'm not here, I guess because I know what he likes and how he likes it, I know his ways, and he knows mine". It's difficult for the nurses when I'm not here, but I guess he doesn't know them."*

Within these relationships, a close bond had been established in which the family caregiver was the only person who could support the patient in these activities. This could have been a burden to the family caregivers, but this was not expressed or demonstrated.

There was more to this attachment than merely knowing the person better than another. This attachment was unlike that referred to by Kitwood which he directed at professional carers (1997). This attachment was in the context of Bowlby's (1969) attachment theory in which attachment is defined as, "an enduring affectional bond of substantial intensity with a significant other", has developed over time. The social theory of attachment style (Bowlby, 1969) acceptance and enmeshment emerged during the data analysis and are discussed further in section 6.4.

#### **6.5.2.4 Occupation**

Occupation refers to being involved in life (Drooker & Surr, 2010) having a meaningful say in all activities whether those activates are hobbies or daily tasks and includes behaviours of empowerment, facilitation, enabling and collaboration.

The PCC family caregivers demonstrated these behaviours consistently, enabling their relative to eat as independently as possible, making sure they had everything they needed, opening the packaging, ensuring everything was in reach. Alternatively, the NPCC family caregivers

disempowered their relatives preventing them from taking an active part in the activity and using imposition to force them into eating when they had expressed their desire not to eat:

*F18/O says "good job" then mother spits the food out.*

*P18/O: "I'm not hungry."*

*F18/O: "Of course you're hungry, just eat it, just swallow, I'm not going away, I can be here all night."*

*P18/O opens her mouth to scream family caregiver puts the spoon in the patient's mouth which she spits out*

*P18/O: "No more."*

*F18/O: "Don't say that to me, you are not allowed to starve, you can't deprive your body of nutrition it's a sin."*

*P18/O: "I don't want any more."*

*F18/O "Too bad, too bad. Don't touch anything just eat."*

*P18/O: screaming arr arrh "I don't want it."*

*F18/O: "Don't say that just eat it."*

*P18/O: "No more."*

*F18/O: "No don't say that you can't say that, you have not eaten anything."*

*P18/O opens mouth to scream family caregiver puts the spoon in the patient's mouth which she spits out again.*

*F18/O: Don't do that, swallow, how would you like it if when I was a child, I spat my food out?*

*P18/O: "You did. No more, no more."*

*F18/O: "Don't tell me that, you cannot tell me that, I will decide when you have had enough, you have not had enough"*

*P18/O: closes her mouth*

In summary, the need for occupation was met by the PCC family caregivers in conjunction with meeting the need for comfort, identity and inclusion demonstrating how these elements overlap. When these elements are not displayed the patient is vulnerable to extreme behaviours from the family caregiver that undermine the patient's self-esteem and person-hood.

#### **6.5.2.5 Inclusion**

Inclusion involves the person feeling included in the social world around them either physically or verbally. A carer can be in physical contact with a person providing personal care yet still fail to include them on a social level. One family caregiver referred to this when describing how a home carer worker was helping his mother to eat:

*F7/I: "I told them, she's not a cement mixer you know."*

Inclusion was very evident in the PCC group who approached mealtimes as a social opportunity, similar to mealtimes outside of the hospital, sitting close to their relative, positively chatting about the food, as well as making everyday conversation:

*P23/O: the patient takes her time eating small bits at a time while the family sit and chat together with her eating a little as well. There was no great focus on the food despite the fact she ate only a small amount. The conversation was about her friend from church whom I do not think she remembered by name, but her son jogged her memory by reminding her of where the friend sits in church. Once she remembered the friend, she engaged in the conversation more, nodding as they talked.*

While the NPCC group showed little in the way of inclusion during mealtimes, mealtime felt more task driven, a time to focus on calorie intake rather than a social event to be shared and enjoyed.

#### **6.5.2.6 Summary**

Those family caregivers who delivered PCC appeared to prioritise the psychological needs of their relative over their physical needs. The need for comfort was the element most often seen being met. By meeting this need other overlapping needs were met, for example, by providing comfort which encompasses warmth and security, the person becomes more relaxed, able to engage with their environment and other people which provides occupation, boosting their self-esteem, which may, in turn, increase their sense of identity.

*F20/O “does it taste ok granddad?”*

*P20/O “it’s ok.”*

*F20/O “just ok, oh sorry about that, more salt.”*

*P20/O “nope, I’ve had enough” (eaten two spoons of the main course)*

*F20/O “Ok shall we carry on watching the film then?”*

*F20/O “Yep”*

*F20 move the food away, and they watch an old war film on a portable DVD player he had brought in from home for about a minute or so chatting about the actors:*

*F20/O “Great actor, one of our favourites, hay Granddad?”*

*P20/O “yep.”*

*F20/O “We like this film a lot, what others do we like? Green Beret that’s a top one, oh and a good western, can’t beat a good western can you, John Wayne, Clint Eastwood?”*

*They watch the film for a few more moments*

*F20/O “fancy a bit of lunch Grandad?*

*P20/O “Yep”*

*He eats half of the meal while watching the film while the grandson chats about the film.*

**Comfort**-Grandson demonstrated genuine concern for his grandad, asking if the food was ok and showed empathy when it was not ok.

**Identity**-Grandson accepted his granddad did not want to eat anymore

**Inclusion**-sat watching the film together enjoying each other's company

**Attachment**-there appears to be a connection between the two

**Occupation**-Grandson encouraged participation in watching the film, he brought the DVD player in from home, asked what film his grandad would like to watch and engaged with him while they watched.

In contrast, those in the NPCC group appeared to prioritise physical needs and the importance of nutritional intake over psychological needs at mealtimes. Prioritisation of physical needs by the NPCC group led to strategies of imposition, intimidation, invalidation and withholding when their relative would not eat:

*P31/O was sitting in bed with her family caregiver sitting next to her pushing a piece of orange into her mouth; she keeps her mouth shut turning her head away from him.*

*F31/O “stop this, you want to die, do you?”*

*P31/O turns her head back but keeps her mouth closed*

*F31/O “don’t do this to me, come on you like orange, come on, this is ridiculous, you are hungry don’t tell me you’re not.”*

*P31/O closes her eyes, and a tear runs down her cheek*

*F31/O “I’m sorry mother, but you will feel better if you just eat something, just eat something.”*

*She did not eat the fruit, and he left the ward without saying goodbye.*

Despite the patient’s evident psychological distress her relative continued to use strategies of

**Imposition**- forcing fruit into her mouth

**Intimidation**- saying, “Do you want to die, do you.”

**Invalidation**- denying her reality and choice.

**Withholding**- leaving without saying goodbye or if he would return

The maintenance of person-hood as suggested by Kitwood (1997) emphasises the psychological and social psychology of the individual in relation to others and the ability of those in the relationship to provide emotional support at a time of high stress and loss.

Despite the homogeneity of the family carers, their observed behaviours at mealtimes were different in terms of person-centred care and the acceptability and applicability of Kitwood’s framework.

Of note patients who did not experience person-centred care were able to hold on to a sense of self and assert their personhood by physically fighting back, shouting, or by keeping their mouth closed tight when being forced to eat. They did not need to have personhood bestowed upon them by others despite the advancement of the disease. This is an important finding that supports the work of Smebye & Kirkevold (2013) in demonstrating patients with advanced dementia do not

need personhood “bestowed” upon them as they remain agents of “self” through their action and this is discussed in greater detail in chapter 7.

The differences in family caregiver behaviours identified above were identified through the search for disconfirming cases as part of the analytic induction methodology outlined in section 4.6.2.1.

#### **6.5.3.1 What are the experiences of family caregivers at mealtimes?**

The experiences of the family caregivers at mealtimes centred around acceptance of their relative’s situation and how emotionally involved they were in their caregiving role. The strength of these experiences appears to originate from their attachment style with their primary caregiver. During this phase of the analysis, two surprise cases were identified. The surprise cases were family caregivers (F21 and F26) from the PCC group who were considered, according to Kitwood’s framework (1997a Pg. 45) to be providing person-centred care during mealtimes but mirrored the behaviours of the NPCC outside of mealtimes. These mirrored behaviours included acceptance issues, a willingness to be enmeshed in the caregiving role and an anxious attachment style. For ease of reading, the two surprise caregivers and the NPCC group will now be referred to as the NPCC2 group, in acknowledgement of the two surprise family caregivers added to the group. The two-surprise family caregiver’s identification number will be prefixed with the word, “surprise”.

#### **6.5.3.2 Acceptance**

Acceptance is considered to be an ability to accept objectively unfavourable and unalterable situations. Some of the first works in the area of acceptance in family caregivers of people living with dementia was conducted by Blom and Duijnstee (1995), who state family caregivers who can accept the changes in their relative’s abilities and behaviours take this in their stride, being able to adapt and be flexible. During the interviews with the family caregivers in this study, acceptance surfaced in discussions about the diagnosis of dementia and family support, in particular the acceptance of the inevitable physical and cognitive decline associated with dementia including a decline in calorie intake. The subthemes, “not giving up” and family support were identified and are discussed below.

#### **6.5.3.3 Diagnosis**

Analysis of the data demonstrated the PCC group of family caregivers were able to accept the diagnosis of dementia, in some cases actively seeking out the diagnosis.

*F6/I: “She used to be with my sister until my sister left to go abroad for a couple of months, so she bought her and then I am the one who took her to be checked for*

*Alzheimer's. She had it but nobody took her and then I took her, and then they diagnosed her, and from there she just stayed with me."*

Those in the NPCC2 group were less able to accept the diagnosis.

*Researcher: "I understand you brought your mother from the States (United States of America) to England."*

*NPCC/F18: "Yes, my brother and sister had her in a care home there diagnosed with dementia, she did not have dementia. I took them to court and moved her here. Only now is her memory failing her, only now."*

One of the surprise cases, also found the diagnosis difficult to accept:

*Researcher: "My first question is when did your mum get her diagnosis of dementia, you spoke to me yesterday about that and said you weren't convinced?"*

*Surprise/F26/I: At the time, she was diagnosed in about 2012, 2013, I think, and she was discharged. I don't believe she had dementia. The diagnosis was, you know like I said, she took a test, she got 25 out of 30, um, to me that's not dementia. The private doctor said she had capacity. Now whether you're saying that 1% of dementia constitutes this, then maybe we all have got dementia. So, as long as you have capacity to say what you want and do, I have no problem with that. But when it impedes that you have been entitled or put in a box that you have dementia and you can't do anything, I think it's absurd."*

#### **6.5.3.3.1 Decline**

Finding the diagnosis of dementia unacceptable was further complicated by the inevitable physical and cognitive decline seen in dementia. As a consequence, the measurable loss of abilities seen in dementia was apportioned to the patient's poor nutritional intake, rather than understood as a consequence of a progressive neurodegenerative disease.

*Researcher: "Have you discussed your mother's future with the consultant, how things might be over the next months or years?"*

*F14/O: "Yes we have had big meetings. It's simple she needs to eat like all of us to survive, but she will not eat, so what can we do, she needs a tube, you know? Then she will be stronger, and she is getting weaker like this. They (the consultant) don't want that. We have to do everything for her as she did for us so we will continue to argue for this."*

*Research: "Why do you think she is not eating?"*

*F14/I “I don’t know, just because she has dementia doesn’t mean she should not eat, we should not make her eat? My sisters wants her alive; I want her alive so she must eat.”*

*Researcher: “You have seen a decline in your mother?”*

*F31/I: “Of course she is declining, she is not eating ...are you going to recheck her swallow like I asked, she is not swallowing because something is wrong there.. or what we watch her starve?”*

A senior speech and language therapist had been involved with this patient and family caregiver for the past month and had concluded the patient’s swallow was affected by the natural progression of her dementia.

Other family caregivers blamed the patient rather than dementia:

*Researcher: “Why do you think she is not eating?”*

*F18/I: “She plays up, always has done...attention seeking, she knows what she’s doing”.*

This statement suggests the family caregiver recognises the “self”; that they acknowledge the person’s identity remains intact. However, their behaviour at mealtimes overrides the person’s self as the family caregiver subjected her to intimidation, threats and physical force. Here her identity is only acknowledged as a negative trait, to blame, rather than to accept.

The inability to accept both the diagnosis and the progressive nature of dementia reflects the family caregiver’s difficulty in coming to terms with the loss of their relative, in terms of the person, the relationship they have with them and their inevitable death. The non-acceptance of their loss resulted in the family caregiver behaving in a way that did not support their relative’s person-hood as seen through Kitwood’s lens.

A surprise family caregiver from the PCC group also found the progressive nature of the disease difficult to accept:

*Researcher: “You say your dad is not eating much.”*

*Surprise/F21/I: “My dad is weak..he does not eat, and they can’t work out why, so I guess he will be able to do less walking and that, you know until they find and treat it?”*

This lack of acceptance of the disease appeared to affect the NPCC2 family caregivers concerning executive decision making for example resuscitation decisions, treatment escalation plans and preferred place of care at the end of life.

Attendance to some family meetings on invitation from the family caregiver highlighted how the families in the NPCC2 resisted entering into these discussions, both in the meetings and during the study interviews:

*Researcher: "How do you see the future?"*

*Surprise/F26/I "let's not start this discussion, I have said before (to the consultant) I will not discuss my mother's death, I will make decisions at the time, not before, sorry I don't mean to be difficult but no, I will not discuss this" His hand was held up as he spoke.*

*Researcher: "Have you thought about what the future may look like for you and your mother?"*

*NPCC/F30/O: "Is my mother dying now? No, so we keep going, do everything, and then we will see. That's it for me."*

*Researcher: "Have you thought about how the future may look for you and your husband?"*

*NPCC/F13/I: "You know we all have our date or time if you like, and when that comes it comes, but while I can I will do everything I will, that's all."*

#### **6.5.3.3.2 Giving up**

Acceptance of their relative's situation was further reflected in the NPCC family caregiver's narrative during mealtimes. Here they talked of not giving up, neither them nor their relative:

Researcher: "I heard you say (.2) to him I'm not giving up; you're going to get better".

NPCC/F8/I: "Yeah I did, I said I'm not giving up on you, you're giving up on yourself, you're not giving up. Do everything possible. You should do everything possible at the right time".

NPCC/F18/O:

P18 "No more."

F18: "Don't say that to me."

P18: "You are not allowed to starve

NPCC/F13/O "take, take, take, take fish take take, take good, good, good good, (calls his name three times). Forces the spoon into his mouth (calls his name) "eat, eat, don't give up eat, eat."

#### **6.5.3.3.3 Family support**

A further similarity noted between the NPCC group, and the surprise family caregivers were their exclusion of other family members. Spouse caregivers in the NPCC were notably caring alone

choosing not to involve adult children or other family or friends to support in care provision or decisions. Adult child carers had actively blocked their siblings for being involved for example through the implementation of a lasting power of attorney (LPA).

*NPCC/F13/I: "No, no-one helps me it's just me, it's just me I care for him just me. His sister visits (rolls her eyes), but I am his wife, till death do us part, in fitness and in health. It is my job to look after him"*

*Surprise/F21/I: "My sisters would spoil him so, I have put a stop to that now, so I look after him". (LPA in place)*

*NPCC2/D26/I "I make the decisions for my mum, not my sister, she comes for an hour a week. I don't want her there any more than that, and I look after my mum. I planned for this all my life; I knew I would care for her. I plan everything". Has LPA in place*

In contrast the family caregivers in the PCC group were supported by both family and friends who came to the ward to visit, and some came to help with the caring role, for example, D6 had her sister, F16 her daughter, F17 her brother, F20 his mother, F24 wife and sister-in-law, F23 sister.

#### **6.5.3.4 Summary**

Despite the differences in how care is delivered during mealtimes, the surprise family caregivers demonstrated similar traits to those in the NPCC group when it came to accepting their relative's situation. For both groups this acceptance is reflected in their opposition to enter into discussions about the future and the inevitable decline of their relative, a discussion that would force them to consider the inconsiderable; the ultimate decline and loss of their relationship. It is also evidenced by their inability to accept reasonably practical and emotional help from friends and family. As a result, Kitwood's framework appears not to be applicable or acceptable to those family caregivers in the NPCC2.

#### **6.5.4 Enmeshment in the caregiving role**

Enmeshment is a concept first introduced by Salvador Minuchin (1967) and refers to an emotionally entwined relationship between two or more people in a family, romantic or friends-based relationship (Lewis, 2013). Physically those involved are separate but emotionally attached. These relationships develop due to a lack of boundaries, in which unlike in functional relationships where emotional connection is a choice, here, there is a feeling of no choice, and the person becomes emotionally trapped and controlled by the relationship. This lack of control can lead to strong emotions of anger and guilt. Anger at the situation which may lead to angry outbursts and

guilt at thinking or saying, "no", to the person and for the outburst, further perpetuating a sense of entrapment. The lack of separation results in not being able to see one's self as an autonomous person. Without identity, the other person's needs cannot be separated from one's own leading to a feeling of responsibility for the other person's well-being at ones' own expense.

The evidence is provided to demonstrate enmeshment relationships in the NPCC2 group when compared with those in the PCC group.

Failing to meet one's own needs was evident on a number of occasions. D8 cancelled her hospital appointments to be with her husband 12 hours a day even though his situation was stable, F2 often forgot to take his medication. While F8 failed to visit her daughter, who was also in hospital with a long-term neurological condition in the hospital half a mile away, this seemed to trouble her, but still she did not visit:

*F8: "I hope I don't live to regret this, but there it is, I can't leave him can I"? Perhaps she was looking for my permission to go.*

F26 gave up his job as an accountant to care for his mother. He had no outside interest or friendships. His mother asked to go out every lunch and supper time to eat, so he took her despite not always wanting to go himself:

*Researcher: "Has anything changed?"*

*Surprise/F26/I: "Um, well no because now I'm taking care of everything anyway she now wants to go out. Her mindset is now out".*

*Researcher: "And do you take her?"*

*Surprise/F26/I: Yes. I have to, there's proof all over North London, with cameras, Starbucks, restaurants, and there's proof there for the last six and a half years, very lunch and evening meal.*

Similarly, F21 would visit her father in the care home every day at lunchtime, leaving work early and returning late jeopardising her job in doing so. With her father in the hospital she decided to take unpaid leave to be with him all day even when his condition was very stable, and she was feeling the financial strain. Once again, this family caregiver did not have hobbies, interests or friends outside caring for her father.

The family caregivers in the NPCC group and the surprise family caregivers seemed to find it difficult to distance themselves emotionally from their relatives, while staying physically close in order to provide care.

Six family caregivers from the NPCC group (F2, F8, F13, F14, F29, F30) plus the surprise family caregivers (F21 and F26) stayed with their relative all day (8 am till 8 pm). Only F12, F20 and F31 from the NPCC came for the evening meal due to work commitments, but they never missed. The reasons behind such commitment were very similar:

*NPCC/F12/O “I have to keep trying otherwise I can’t rest”. Having taken some banana and a sip of water after 40 minutes of trying the daughter said, “I’ll sleep now”, and left the ward.*

The differences between the surprise cases and the NPCC group was how they delivered person-centred care, remembering they were in the PCC group and of note their relatives were in well-being during mealtimes (Well-being scores F21 = 0.5, F26 = 1.2). This ability to deliver person-centred care may be the result of their acceptance of their enmeshed relationship with their relative, which protects them from the adverse effects if the enmeshed relationship is enabling them to deliver person-centred care at mealtimes.

*Researcher: “Okay, do you, do you think that you looking after your Mum dominates your life?*

*Surprise/F26/I “Yes, it does dominate my life, yes. It has to; there is no other way. If it didn’t dominate my life, then it means that I am not working around my mother, it’s as simple as that. You must understand, most carers do not do it 24/7. I do, okay. And if you’re going to do something, you’ve got to do it correctly, simple as that. Otherwise, don’t do it.”*

*Researcher: “Do you think that you looking after your dad dominates your life?*

*Surprise/F21/I “Does it dominate, I haven’t really thought of it like that, he’s my dad, I’ll do anything for him, whatever, is that what you mean?”*

*Researcher: “yes I guess so. Do you have time for yourself?”*

*Surprise/F21/I: “No not really, but I don’t want to do anything else, so it’s fine.”*

In this study family caregiver enmeshment in the carer role suggests they have no sense of their own identity other than that based on being the primary caregiver. The relative's needs were not separated from their own, leading to a sense of responsibility for their well-being. Their own well-being and needs were ignored. Those who were able to accept this were able to provide person-centred care at mealtimes but unable to make person-centred decisions about the future.

#### **6.5.4.1 Summary**

The evidence presented demonstrates the ability of the family caregiver to accept the diagnosis of dementia, the decline in their abilities and the corresponding threat to their life has consequences for the acceptability and applicability of Kitwood's framework.

The denial or wishful thinking and enmeshment in the caregiving role seen in the NPCC2 group created difficulties in making decisions about the future and accepting support in their caring role. The evidence from this study suggests the family caregiver's emotional distress response to the "loss" of their relative may be in part due to their primary attachment style, which manifests itself as difficult in accepting their situation and enmeshment in the caregiving role as discussed below.

#### **6.6 Attachment theory**

According to Bowlby's (1969) attachment theory humans seek the proximity of the primary caregiver in times of both physical and emotional threat throughout the life-span. The responsiveness of the primary caregiver in childhood sets the attachment orientation and guides the behaviour and expectations in other relationships throughout adulthood. When the primary caregiver is predictable, consistent and comforting in their responses, secure attachments are developed, enabling the person to develop close relationships with others. Unresponsiveness, unpredictability and inconsistency toward the individual can lead to an insecure attachment styles, resulting in a tendency towards anxiety of rejection, loss or discomfort with close relationships and poor self-esteem.

Four attachment types have been described;

- 1) Secure attachment: in which the person is satisfied with their relationships which feature honesty, support and independence.
- 2) Dismissive -avoidant or anxious-avoidant attachment: these adults tend to keep their distance from others, feeling they do not need human contact. They also tend to isolate themselves from others and can shut down emotionally when there is the possibility of a harmful situation.
- 3) Anxious-preoccupied or anxious-resistant attachment: refers to those who feel desperate for love and affection and need their partner for them to feel "complete". They seek security and safety in their relationships which can lead to clingy, demanding, and jealous behaviours.

4) Fearful-avoidant or avoidant-disorganised attachment: This second type of avoidant style sees behaviour that is ambivalent. These adults avoided their feelings as they are likely to become overwhelming resulting in emotional outbursts and a fear of being hurt. Yet, they are drawn into relationships while at the same time being fearful of getting hurt.

While described discretely attachment styles should be considered as a continuum of emotional regulation, with anxious-avoidant attachment at one end, anxious-resistant at the other, and secure attachment falling at the midpoint, with avoidant-disorganised attachment displaying strategies and behaviours from across the spectrum. These four descriptions for attachment styles are used in a wide range of different literature, including health, education and counselling. Attachment theory is also widely recognized as offering a useful framework for understanding inter-personal relationships for example, marriage guidance (Holmes, J. 2015), student counselling (McChrystal 2011) young offenders (Ansbro, 2008) and psychotic behaviours (Berry et al. 2006).

Further research has established the influence on all forms of dyads not just infant and parent and how these attachments can influence feelings and behaviours in all phases of life, including how we respond to illness, changing roles and responsibilities, dependency, loss, and adjusting to old age (Bradley & Cafferty, 2001; Browne & Shlosberg, 2006).

The caregiving system is activated to ensure protection is provided to others in times of need and attachment style may influence that response. Early work in this area has demonstrated the way family caregivers regulate their emotions and cope with stressful situations differs depending on their attachment style (Collins & Read, 1994). In a study by Carpenter (2001) daughters with a secure attachment style were found to provide more emotional care to their mothers when compared to insecure attached daughters and Daire's (2002) study showed how a positive relationship between parents and sons in childhood resulted in the sons' experiencing less distress in their caregiving role when their parent was in an institution. In addition, Chen et al. (2014) demonstrated securely attached family caregivers cope with their loss by gradually letting go and learning to distance themselves emotionally while staying physically close. Those who were insecurely attached struggle to cope with the loss of the security and support the relative provided and fought against the reality of the situation as a way of coping. Carpenter (2001) argues in his study of daughters that securely attached family caregivers provide more emotional support as they are seeking to prolong the nurturance they receive back from the mother. While those with

insecure attachments avoided any emotional care in fear of rejection providing instrumental care only.

Other established social theories for example carer burden and grief were considered as explanations for the behaviours witnessed in this study by family caregivers. Carer burden did not fully explain the sense of enmeshment that dominated the family caregivers in this study. However, the theory of grief does resonate with the studies' findings. Bowlby's attachment theory was established from his studies of children mourning the separation from their primary caregiver, from which he postulated 4-stages of grief (Bowlby, 1961), shock and numbness, yearning and searching, despair and disorganisation, and finally re-organisation and recovery. Bowlby (1961) stated that even after recovery the loss remains, all be it hidden deep inside the brain, continuing to influence actions. When faced with the prospect of another loss as seen when a diagnosis of dementia is given either to the spouse who replaced the absent primary caregiver or to the primary caregiver with whom a newly founded, the long-awaited relationship has been established, their enmeshment in the relationship is threatened, and their behaviour becomes desperate.

This study did not set out to test the relevance of attachment style in family caregiver delivered care. Therefore, it is only possible to describe in general terms family caregiver behaviours of secure or insecure attachment style. However, in keeping with qualitative analysis as described in section 4.6.2.5 methodology rational generalisations developed from the data were linked to the formal body of knowledge in the form of attachment theory theories. As such the findings from phase 2 suggests when the adult child with an insecure attachment style takes on the role of caregiver for a parent, the role provides an opportunity to develop the close relationship they were once denied. However, the relationship can become too powerful, developing into an enmeshed relationship where the wants of one become the wants of both. Enmeshment is seen in dyad D26 where the parent wants to go out every day for lunch and dinner, so they go out every day for lunch and dinner, every day for six years. Over time as the relative's health declines, witnessed by, for example, their reduced nutritional intake, this hint of the inevitable loss of their newly established relationship becomes unthinkable. In desperation, desperate measures are taken which can include extreme behaviours on the part of the family caregivers as seen in this study. As in Carpenter's (2001) study, the insecurely attached family caregivers in the current study prioritised their own needs for security over the emotional needs of their relative, all be it subconsciously.

The same situation existed for spouse caregivers in the current study. The insecurely attached spouse caregivers find the attachment figure they were denied as a child in their marital relationship. For some, this develops into an enmeshed relationship, with the attachment figure becoming their “rock” as described by dyad D30, and their world revolves entirely around them. This does not pose a problem until the security of the relationship is threatened, in this case by the diagnosis of dementia. As the inevitable decline takes place including the decline in nutritional intake the fear and anxiety of loss takes over, and denial dominates their narrative and behaviour.

The evidence above demonstrates Kitwood’s framework of person-centred care is acceptable and applicable to family caregivers who have secure attachment styles.

To illustrate further the connection between acceptance, enmeshment and attachment styles family caregiver’s case examples are presented.

#### **6.6.1 Secure attachment**

Taken from participatory observations and interview with PCC/D17

PCC/F17 talked of being close to her dad while laughing about his frailties she said with affection,

“Oh, he can be very stubborn, but I can get around him, no one else can”, yet she had a realistic understanding of her father’s future saying, “it’s hard when he does not eat...I know he can’t go on like this, ..... so long as he is comfortable, not distressed that’s the best I guess”.

F17 was upset at the impending loss of father but had come to terms with the situation. F17 was able to distance herself emotionally while staying close providing personal care and making decisions, suggesting she had a secure attachment with her father. F17 came to visit most days at around lunch time and stayed until after supper. Some days she did not come as she had, “jobs around the house to do”, or was going out for lunch with a friend. On these occasions her brother would come into the hospital, they would update each other over the phone. F17 was able to maintain other relationships during this challenging time which provided support and comfort, again suggestive of a secure attachment style (Bowlby, 1988).

#### **6.6.2 Insecure attachment (marital partner)**

Derived from participatory observation and interviews with F31 and her son NPCC/ F31 F31 was distressed by the diagnosis of dementia in her husband, her friend’s husband had been diagnosed a couple of years earlier, so she understood the implications of the diagnosis. F31 became more diligent in her care for him, never leaving his side, even in the early stages of the

disease. As the disease progressed F31 became according to her son more distressed finding his physical and cognitive decline difficult to accept. Her son had witnessed her shouting and crying when his father was unable to complete everyday tasks, for example, laying the table. Despite the decline in her husband's appetite F31 continued to prepare food in the same quantities, to be eaten at set mealtimes, at the table, as they had always done. P31's inability to eat his usual portions caused much distress for F31. When he had eaten what he wanted, his wife resorted to imposition and intimidation to encourage him to eat his usual amount. P31 would resist this by pushing his wife away, further increasing F31's distresses. The patient's son decided to provide necessary care while in hospital insisting his mother stay at home.

Her son told the story of how his mother who was born in Italy had lived on a farm with her family. Aged 5 her father was sent to war, she would stand looking for him to return every day from the kitchen window. Unfortunately, her father did not return, perhaps resulting in the loss of her primary attachment figure. Aged 19 she left her family and came to London to train as a nurse at St Bartholomew's Hospital. There she met her husband, and they married once she had completed training. Once married she left nursing and the couple set up and ran their family business. F31 was devoted to her husband; he was always the focus of her attention even after their children were born. F31 did not have friends of her own and only went out with her husband. Their son referred to his father as his mother's "rock", adding "they were inseparable", only since this illness have they spent time apart.

This short history provides insight into F31's anxious attachment to her husband. P31 was a stable husband who was the source of his wife's security, perhaps as a replacement for her father. When dementia threatened this security, her anxiety was activated, and she tried desperately to hold on to "her rock", by keeping a well-established routine. When this was no longer possible, and she could no longer control the situation her anxiety increased further, and her behaviour towards her husband became imposing and intimidating. P31's retaliation further compounded the distress, and their son stepped in to alleviate the situation.

### **6.6.3 Insecure attachment (adult child)**

Derived from participatory observation and bedside interviews NPCC/F18.

P18 lived in a care home in America where her other children resided. F18 disagreed with her mother's diagnosis of dementia and her care arrangements, therefore F18 took her siblings to court to gain permission to bring her mother from a care home there to a care home in England.

The family caregiver refused to discuss her mother's future, denied her siblings any contact, and resorted to intimidation and imposition when trying to support her to eat.

This behaviour indicates someone trying to establish control of a situation where they feel powerless. There is an inability to be objective about the situation indicating an insecure attachment style (Bowlby, 1988). This is further supported by F18's admission that she and her mother had an estranged relationship; she was "an academic who put work and colleagues first. None of us have been able to match up to her, none of us could get close to her".

Once in London F18 eventually accepted the diagnosis of mild cognitive impairment despite a MoCA© score of 12/30 suggesting a severe stage of the disease.

#### **6.6.4 Insecure attachment (adult child)**

Derived from participatory observations and interview Surprise/D26

F26 described his relationship with mother as close; they had always lived together despite F26 having his own home 1 mile away which he never moved into. F26 came to the ward at 9 am each morning leaving at 7 pm for eight weeks until his mother was discharged home. F26 was diligent in his care of his mother, at home he maintained a spreadsheet of her food intake, bowel movements, and medication. On the ward, this diligence continued as he made copious notes of all interactions with health care staff, domestics and volunteers. Since becoming the primary carer for his mother, F26 had stopped working as an accountant and did everything for and with his mother. P26 liked to go out to eat so F26 took her out for lunch and supper every day when they were at home. He had power of attorney and excluded his sisters from being involved in the delivery of care and discussion making. When asked if he found it difficult caring for his mother, he replied;

*"It wasn't as dramatic as people think. Like I said to you, her dementia was not a problem, was not a problem to me. Where we could converse, and have a good conversation, did we have that all our lives? No. It was always do this, do that, go this, go there. It wasn't a conversation whereby um, you could sit down as friends. Mum never had friends. It was "do that, I want this, I want this painting done, do that". My Father's death was absolutely catastrophic for my Mother, absolutely catastrophic. It was the end of the world for her. It was the 5<sup>th</sup> May 5<sup>th</sup> May 1981. My Father was age 53. Basically, my age. And it totally shook her, absolutely shook her, without a shadow of a doubt. She was just totally stunned. Err, Dad was her life, her soul, everything. She had nobody else. Um, so Dad was her everything, everything".*

The impression from the data collected from this dyad was one of the family caregivers adapting to the role of caregiver in a compulsive manner for a relative who he desperately wanted recognition from, a recognition that had only been afforded to his father. F26 took control of all aspects of his mother's care, excluding siblings, neglecting his own needs, yet allowing his mother to control him;

*"Mum wants something, and she'll get it. She'll repeat herself and repeat herself and repeat herself. Much like, "have you checked the door? Have you checked the windows?" "We're going out, we're going out, we're going out." It's as simple as that. Mum always got want she wanted she was spoilt in that way".*

However, when decisions needed to be made about his mother's future, he refused to have any discussions. There was a sense he was seeking confirmation from his mother that he was a good son and deserved her love for his diligence to meet her care needs. The compulsive care for her was as a result of an anxious attachment style.

#### **6.6.5 Summary**

Evidence has been presented that support attachment theory as a framework for understanding family caregiver behaviour around acceptance and enmeshment and how their attachment style affects the acceptability and applicability of Kitwood's theory of person-hood.

Kitwood's framework and the maintenance of personhood identifies the importance of close relationships, with attachment as one of its five key elements. Through attachment with caregivers, both family and professional, security, trust and the valuing of the individual are promoted. The promotion of personhood was seen in this study to depend on a secure attachment style.

The two surprise cases demonstrated anxious attachment, difficulties with acceptance and enmeshment in their caregiving role similar to that seen in the NPCC group. This was evident by the difficulty these family caregivers had with engaging in discussions about what the future might look like for them and their relative. These conversations appeared to be taking them to an uncomfortable place they were not yet ready to explore. Unlike the NPCC group, they did provide person-centred care at mealtimes. There was a sense from these two caregivers that they were content with their role as primary carer and had accepted their enmeshed caregiving role.

Relationships in which an anxious attachment prevailed all patients were subjected to intimidation, threats and invalidation at mealtimes unless the family caregiver had adapted to their role and the feelings of entrapment had been endured, seen in the two surprise cases. When the enmeshed care role was accepted, as the surprise cases had done, the carer was able to provide person-centred care during mealtimes. However, all family caregivers both the NPCC group and the surprise cases were unable to make decisions about the future that would be considered to be in the person's best interests. A secure attachment style is necessary for family caregivers to provide person-centred care as described by Kitwood (1997).

These findings provide a significant extension of previous studies in the field of family caregiving in dementia and make a unique contribution by recognising attachment theory as a concept to the transferability of Kitwood's framework of person-centred care.

#### **6.6.6 New qualitative proposition**

The surprise cases allowed for the refinement of the qualitative proposition in keeping with the methodology used in analytic induction (Robson, 2002) as described in section 4.6.2.1.

The evidence presented above led to a redrafting of the phase 2 proposition from:

Kitwood's theory of person-centred care can be applied to the family care situation and be used to understand the type of support given by family carers to their relatives with dementia at mealtimes.

To

Kitwood's theory of person-centred can be applied to the family care situation and be used to understand the type of support given by family carers to their relatives with dementia at mealtimes. The family caregiver attachment style affects person-centred decision making.

### **6.7 Integrated Results**

Table 6.7 presents the quantitative data for the two groups established in phase 2, those receiving person-centred care from their relative at mealtimes and those who are not. The well-being scores and calorie intake measurements were used to determine differences between the two groups. The remaining data, FAST, MoCA© BACS (nurturing and monitoring) scores were not considered robust enough for statistical evaluation.

**Table 6.10 Outcome measures for person-centred care and non-person centred care groups**

	Person-centred N = 9	Non-person- centred n = 9
<b>Age range</b>	79-96	77-89
<b>Mean (SD)</b>	87.5 (4.81)	83.65 (4.45)
<b>Male</b>	4	3
<b>FAST range</b>	6.6-7.6	6.8-7.8
<b>Mean (SD)</b>	6.93 (0.32)	7.38 (0.38)
<b>MoCA range</b>	0-17	0-12
<b>Mean (SD)</b>	6.63 (7.27)	1.33 (4.00)
<b>Calories range</b>	550-1400	200-750
<b>Mean (SD)</b>	938 (292)	481 (230)
<b>Well-being range</b>	0.4-2.4	-1.2 - -2.9
<b>Mean (SD)</b>	1.025 (0.73)	-1.99 (0.69)

**6.7.1 Hypothesis 6 – Patients who receive person-centred care from their family caregiver at mealtimes have higher well-being scores at mealtimes.**

The well-being score measures in phase 1 were compared between the patients who received person-centred care from their family caregiver and those who did not.

A Mann-Whitney U test revealed a significant difference in the well-being levels for patients receiving person centred care ( $Mdn = 1.20, n = 18$ ) and those receiving non-person-centred care ( $Mdn = 1.60, n = 18$ ),  $U = .000, z = -3.587, p = .000, r = 0.08$ .

Patients who received person-centred care from their family caregivers at mealtimes have higher well-being scores at mealtimes when compared to those patients who do not receive person-centred care from their family caregiver.

**6.7.2 Hypothesis 7- Patients who receive person-centred care from their caregivers at mealtimes have a higher calorie intake.**

The calorie intake measures in phase 1 were compared between the patients who received person-centred care and those who did not.

A Mann-Whitney U test revealed a significant difference in the calorie intake for patients receiving person centred care ( $Mdn = 1000, n = 18$ ) and those receiving non-person-centred care ( $Mdn = 600, n = 18$ ),  $U = 13.00, z = -2.44, p = .014, r = -0.44$ .

Patients who received person-centred care from their family caregiver at mealtimes have a higher calorie intake.

### **6.7.3 Summary**

The above results demonstrate:

- Patients who receive person-centred care have higher well-being scores.
- Patients who receive person-centred care have higher calorie intake.

#### **6.7.3.1 New mixed method proposition**

The evidence presented above led to a redrafting of the mixed method proposition from:

How do the qualitative differences between family caregiver behaviours (person-centred and non-person centred) help to explain the measured quantitative differences seen in the patient's well-being and calorie intake?

To

When family caregivers are able to provide person-centered care at mealtimes, their relatives have higher well-being scores at mealtimes and higher calorie intake.

### **6.8 New Starting Proposition**

In this chapter, the results of both phase 1 and 2 have been presented followed by the integration of both sets of data. These results have allowed for the development of the initial propositions which were first offered in section 3.13 and are presented in figure 6.1.

The starting proposition has been rewritten following analysis of both data sets from:

Kitwood's theory of person-centred care is transferable to family caring for relatives with dementia.

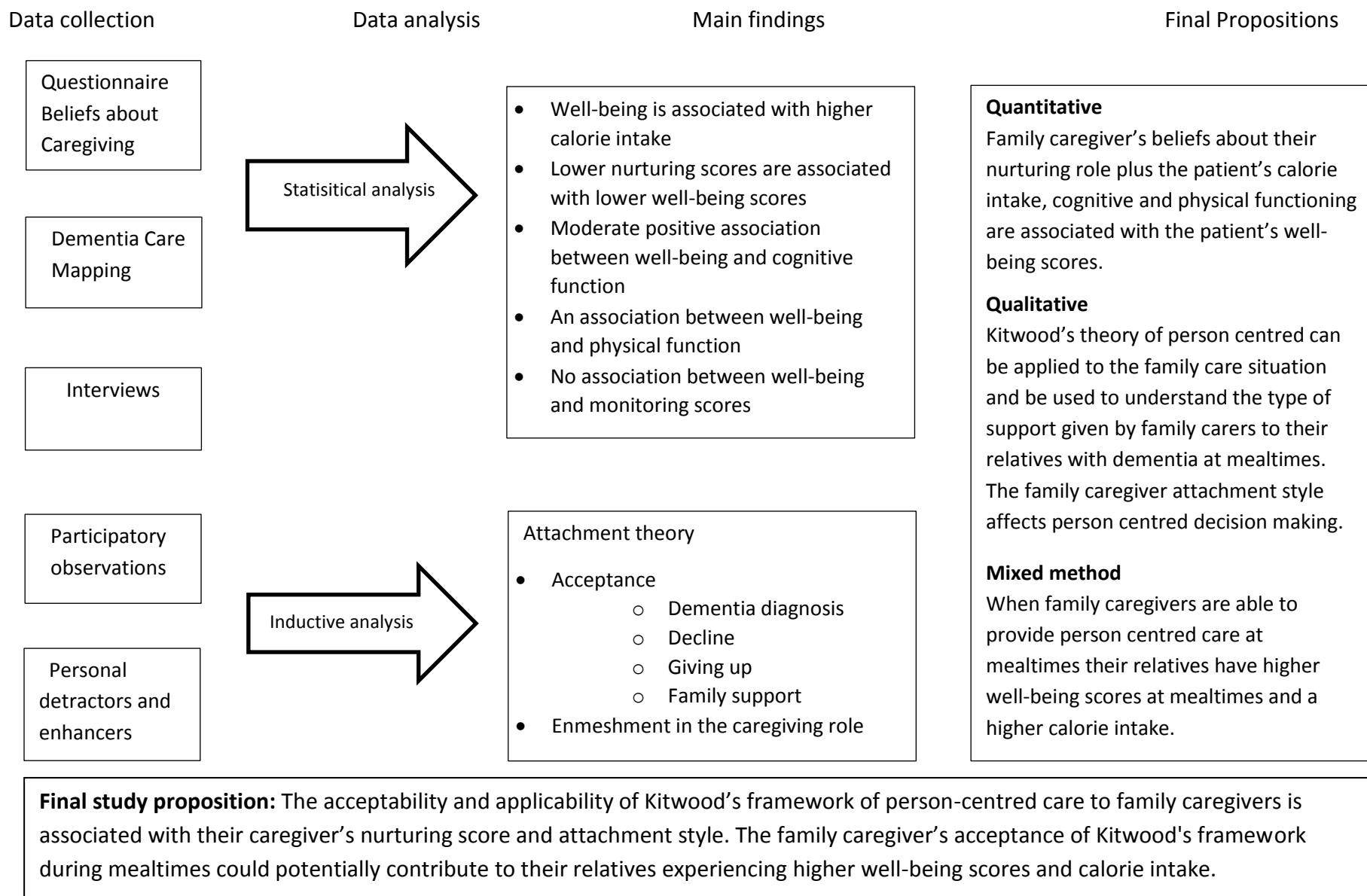
To

New starting proposition

The acceptability and applicability of Kitwood's framework of person-centred care to family caregivers is associated with their caregiver's nurturing score and attachment style.

The family caregiver's acceptance of Kitwood's framework during mealtimes could potentially contribute to their relatives experiencing higher well-being scores and calorie intake.

**Figure 6.1 Diagrammatic summary representation of the emerging findings arising from a convergent parallel mixed method approach**



# Chapter 7 Discussion

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## 7.0 Introduction

This study aimed to measure and explore the applicability and acceptability of Kitwood's theory of personhood to family caregivers when their relatives with dementia refuse to eat. This chapter will discuss the integrated findings and the implications for clinical practice. The study findings and other published literature will then be used to help address the issues raised in the review of Kitwood's work discussed in section 2.5

- How does a diagnosis of dementia position a person as a person within families?
- Do people with dementia need personhood bestowed upon them?

These issues will be explicitly discussed from the viewpoint of family caregivers.

The question regarding how accurately the behaviours of people with dementia can be interpreted regarding their well-being has been discussed previously in the section on the research limitations (section 5.9.2.2).

## 7.1 Personhood and dementia: revisiting Kitwood's theory

In developing his work on dementia care, Kitwood made it clear that he intended to understand the experience of dementia from the persons' perspective and importantly to establish how best to care for those in need (Kitwood, 1997c). In doing so Kitwood's theories of personhood and person-centred care are intricately linked, however, the findings of this study demonstrate this conceptual link to be highly problematic, as according to Kitwood without person-centred care the person with dementia lacks personhood, (Kitwood, 1990; Kitwood, 1993a, 1993c; Kitwood and Benson, 1995; Kitwood and Bredin, 1992). Did Kitwood mean that without person-centred care there is a lack of well-being in their personhood? It seems he has merged the two concepts thus they have come to mean the same thing when philosophically and conceptually they are very different. Indeed, the researcher had difficulty knowing which of the two terms to use when discussing Kitwood's work.

This study has tried to develop Kitwood 's frame work in terms of family caregiver relationships and the maintenance of their relative's personhood. Previous studies from Smebye & Kirkevold's (2012 & 2013) have also aimed to increase our understanding of how family and professional caregiver's relationships influence personhood in people living with dementia. Both Smebye & Kirkevold's (2012 & 2013) papers are from the same study in which semi-structured interviews with professional and family carers and observations of activities between professional carers and residents in sheltered accommodation and their own homes were used. The first paper (2012) examined decision making and the second (2013) how relationships uphold personhood. Initially,

the data were analysed using inductive analysis with an interpretive approach, followed by a deductive analysis, applying the VIPS theoretical framework for person-centred care (Brooker 2007) developed from Kitwood's framework, a similar approach to the current study.

The authors identified family relationships based on a "close emotional bond", as one that upholds personhood. This was evidenced through respect of identity, trust, valuing personal characteristics, past and present achievements and a willingness to provide care. These characterise appear akin to those of the family caregiver's in the PCC group of this study, who were willing caregivers able to prioritise psychological needs over physical needs when necessary. Both sets of family caregivers were seen to respect their relative's ability to make or share decision making regarding daily activities using negotiation, for example, "if you eat a little bit you will feel better" but respecting their preferences even if that meant not eating.

A second family relationship identified by Smebye & Kirkevold (2013) was "reluctant helping", which the authors describe as being dominated by power struggles. In these relationships the caregiver is unable to see the situation from their relative's perspective blaming the person's behaviour on ill intentions rather than the dementia diagnosis. Care was delivered out of duty and obligation. These family caregivers were considered not to be sustaining their relative's personhood, and to be avoidant in their behaviour, becoming emotionally and physically distant from their relative and from health care professionals. While not avoidant, the family caregivers in the NPCC group of the current study do demonstrate comparable behaviours in terms of decision making. In these cases, the relative with dementia is negatively positioned by the family caregiver as someone who cannot make decisions or have a choice. This unjust standing provokes a strong determination in their relative who refuses the food forced upon them or as seen in the Smebye & Kirkevold study (2012) unnecessary arguments and disagreements.

In Smebye & Kirkevold study (2012 & 2013) avoidant family caregivers were identified as not able to sustain their relative's personhood. This avoidant behaviour contrasts with that of the NPCC family caregivers in the current study who were enmeshed in the relationship, finding it impossible to separate their own needs from those of their relative; a feature not identified in Smebye & Kirkevold's study. The differences seen in the findings of the two studies may be due to the inclusion criteria and the study settings. The current study excluded family caregivers who did not visit their relative for at least one mealtime per day possibly overlooking those avoidant family caregivers. The participants in the current study were in a more advanced stage of dementia than Smebye & Kirkevold (2012 & 2013) participants and in an acute hospital setting following an acute

admission both could account for the displays of distress and enmeshment from the family caregivers in the NPCC as they witness the decline in their relative in an unfamiliar environment.

In this study, the family carers used different strategies to fulfil their perceived responsibilities based on experience and culture, where culture is more than ethnicity. Experience comes from learnt consequences, for example, when a family caregiver tells her relative she must eat otherwise she cannot go home, and she eats, the strategy of using threats is seen to be successful, and a warranted belief becomes established. The consequences of one's action are learnt over the likely consequences of another action (Morgan, 2014(a) Pg. 26). Importantly, from a pragmatic worldview no two situations are ever the same, and therefore the consequences of our actions and beliefs can change over time, meaning learning can take place. Alongside the learnt experiences of family caregiving, there is a cultural perspective. According to Brislin et al. (1973) an early leader in cross-culture research methods, "Culture refers to widely shared ideals, values, formation, and uses of categories, assumptions about life, and goal-directed activities that become unconsciously or subconsciously accepted as right and correct by people who identify themselves as members of a society". These cultural and learnt perspectives of care, treatment and the meaning of illness may be different from those of healthcare professionals, who may make value judgements of the family caregiver based on their own beliefs about person-centred care which is professionally driven by Kitwood's interpretation of what good dementia care is. When family caregivers enter the world of the hospital ward and are perceived to be rejecting the principles of person-centred care, behaviours such as force-feeding are greeted with shock in a similar way to when any taboo in society is broken as this is considered to be a taboo. Family caregivers in this study believed their behaviour was perfectly reasonable and right, believing it was the healthcare professionals who were wrong in what was an extremely complex situation. Family caregivers said it was wrong to let their relative "starve to death". They did not view the patient's action of refusing food as decision directed, for them the patient was incapable of making that decision, therefore to stand by and do nothing was incomprehensible. This raises questions about the decision-making process in dementia care and the positioning of the person with dementia by the family caregiver and the healthcare professional. Decision making in this context, both from a legal and professional perspective revolves around capacity and competence and is associated with formal decisions involving the patient, healthcare or legal professional and the family, for example, informed consent, financial arrangements and living independently and rests on whether the patient can decide. The determination of capacity is outlined in the Mental Capacity Act (2005) in England and promotes the patient's autonomy and personhood and despite a lack of capacity,

coupled with an emphasis on the protection of liberty and self-determination, is very much in keeping with Kitwood's theory of personhood and person-centred care. However, most decisions are more often made around informal aspects of daily life and are made within a family setting. In the context of patients who are considered not to be eating enough, the family caregivers in the NPCC group made the decision to force feed them, deciding they lacked the capacity to make the decision; acting in a way that did not respect their autonomy, positioning themselves in authority over the patient, putting their own needs above those of the patient. Despite this all the patients in the study exposed to this forced attention, "held their own" consistently refusing to eat their main meal but choosing to eat ice cream or yoghurt type desserts, maintaining their personhood despite being in very advanced stages of dementia. This is contrary to Kitwood's theory that personhood is "bestowed" upon a person by others as discussed in chapter 2 section 2.4. Earlier studies have also demonstrated how people with moderate dementia can uphold their right to make decisions supporting their personhood (Sabat et al. 1999; Feinberg et al. 2001; Moye et al. 2007; Clark et al. 2008; Whitlatch et al. 2009; Smebye & Kirkevold, 2012). Smebye & Kirkevold (2013) in part agree with the findings of this current study. In the first instance, Smebye & Kirkevold (2013) demonstrate that when patients are in relationships that position them as agents, capable of interactions, personhood is maintained through their actions and what they say. However, they go on to assert that while some patients can uphold their personhood, those with more advanced dementia who are not in supportive relationships need others to validate their worth and identity. This current study counters these findings by demonstrating that patients with advanced dementia can make decisions, be they intuitive ones, regarding eating based on according to Mozley et al. (1999) and Moye & Karel (1999) emotions, needs, values, preferences, or habits. Building on this assumption, despite very advanced cognitive decline people with dementia, can still value a situation, take meaning from it and act in a way that states their preference, thereby maintaining their personhood, something independent of cognition.

The observations from the current study would suggest patients in advanced stages of dementia can make decisions and influence their situations around food intake and unlike the image of dementia depicted by Kitwood's definition of personhood are not passive recipients of care. When a patient's autonomy is consistently threatened as is the case with force-feeding, their behaviour is that of a distressed person, shouting, and spitting as this is the only means of response left to them. These behaviours are according to Kitwood (1997) a response to poor care, not a manifestation of the dementia illness itself. In this study individuals' right to make autonomous

decisions were denied by the family caregivers in the NPCC at mealtimes which may have been the reason for the lower well-being scores and lower calorie intake seen in this group.

In contrast to the NPCC group, the two surprise cases identified in this study were able to provide person-centred care and facilitated as much as possible their relative's autonomy at mealtimes. Yet, they shared similar characteristics to the participants in the NPCC group being unable to distance themselves emotionally from their relative, becoming increasingly enmeshed in their caregiving role, unable to accept the situation and make decisions about the future in their relative's best interest. The evidence presented in this thesis demonstrates how this behaviour is linked to the family caregiver's attachment style and has a historical background mostly unknown to the professional caregivers.

People are not seen to exist in isolation of others as their decisions have a bearing on those within their social network. In caring relationships, decisions are made in the context of the history of that relationship and the broader social milieu. There is a professional move away from person-centred care (McCormack et al. 2015) towards one that is relationship centred advocating the primacy of building therapeutic relationships between the patient, family caregiver and professional (Soklaridis et al. 2016, Watson 2016). A move towards relationship centred care may go some way in explaining why, despite the shock of witnessing the family caregiver behaviour and the potential psychological harm caused, no safeguarding alerts were issued by the professional caregivers involved in the care of patients in this study. This may reflect the healthcare professional's uncertainty of the validity of the scientific, mainly qualitative data, on which the adoption of person-centred care is based. That said, it would be difficult for any healthcare professional to raise a critical objection to person-centred care, an approach that has become the hallmark of quality particularly in older people services and specifically in dementia care (McCormack, 2001) and now features in almost all policy documents and practice guidelines dating back to the National Service Framework for Older People (Department of Health, 2001). This presents a hidden dilemma for professionals between espoused professional belief systems supported by research, e.g. person-centred care, and the lived reality of practice in complex interconnected and interdependent real-life situations. Arguably, person-centred care is atomistically promoting the autonomy of the patient/professional dyad over the wider social context. Given the limited quantitative evidence supporting person-centred care in this situation, perhaps a more cautious judgement is warranted. Indeed, the emphasis on the individual and autonomy is together promoting an increase in the patient's involvement, however, person-

centred care may be impossible to implement in the context of older people with dementia in an acute hospital setting (McCormack, 2001). Nolan et al. (2002) pointed out that person-centred care was unable to, "Capture the interdependencies and reciprocities that underpin caring relationships", and proposed, "The Relationship Centred" approach to care delivered through, "The Senses Framework" (Nolan, 2001; Nolan et al. 2002; 2003, 2004). The differences in emphasis between person-centred care and relationship centred care are outlined below (Dupuis et al., 2012 pg. 217)

### **Person-centred care**

- The focus is on the person rather than the medical diagnosis
- Efforts are directed toward nurturing continued strengths and abilities
- Attention is given to meeting the needs of the person

### **Relationship centred care**

- The focus is on enhancing the care experience for the person, family, and staff
- Efforts are directed toward building and nurturing relationships
- Attention is given to meeting the needs of the person, family, and staff

The limitations inherent in the person-centred care model may explain why the healthcare professionals in this study did not report any safeguarding issues, recognising the reciprocity and interdependency that exists between the triad of patient, family caregiver and health professionals. Despite the family caregiver's behaviours at mealtimes and difficulty making advanced decisions, the healthcare staff were able to identify the family caregiver's behaviours were not malicious acts to cause harm. The experiences of the triad in unfounded child abuse allegations are a reminder of the lasting damage that can result from a heavy-handed approach when relationships are interdependent and reciprocal (Gambrill & Shlonsky, 2000; Cuccaro-Alamina, 2017). The healthcare professionals caring for the dyads in this study considered the consequences of submitting a safeguarding alert against a family caregiver. Would it have been right to disrupt this relationship? Good dementia care may necessitate choosing between conflicting responsibilities, values and the bioethical principles of autonomy, justice, and non-maleficence. Conceptualising care through a model of person-centeredness may not provide healthcare professionals with a practical framework that is relevant to current healthcare where family caregivers play such a pivotal role. Conversely, family caregivers in the NPCC group can give rise to complaints at an individual hospital level and inquiries on a larger scale. Without an understanding by clinicians or by those investigating concerns, of relationship centred care and attachment styles as described in the finding of this study, it could be the case that clinicians are found to have neglected patients for want of

being able to address the carers concerns within a person-centred framework. The findings of this study explain how everyone is working within their version of best interest, but with a different understanding as to what best interest means in each case.

In the experience of the researcher, nurses find building therapeutic relationships with family caregivers who employ non-person-centred behaviours difficult, perhaps due to their conflicting priorities of care as discussed in chapter 1. Previous research has demonstrated attachment style as an indicator of social and emotional development (Thompson, 2015). This study has contributed to this narrative, showing a link between attachment and the strategies employed by family caregivers at times of increased anxiety. Family caregivers with secure attachment styles are likely to be able to identify, articulate and reflect on their strong feelings, reducing their anxiety levels (Thompson, 2015).

In contrast, those with insecure attachment styles are less able to process their thoughts, maintaining higher anxiety levels. The inability to “work through” their emotions leads family caregivers to employ strategies of intimidation and threats in a vain attempt to reduce their anxiety. Acknowledging the contribution attachment theory plays in the actions taken by family caregivers’ nurses would have therapeutic strategies to deploy in what can be very damaging exchanges. Therapeutic relationships are core to nursing (Fahrenwald et al. 2005) being reciprocal, built on trust and empathy. Empathy allows the nurse to identify with the family caregiver’s emotional state (Bruners et al. 2010) which with time leads to a shared understanding and sense of being listened to. The trust and respect fostered in this relationship provides a solid foundation on which to understand the family caregiver’s ability to cope with adversity, and emotional difficulties. The nurse can sense the family caregiver’s strong feelings, provide them with words to articulate these feelings, “working through” their emotions perhaps for the first time. Utilising therapeutic relationships in this way may help to reduce the impact of an insecure attachment style. However, any unkept promises could mirror the behaviours of attachment figures from childhood reinforcing their insecurity (Ansbro, 2008).

While acknowledging attachment style is not the only influence on the family caregiver’s behaviours the development of therapeutic relationships could reduce the impact of the attachment style and enhance the patient’s well-being. However, there is a wealth of literature which highlights how the structure and organisation of hospital nursing mitigate against nurses building and sustaining these therapeutic relationships with patients and family caregivers

(Bridges et al. 2012, Featherstone et al. 2018). A ward focused on tasks, routines, and reducing length of stay, (Ryan et al. 2017, Langhorn et al. 2014, Williams et al. 2009), targets and matrix (Patterson et al. 2011) along with shift patterns, unpredictable and inadequate staffing levels, perceived lack or lack of specialist education (Maben et al. 2012) and the increase in the health and social complexity of the patients (Bridges et al. 2012) conspire to create the all too real possibility of “unkept” promises. Conscious of the limitations imposed by the working practices and ward culture nurses avoid building meaningful relationships choosing instead to maintain a distance at the cost of the patient’s, family caregiver’s and their well-being (Maben et al. 2012).

Across the NHS acute hospitals have appointed dementia nurse specialists who have made a significant contribution to the experience of patients, their family caregivers and staff (RCN 2013). Nurse specialists are well positioned to interpret and mediate between institutional drivers and the needs of patients, their family caregivers and ward nurses

Therapeutic relationships are a 2-way process, requiring both parties to demonstrate trust, empathy and openness. For family caregivers with insecure attachment entering into such a relationship may prove difficult. Family caregivers with avoidant insecure attachment may resist the nurse’s approaches remaining cold and ambivalent, while the anxiously insecure attached family caregivers may become overly dependent on the relationship. Nurse specialists need to be aware of the potential challenge’s attachment style can bring to the relationship and develop strategies to manage expectations, trust and closure of their involvement.

Relationships are an essential aspect of high-quality dementia care with the interconnectedness between all parties being essential to understanding their meaning of caring (Smebye & Kirkevold, 2013). Relationship centred-care has been less integrated into nursing practice, education, and policy than person-centred care perhaps because the nurse has no prior relationship on which to base the encounter. However, for the family caregiver, while person-centred care is important, their relationship is primary, it is the reason they provide care. Therefore, as family caregivers become increasingly pivotal in healthcare provision, it would seem prudent not to dismiss Kitwood’s theory of person-centred care but to develop the ideas of relationships within it further.

## **7.2 Strengths and limitations**

As in all studies this study has its strengths and limitations which are discussed below.

### **7.2.1. Strengths**

#### **7.2.1.1 Mixed method study design**

One of the major strengths of this study is the use of the mixed method convergent parallel design. This design allowed for the investigation of a complex issue which arose from practice. One that required analysis of patient and family caregiver realities, through the lens of professionally accepted standards of care set out in Kitwood's framework. Creswell and Plano Clark (2010, p.73) note the overall purpose of a convergent parallel design is to facilitate a more "complete understanding of a topic" as such, this design allowed for the collection of patient well-being scores, calorie intake and function scores along with the family caregivers BACS scores (Philips et al. 1997), which were contextualised through the semi-structured interviews and participatory observations. Without employing a mixed methodology, the final study proposition would not have been developed; specifically, the association between calorie intake family caregiver and family delivered person-centred care

#### **7.2.1.2 Steering group**

The use of a steering group (blind to all results other than the observational data) in the classification of person-centred and non-person-centred care added to the trustworthiness and rigor of the study findings. Left to the researcher to determine the classification the study would have been open to questions of bias based on preconceived ideas and assumptions regarding the family caregivers. These assumptions may have arisen from the researcher's beliefs and values as set out in section 4.1.1 and from knowledge of the phase 1 results.

#### **7.2.1.3 Practice-based research**

This study's questions emanated from clinical practice, where patterns of behaviour were noted by family caregivers when their relative did not eat. Research generated from practice has the potential to have an impact on the quality of patient care as the results are immediately applicable to day-to-day practice (Dickerson 2012).

This was a courageous study to undertake. Those in practice recognise the dilemmas described in this study, however, there is little published in the literature specifically addressing the issues of

family caregivers force feeding patients and the moral conflict imposed on healthcare professional bound by the law, and their professional and moral codes. The undertaking of this study and the resultant publications and presentations have the potential to start conversations that explore this common moral dilemma further.

This research also provides support for family delivered person-centred care providing healthcare professional with the evidence when families are unsure how best to care for their relative at mealtimes.

### **7.2.2 Limitations**

This research has limitations that need to be acknowledged when interpretation the findings. The limitations of the research have been grouped into three categories; research design, research participants, and research outcomes.

#### **7.2.2.1 Research design**

#### **7.2.2.2 Analytic induction**

A limitation of analytical induction (AI) is that it risks imposing a pre-determined theoretical framework on the data which may shape the final interpretation of the data, thereby reducing the extent to which the researcher can claim that the findings reflect the authentic perspective of the participants. However, the study proposition as outlined at the beginning of the research process was underpinned by a theoretical focus on personalized care derived from Kitwood, and this informed the use of AI. It is acknowledged that had the researcher used Grounded Theory or thematic analysis, different findings may have arisen as argued in section 4.6.2.4.

AI may also pose an inherent threat to the validity of the study due to the lack of guidance on the number of surprise cases necessary to be confident of the final proposition. However, AI does demand the inclusion of all data in the analysis to identify surprise cases rather than saturation of the data, while not necessarily using all the available data as in Grounded Theory (Glaser & Strauss 1967).

Finally, there is a constant need to keep thinking about alternative explanations for the findings when using AI. This can lead to attention drifting away from the original research question due to the complexity inherent in social science research. This risk was limited in this study by the research steering group who are tasked with keeping the study focused on the research questions.

#### **7.2.2.3 Sampling and sample size**

It is recognised that the use of a convenience sample in this study could have introduced issues in terms of representativeness of the sample and therefore generalisation of the findings. It is also

acknowledged that the sample size is small due to the limitations placed on a single researcher in full-time employment conducting the study. The small sample size raises concerns about the power of the study. Therefore, caution is necessary in the interpretation of the statistical tests.

#### **7.2.2.4 Dementia Care Mapping**

The researcher is a trained Dementia Care Mapper and has completed several mapping sessions achieving good inter-relator reliability before conducting the research. However, determining the well-being of patients who were in the very advanced stages of dementia remained challenging. Patients in FAST stage 7 (Reisberg et al. 1988) are unable to change their facial expression, without which displays of emotion were difficult to interpret. For this reason, these patient's well-being scores were calculated based on a feeling of empathy; sensing what it must be like for the patient in this situation as suggested by The Bradford Dementia Group (1997). The subjectivity of dementia care mapping has been criticised in the past as discussed in section 2.3 and is upheld by the researcher here. That said, when a patient in the advanced stages of dementia eats ice cream but keeps their mouth closed for the main meal, and the family caregiver continues to tap their lips with a teaspoon of food for 15 or 20 minutes, it is not difficult to conclude that this would result in a state of relative ill-being. The limitations inherent in Dementia Care mapping posed a potential problem in terms of data interpretation, however, this was overcome through discussions with other onsite dementia care mappers, PhD support group and the research steering group.

#### **7.2.2.5 Research participants**

Fifteen (48%) non-British dyads were recruited to phase 1 of the study with eight (26%) agreeing to take part in phase 2. Despite nearly 50% of participants being from a non-British heritage, the overall numbers recruited to the study were small, but the ethnic diversity was large. There was a missed opportunity for this study to determine any cultural differences between the PCC and the NPCC groups, who we know experience greater stress, depressive symptoms and unmet needs than those from other groups (Akarsu, 2019). As discussed in section 4.1.2 my position as a white middle-class British female may have created a feeling of mistrust, perhaps proving a barrier in the recruitment of non-white British dyads. There is a lack of awareness and acceptance of dementia as a disease in some non-British communities (Cooper et al. 2010). There remains a belief in some cultures that the signs and symptoms of dementia are the signs of old age. These beliefs can be coupled with a strong sense of privacy around personal matters that are not for discussion with healthcare professional, where a sense of mistrust may remain (Lawrence et al. 2008, Berwald et al. 2016). These beliefs may have precluded non-white British dyads from participating in the study.

Equally, the non-white British dyads who were recruited may not have been so forthcoming in their interviews. A larger study should look to overcome this limitation as the numbers of non-British people with dementia is set to increase (Age UK 2016)

It should be noted that the research participants behaviours at mealtimes may have been influenced by the acute admission to hospital due to the uncertainty this can bring. The ward environment may have influenced behaviours owing to the presence of other patients, family and professional caregivers. Mealtimes in hospital are different from those at home and may have resulted in the family caregivers' and patients experiencing a lack of control over food quality, timings and service raising anxiety levels and testing coping strategies.

#### **7.2.2.6 Inclusion criteria**

Nurturing as measured by the BACS (Phillips et al 1998) contributed to the findings in this study, this may, however, have been a consequence of the study inclusion criteria. Family caregivers who visited their relative at least one mealtime per day were recruited, thereby selecting a group who may be more likely to be highly nurturing (low nurturing scores). Further research would need to consider the inclusion of family caregivers who do not visit at mealtimes as a comparison group. As discussed in section 7.1 the inclusion of family caregivers who did not visit at mealtimes may have identified avoidant family caregivers as identified by Smebye & Kirkevold (2013) .

#### **7.2.2.7 Limited input from patients**

The study proposal included interviewing patients; unfortunately, this proved to be more difficult than expected due to their advanced stage of dementia. The inclusion of the patient would have provided greater insight into their experiences of mealtimes to support or refute the Dementia Care Mapping results; further studies should attempt to address this.

### **7.2.3 Research outcomes**

#### **7.2.3.1 Attachment theory**

This study did not set out to establish causation but warranted beliefs in line with a pragmatic worldview (Morgan, 2014). Indeed, analytic induction used in the analyse of the qualitative data does not set out to predict who will or will not act one way or another, but when a person does act a certain way AI can ascertain what happened along the way. Therefore, the study aimed to establish plausible warranted beliefs about person-centred care from a family caregiver's perspective that may be adapted in light of future new evidence through disconfirming cases.

It should be stated that attachment style was not a measure incorporated into the study design, and therefore not empirically tested in this study. While attachment style did emerge as a theme caution is necessary in interpreting the findings specifically, in differentiating between anxious and avoidant subgroups of the insecurely attached caregivers. However, there has been growing interest and a small body of evidence in patterns of caregiving behaviour that are in line with attachment style (Crispi et al. 1997, Cooper et al. 2008, Nelis et al. 2012). Perren et al. (2007) studied married couples, in which one was living with dementia and the other was the main caregiver. The findings show that where there was an increase in the person with dementia's need for emotional support, family caregivers with an avoidant attachment style were unable to meet the increasing need and withdrew emotionally from the relationship, creating a vicious cycle of behaviours. The results from this study add to the increasing body of evidence supporting the use of attachment theory as a useful explanatory framework for understanding interrelationships between people with dementia and family caregiving.

## 7.4 Summary

In chapter 1 of this thesis, the moral dilemmas encountered by nurses when their beliefs about the priorities of care are in opposition to that of family caregivers were discussed. Nurses are educated in Kitwood's theory of dementia care which asserts the maintenance of personhood as primary; achieved through person-centred care (Kitwood 1997). The professional learning of nurse's contrasts with the experiential learning by family caregivers. This study demonstrates how family caregivers with insecure attachment when faced with the prospect of losing their attachment figure find person-centred care not to be applicable or transferable. Rather the patient is positioned without autonomy and experiences relative ill-being. The current organisation of nursing and the culture of older peoples' wards fail to support nurses in building therapeutic relationships which would improve the experience and outcomes for the triad in terms of compassion, empathy and moral (Maben et al. 2012, Bridges et al. 2012).

High quality dementia care is skilled clinical work requiring high levels of knowledge. Skilled work is quite distinct from care work often associated with dementia care. There is an assumption that the care of patients with dementia is essentially unskilled work that can be carried out in a way that requires a minimally trained workforce. An independent review of the recruitment, training, management, development and, support of health care assistance identified 1.3 million unregistered frontline staff were delivering to bulk of the hands-on care to some of the most vulnerable people in society (DoH, 2013). The review highlighted a

fundamental shortfall in training standards for the care staff on whom health and social care services are so dependent. At the time of the review training had been left to the employer's discretion, which in some cases meant staff training consisted of watching a DVD in their own home prior to commencing working unsupervised.

The assumption that caring is unskilled work stems from a legacy of caring being regarded as women's work (Davies 1995). Treatments have become increasingly technical and are used to treat an older, more ethnically diverse population with more long-term conditions than ever. Nurses are expected to administer and oversee these treatments, in all settings, yet, the need for a degree-only profession was heavily scrutinised in the public media. In addition, dementia care as unskilled work stems according to Kitwood (1977) from the historical contextualisation of dementia in a predominately biomedical model legitimising the nihilism that surrounded the diagnosis. In a model that does not recognise the person, psychological needs take a back seat, needs are seen as physical, the need for respect, autonomy, dignity, and compassion are superfluous. Despite the improvements seen in dementia care much of which is a result of Kitwood's theory (1977 Pg. 44) the assumption of unskilled work prevails.

While Kitwood takes credit for the now widely accepted theory of person-centred care some commentators lay the blame for its slow and painful journey into practice at Kitwood's feet (Bartlett and O'Connor, cited in Baldwin & Clapstick, 2007 Pg. 181). As discussed in chapter 2, Kitwood placed dementia care in the non-political arena of relationships with paid carers. By focusing on the individual and the quality of care they delivered the responsibility of the maintenance of personhood laid in the hands of the individual rather than society, reducing the scope for Kitwood's theory as an agent for political change.

This assumption that care work does not require a knowledge base means that maintaining personhood can be interpreted as doing what the patients wants, putting the paid carer in a subservient role. When the paid carer follows the patients lead the job appears simple, and one paid carer can substitute for another without any problems. The difficulty here comes when the patient decides to do or not do something that may be harmful, for example, not to wash. It is in these situations that skill is required to keep the patient safe while maintaining their autonomy and dignity with compassion. Difficulty also arises in a model of care that requires only minimal training when the family caregiver needs are contrary to those of the patient. Now the nurse is faced with a dilemma for which she/he is not prepared.

The results of this study acknowledge care work does require knowledge and the restructuring of the delivery of care around transformative relationships, challenging engrained system assumptions. Education and skilled senior clinical roles were considered to be a key omission in the hospitals enrolled in the recent study by Featherstone et al. (2018), in which ward nurses were observed to be unable to respond to the needs of their patients due to the competing priorities of the ward and organisation. Featherstone et al. (2018) observed timetabled tasks taking priority over individual patient needs, for example, a patient requiring assistance to drink a glass of water outside of mealtimes was likely to be left to their own devices, in contrast at timetabled mealtimes the patient would receive assistance with eating and drinking whether they required it or not.

The poor ward environment means when a family caregiver positions themselves in authority over the patient and the patient experiences ill-being the ward nurse emotionally withdraws, as a result of the emotional distress caused by not being in a position to advocate for the patient as this advocacy would be against the family caregiver (Maben et al. 2012, Ryan et al. 2017). This withdrawal has been interpreted as a lack of care and compassion by family caregivers and fed into major inquiries (The Patient Association 2009, Mid Staffordshire NHS Foundation Trust Inquire 2010, Parliamentary and Health Service Ombudsman 2011, CQC 2013, CQC 2013a). The hospital in the current study invests highly in the nursing workforce, providing adequate staffing levels, high levels of education and senior clinical nursing roles. The senior clinical nurses provide the relational aspects of care that can be dominated by routines, releasing the ward nurse to focus on providing high quality caregiving tasks. Whether taking the responsibility for the relational aspects of care away from the ward nurse reduces their moral distress and improves morale or simple fosters the unskilled assumption of care has yet to be answered.

A concept of therapeutic relationships has proven challenging to introduce into day-to-day practice within the context of a performance-dominated health care systems (Maben 2012), the introduction of the nurse specialist role may be an achievable option that meets the needs of the patient, family caregiver and ward nurse within current delivery structures.

# Chapter 8 Conclusion

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## 8.0 Introduction

Chapters 1 and 2 of this thesis critically appraised Kitwood's theories of personhood and person-centred care and presented some observations from clinical practice questioning the relevance of person-centred care to family caregivers, specifically at mealtimes when patients with dementia were not eating. The review of the literature identified a gap in Kitwood's work regarding how applicable and acceptable his theories are to family caregivers and the impact this has on the behaviour of their relatives. Chapter 3 provided a literature review of the evidence base for interventions when patients with dementia stop eating in an attempt to establish best practice for when observing family caregivers supporting their relatives to eat. Chapter 3 concluded by presenting the starting propositions for the study (3.13) which were addressed by conducting a convergent mixed parallel method study (4.2), detailed in chapter 5. In chapter 6 the findings were presented, and revised propositions given. In chapter 7 the inherent issues with Kitwood's theory of person-centred care were discussed. This thesis concluded by considering the new knowledge acquired as a result of this research, implications for practice, and recommendations for further research.

## 8.1 Key findings and new knowledge

The results from this study suggest that the sample size is too small to demonstrate that person-centred care delivered by family caregivers might be associated with an increase in patient well-being and calorie intake. The findings also identify an association between family caregiver delivered person-centred care and their primary attachment style. These associations have not previously been identified and were achieved through the merging of the qualitative and quantitative data, providing a comprehensive picture of the relevance of Kitwood's theory of person-centred care under the study conditions. The integration of the qualitative and quantitative data demonstrates how the methodology used has been able to provide an evidence-based theoretical explanation as to the acceptability and applicability of Kitwood's theory of person-centred care. However, it is acknowledged that further robust research is required using the same methodology with an increased sample size, in order to determine whether PCC by family care givers does increase calorie intake and wellbeing in people with dementia.

## **8.2 Implications for Practice**

The findings from this study need further testing before they can be generalised to acute hospital and care home settings. However, the study does have implications for practice as it identifies healthcare professionals in a state of flux, caught between protecting the patient's psychological well-being, while sustaining a therapeutic relationship with family caregivers should their care practices fall short of that considered acceptable. At times when family caregivers were force feeding their relative the staff on the ward refrained from placing a safeguarding alert into social services, unsure of the best course of action. The results of this study suggest healthcare professionals need to react to the actions of relatives who undermine the well-being of their relatives at mealtimes while considering the consequences their actions may have on their relationship with the relative and the dyad's relationship. This is a complicated situation at a time when the ethical principle of advocacy is overshadowed by operational priorities. An overhaul of the assumptions guiding care delivery may be required to address these conflicting principles, in the meantime the appointment of senior clinical nurses may bridge the gaps between the patient, family caregiver and ward nurse.

## **8.3 Recommendations for future research**

The findings from the mixing of the data from phase 1 and 2 demonstrate a significant association between receiving person-centred care at mealtimes from a family caregiver and patient well-being scores and calorie intake. The small sample recruited to the study necessitates caution when interpreting these findings; therefore, it is important that these results are not considered to be the end to this line of enquiry. The researcher intends to publish the study findings and is due to present the research at the Royal Collage of Nursing International Research Conference September 2019. These academic activities will generate open conversations about family caregiver behaviours at mealtimes and the importance of the delivery of person-centred care. The researcher also anticipates an adequately powered study to be carried out to re-examine the study propositions and to test attachment theory in this setting empirically. Should further research findings support the proposition that a patient's tendency towards well-being and eating more is dependent on the delivery of person-centred care, family and professional caregivers would need to know if they are concerned about calorie intake they should focus on the person's well-being through the delivery of person-centred care. Should further research support the theory of family caregivers with an insecure attachment styles being less able to provide person-centred care interventions would need to be found for their early recognition and how they can be supported.

## **8.4 Concluding remarks**

This thesis was derived from clinical practice with the aim of examining and measuring the relevance of person-centred care to family caregivers of patients with dementia who were not eating. The thesis moved to question the relevance of person-centred care to both family and professional caregivers in the context of health care today.

Helping families to maintain the person-hood of the family member with dementia and uphold their well-being requires an understanding of the family attachment style and the opportunity and ability to work with the family to realise the care goals they aspire to.

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A Systematic Review and Meta-Analysis of Ethnic Differences in Use of Dementia Treatment, Care, and Research

# Appendix

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## Appendix 1: Tom Kitwood

Born in Lincolnshire in 1937, Kitwood graduated from King's College Cambridge with a BA in natural science. Following graduation, a Christian at this time, he trained for the priesthood and was ordained in 1962. Following a period teaching in a public boys' school he moved to Uganda to teach chemistry where he also took on the role of school chaplain. Kitwood remained in Uganda with his wife and new son working on his interest in how those in poverty could achieve empowerment. In 1971 a military coup led by Idi Amin forced him to return to England, not before contributing to efforts to protect those subject to persecution from the new regime. On his return he denounced his faith, and became committed to socialist and pacifist activities and the Labour movement, perhaps a reflection of how the widespread brutalities in Uganda affected him (Baldwin & Capstick, 2007).

Once back in England Kitwood continued with his academic studies, completing an MSc in the Psychology and Sociology of Education and PhD on "Values in Adolescent Life"; how moral development changes from childhood to adulthood. This work was supervised by Professor Rom Harré, whose work on ethogenetic social psychology became a great influence on Kitwood (Baldwin & Capstick, Pg xxv).

Kitwood's work from this time to when his attention turned to dementia centred on having moral concern for 'others' to enable forms of moral praxis or empowerment (Kitwood, 1990 p 68) (cited in Dewing, 2008). In this his seminal work, Dewing (2008) argued that Kitwood reveals his philosophical values and theoretical ideas, recognising how people with dementia had been positioned as 'other', and viewed as not persons.

In 1992, Kitwood became a senior lecturer in Interdisciplinary Human Studies and practiced as a psychotherapist. As an educator Kitwood was popular and entertaining using role-play and other teaching methods experimental for the time. His ability to engage with his audience may have developed when a practicing minister; he is described by Baldwin and Clapstick (2007), who worked with Kitwood, as charismatic and charming. In any event his ability to inspire others may have played a significant part in his success in establishing his theories of dementia into mainstream practice.

Kitwood's interest in dementia came about as a result of his role as supervisor for a clinical psychologist and a psychiatrist who were conducting research in dementia in 1985. During this time Kitwood was asked by Bradford Health Authority to evaluate a day care service. From here his interest in dementia deepened and become the main focus of his work inspiring him to develop Dementia Care Mapping.

Kitwood started working with Kathleen Bredin at this time, in particular on the development of Dementia Care Mapping. It was Bredin's Rogerian humanistic psychology interests that influenced the concepts of person-centred care.

In 1992 Kitwood set up the Bradford Dementia Research Group, later to drop ‘research’ from the title. The BDG as it became known has since developed from a small research unit concerned with the development of Dementia Care Mapping to a large group of academics working on a range of topics including education, family support, leadership and service development, with both graduate and undergraduate programmes of education.

In 1998 Kitwood became professor of psych-gerontology. That year he was also awarded the Age Concern Book of the Year Award for *Dementia Reconsidered*. The weekend after the award ceremony aged 61 Kitwood died suddenly at home from an undetected heart condition.

In the short time Kitwood spent working in the field of dementia care, the last 10 years of his life, he challenged the prevailing biomedical approach to dementia, successfully changing the way people living with dementia are viewed today. He developed an observation tool, Dementia Care Mapping, to measure well-being and ill-being, providing a platform for others to see the world from the perspective of the person with dementia, and promoted person-centred care which is now accepted internationally as the cornerstone of service provision.

While Kitwood’s theories were developed within the dementia agenda his ultimate concern according to Dewing (2008) was, “of a moral concern for others”. It is with this in mind this review is undertaken.

## **Appendix 2 QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES**

### COMPONENT RATINGS

#### A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

- 1 Very likely
- 2 Somewhat likely
- 3 Not likely
- 4 Can’t tell

(Q2) What percentage of selected individuals agreed to participate?

- 1 80 - 100% agreement
- 2 60 – 79% agreement
- 3 less than 60% agreement
- 4 Not applicable
- 5 Can’t tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

## B) STUDY DESIGN

Indicate the study design 1 Randomized controlled trial 2 Controlled clinical trial 3 Cohort analytic (two group pre + post) 4 Case-control 5 Cohort (one group pre + post (before and after)) 6 Interrupted time series 7 Other specify \_\_\_\_\_ 8 Can't tell

Was the study described as randomized? If NO, go to Component C.

No

Yes

If Yes, was the method of randomization described? (See dictionary)

No

Yes

If Yes, was the method appropriate? (See dictionary)

No

Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

## C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

1 Yes

2 No

3 Can't tell

The following are examples of confounders:

1 Race

2 Sex

3 Marital status/family

4 Age

5 SES (income or class)

6 Education

7 Health status

8 Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

1 80 – 100% (most)

2 60 – 79% (some)

3 Less than 60% (few or none)

4 Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

#### D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

1 Yes

2 No

3 Can't tell

(Q2) Were the study participants aware of the research question?

1 Yes

2 No

3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

#### E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

1 Yes

2 No

3 Can't tell

(Q2) Were data collection tools shown to be reliable?

1 Yes

2 No

3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

#### F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

1 Yes

- 2 No
- 3 Can't tell
- 4 Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

- 1 80 -100%
- 2 60 - 79%
- 3 less than 60%
- 4 Can't tell
- 5 Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

#### G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

- 1 80 -100%
- 2 60 - 79%
- 3 Less than 60%
- 4 Can't tell

(Q2) Was the consistency of the intervention measured?

- 1 Yes
- 2 No
- 3 Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

- 4 Yes
- 5 No
- 6 Can't tell

#### H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)

Community                    organisation/institution                    practice/office                    individual

(Q2) Indicate the unit of analysis (circle one)

Community                    organisation/institution                    practice/office                    individual

(Q3) Are the statistical methods appropriate for the study design?

- 1 Yes
- 2 No

3 Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

1 Yes

2 No

3 Can't tell

3

#### GLOBAL RATING

COMPONENT RATINGS Please transcribe the information from the grey boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A Selection bias	Strong	Moderate	Weak	
	1	2	3	
B Study design				
	1	2	3	
C Confounders				
	1	2	3	
E Blinding				
	1	2	3	
F Data collection methods				
	1	2	3	
G Withdrawals and dropouts				
	1	2	3	Not applicable

GLOBAL RATING FOR THIS PAPER (circle one):

1 STRONG (no WEAK ratings)

2 MODERATE (one WEAK rating)

3 WEAK (two or more WEAK ratings)

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No      Yes

If yes, indicate the reason for the discrepancy

1 Oversight

2 Differences in interpretation of criteria

3 Differences in interpretation of study

Final decision of both reviewers (circle one): 1 STRONG    2 MODERATE    3 WEAK

## **Appendix 3 Quality Assessment Tool for Quantitative Studies Dictionary**

The purpose of this dictionary is to describe items in the tool thereby assisting raters to score study quality. Due to under-reporting or lack of clarity in the primary study, raters will need to make judgements about the extent to which bias may be present. When making judgements about each component, raters should form their opinion based upon information contained in the study, rather than making inferences about what the authors intended. Mixed methods studies can be quality assessed using this tool with the quantitative component of the study.

### **A) SELECTION BIAS**

(Q1) Participants are more likely to be representative of the target population if they are randomly selected from a comprehensive list of individuals in the target population (score very likely). They may not be representative if they are referred from a source (e.g. clinic) in a systematic manner (score somewhat likely) or self-referred (score not likely). (Q2) Refers to the % of subjects in the control and intervention groups that agreed to participate in the study before they were assigned to intervention or control groups.

### **B) STUDY DESIGN**

In this section, raters assess the likelihood of bias due to the allocation process in an experimental study. For observational studies, raters assess the extent to which assessments of exposure and outcome are likely to be independent. Generally, the type of design is a good indicator of the extent of bias. In stronger designs, an equivalent control group is present and the allocation process is such that the investigators are unable to predict the sequence.

**Randomized Controlled Trial (RCT):** An experimental design where investigators randomly allocate eligible people to an intervention or control group. A rater should describe a study as an RCT if the randomization sequence allows each study participant to have the same chance of receiving each intervention and the investigators could not predict which intervention was next. If the investigators do not describe the allocation process and only use the words ‘random’ or ‘randomly’, the study is described as a controlled clinical trial. See below for more details. Was the study described as randomized? Score YES, if the authors used words such as random allocation, randomly assigned, and random assignment. Score NO, if no mention of randomization is made.

Was the method of randomization described?

Score YES, if the authors describe any method used to generate a random allocation sequence.

Score NO, if the authors do not describe the allocation method or describe methods of allocation such as alternation, case record numbers, dates of birth, day of the week, and any allocation procedure that is entirely transparent before assignment, such as an open list of random numbers of assignments.

If NO is scored, then the study is a controlled clinical trial.

Quality Assessment Tool for Quantitative Studies Dictionary

Was the method appropriate?

Score YES, if the randomization sequence allowed each study participant to have the same chance of receiving each intervention and the investigators could not predict which intervention was next. Examples

of appropriate approaches include assignment of subjects by a central office unaware of subject characteristics, or sequentially numbered, sealed, opaque envelopes.

Score NO, if the randomization sequence is open to the individuals responsible for recruiting and allocating participants or providing the intervention, since those individuals can influence the allocation process, either knowingly or unknowingly.

If NO is scored, then the study is a controlled clinical trial.

**Controlled Clinical Trial (CCT):** An experimental study design where the method of allocating study subjects to intervention or control groups is open to individuals responsible for recruiting subjects or providing the intervention. The method of allocation is transparent before assignment, e.g. an open list of random numbers or allocation by date of birth, etc.

**Cohort Analytic (two group pre and post):** An observational study design where groups are assembled according to whether or not exposure to the intervention has occurred. Exposure to the intervention is not under the control of the investigators. Study groups might be non-equivalent or not comparable on some feature that affects the outcome.

**Case Control Study:** A retrospective study design where the investigators gather ‘cases’ of people who already have the outcome of interest and ‘controls’ who do not. Both groups are then questioned or their records examined about whether they received the intervention exposure of interest.

**Cohort (one group pre + post (before and after):** The same group is pretested, given an intervention, and tested immediately after the intervention. The intervention group, by means of the pre-test, act as their own control group.

**Interrupted time series:** A study that uses observations at multiple time points before and after an intervention (the ‘interruption’). The design attempts to detect whether the intervention has had an effect significantly greater than any underlying trend over time. Exclusion: Studies that do not have a clearly defined point in time when the intervention occurred and at least three data points before and three after the intervention.

**Other:** One time surveys or interviews

### **C) CONFOUNDERS**

By definition, a confounder is a variable that is associated with the intervention or exposure and causally related to the outcome of interest. Even in a robust study design, groups may not be balanced with respect to important variables prior to the intervention. The authors should indicate if confounders were controlled in the design (by stratification or matching) or in the analysis. If the allocation to intervention and control groups is randomized, the authors must report that the groups were balanced at baseline with respect to confounders (either in the text or a table).

### **D) BLINDING**

(Q1) Assessors should be described as blinded to which participants were in the control and intervention groups. The purpose of blinding the outcome assessors (who might also be the care providers) is to protect against detection bias.

(Q2) Study participants should not be aware of (i.e. blinded to) the research question. The purpose of blinding the participants is to protect against reporting bias.

## E) DATA COLLECTION METHODS

Tools for primary outcome measures must be described as reliable and valid. If ‘face’ validity or ‘content’ validity has been demonstrated, this is acceptable. Some sources from which data may be collected are described below:

Self-reported data includes data that is collected from participants in the study (e.g. completing a questionnaire, survey, answering questions during an interview, etc.).

Assessment/Screening includes objective data that is retrieved by the researchers (e.g. observations by investigators).

Medical Records/Vital Statistics refers to the types of formal records used for the extraction of the data.

Reliability and validity can be reported in the study or in a separate study. For example, some standard assessment tools have known reliability and validity.

## F) WITHDRAWALS AND DROP-OUTS

Score YES if the authors describe BOTH the numbers and reasons for withdrawals and drop-outs.

Score NO if either the numbers or reasons for withdrawals and drop-outs are not reported.

Score NOT APPLICABLE if the study was a one-time interview or survey where there was not follow-up data reported.

The percentage of participants completing the study refers to the % of subjects remaining in the study at the final data collection period in all groups (i.e. control and intervention groups).

## G) INTERVENTION INTEGRITY

The number of participants receiving the intended intervention should be noted (consider both frequency and intensity). For example, the authors may have reported that at least 80 percent of the participants received the complete intervention. The authors should describe a method of measuring if the intervention was provided to all participants in the same way. As well, the authors should indicate if subjects received an unintended intervention that may have influenced the outcomes. For example, co-intervention occurs when the study group receives an additional intervention (other than that intended). In this case, it is possible that the effect of the intervention may be overestimated. Contamination refers to situations where the control group accidentally receives the study intervention. This could result in an under-estimation of the impact of the intervention.

## H) ANALYSIS APPROPRIATE TO QUESTION

Was the quantitative analysis appropriate to the research question being asked?

An intention-to-treat analysis is one in which all the participants in a trial are analysed according to the intervention to which they were allocated, whether they received it or not. Intention-to-treat analyses are favoured in assessments of effectiveness as they mirror the noncompliance and treatment changes that are likely to occur when the intervention is used in practice, and because of the risk of attrition bias when participants are excluded from the analysis.

Component Ratings of Study: For each of the six components A – F, use the following descriptions as a roadmap.

#### A) SELECTION BIAS

Good: The selected individuals are very likely to be representative of the target population (Q1 is 1) and there is greater than 80% participation (Q2 is 1).

Fair: The selected individuals are at least somewhat likely to be representative of the target population (Q1 is 1 or 2); and there is 60 - 79% participation (Q2 is 2).

'Moderate' may also be assigned if Q1 is 1 or 2 and Q2 is 5 (can't tell).

Poor: The selected individuals are not likely to be representative of the target population (Q1 is 3); or there is less than 60% participation (Q2 is 3) or selection is not described (Q1 is 4); and the level of participation is not described (Q2 is 5).

#### B) DESIGN

Good: will be assigned to those articles that described RCTs and CCTs.

Fair: will be assigned to those that described a cohort analytic study, a case control study, a cohort design, or an interrupted time series.

Weak: will be assigned to those that used any other method or did not state the method used.

#### C) CONFOUNDERS

Good: will be assigned to those articles that controlled for at least 80% of relevant confounders (Q1 is 2); or (Q2 is 1).

Fair: will be given to those studies that controlled for 60 – 79% of relevant confounders (Q1 is 1) and (Q2 is 2).

Poor: will be assigned when less than 60% of relevant confounders were controlled (Q1 is 1) and (Q2 is 3) or control of confounders was not described (Q1 is 3) and (Q2 is 4).

#### D) BLINDING

Good: The outcome assessor is not aware of the intervention status of participants (Q1 is 2); and the study participants are not aware of the research question (Q2 is 2).

Fair: The outcome assessor is not aware of the intervention status of participants (Q1 is 2); or the study participants are not aware of the research question (Q2 is 2).

Poor: The outcome assessor is aware of the intervention status of participants (Q1 is 1); and the study participants are aware of the research question (Q2 is 1); or blinding is not described (Q1 is 3 and Q2 is 3).

#### E) DATA COLLECTION METHODS

Good: The data collection tools have been shown to be valid (Q1 is 1); and the data collection tools have been shown to be reliable (Q2 is 1).

Fair: The data collection tools have been shown to be valid (Q1 is 1); and the data collection tools have not been shown to be reliable (Q2 is 2) or reliability is not described (Q2 is 3).

Poor: The data collection tools have not been shown to be valid (Q1 is 2) or both reliability and validity are not described (Q1 is 3 and Q2 is 3).

F) WITHDRAWALS AND DROP-OUTS - a rating of:

Good: will be assigned when the follow-up rate is 80% or greater (Q1 is 1 and Q2 is 1).

Fair: will be assigned when the follow-up rate is 60 – 79% (Q2 is 2) OR Q1 is 4 or Q2 is 5.

Poor: will be assigned when a follow-up rate is less than 60% (Q2 is 3) or if the withdrawals and drop-outs were not described (Q1 is No or Q2 is 4).

Not Applicable: if Q1 is 4 or Q2 is 5.

#### **Appendix 4 Grade of each intervention by design**

<b>HIGH</b>	2+ randomised control trials or 1 randomised control trial plus 2 high quality observational studies or 3 high quality observational studies
<b>MODRATE</b>	1+ randomised control trial plus 1 high quality observational studies or 3 high quality observation studies
<b>LOW</b>	<3 high quality observation studies  Observation studies include cohort studies, case-control studies, interrupted time series studies and control before and after studies

## Appendix 5 Grading questions in GRADE tool to evaluate overall strength of evidence from combined studies

<b>Criteria</b>	<b>Rating system</b>	<b>Definition</b>
As a body of evidence, are the study designs the strongest designs to answer the question?	-1	Determination of strongest design is outcome dependent. RCTs are not always feasible and in some cases observational studies provide better evidence
Based on the number of studies and the number of patients is this sparse? (Quality of evidence)	-1	Sparse refers to <3 studies per outcome; <2 RCTs are appropriate
Is the quality of the study acceptable? (Study quality)	-1	Study quality refers to the study methods and execution and is reflected in the individual study quality assessment (strong, moderate, weak)
Are there important inconsistencies across the studies? (consistency of results)	-1	Consistency refers to similar estimates of the effect. Inconsistency is demonstrated through differences in direction of the effect and significance of difference across all studies. For outcomes for which equivalent non-significant outcomes are favourable across groups, inconsistencies are present when the significant difference favours the comparison group
Is there concern about the directness of the evidence?	-1	Directness is the extent the participants, measures and outcomes are similar to the population of interest
Is there a high probability of reporting bias?	-1	Reporting bias refer to publication bias and selective reporting outcomes, that would result in more significant differences in comparison groups that actually exist.

## Appendix 6: Final strength definitions

<b>EVIDENCE GRADE</b>	<b>DEFINITION</b>
<b>HIGH</b>	High confidence that the evidence reflects the true effect. Further evidence is very unlikely to change our confidence in the estimate of effect
<b>MODERATE</b>	Moderate confidence that the evidence is a true effect. Further research may change our confidence in the estimate of true effect and may change the estimate
<b>LOW</b>	Low confidence that the evidence is a true effect. Further research is likely to change our confidence in the estimate of the effect and is likely to change the estimate of effect
<b>INSUFFICIENT</b>	Evidence is either unavailable or does not permit a conclusion



## Appendix 7: Family Caregiver Information Sheet



Trust Logo

### **Defining the care needs of family caregivers of people with severe memory problems during mealtimes**

#### **Family Caregiver Information**

##### **Invitation**

You and your relative are being invited to take part in a research project. Before you decide if you think you would like to participate, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

##### **What is the purpose of the study?**

Many people with dementia experience difficulties with either eating very little or refusing to eat anything at all. Current research suggests that family members and carers of people with memory problems may find this challenging or upsetting at times. The researcher is interested in exploring in detail the way family caregivers support their relative to eat, what they do when this proves difficult and how this situation feels for them. This information will help healthcare staff better understand how nurses can support family caregivers when people with dementia refuse to eat or eat very little and inform a model of care to improve the overall quality of care that people with dementia and their family caregivers currently receive.

##### **Why have I been invited to take part?**

You have been invited to take part in this study because your relative has been identified as having memory problems and you are a family caregiver. The researcher would need you both to join the study.

##### **Do I have to take part?**

- No. It is up to you to decide whether or not you want to take part in this study.
- If you do decide that you would like to take part you will be asked to sign a consent form.
- If you do not to take part, or you want to drop out of the study at any time this will not affect the medical or nursing care that your relative receive in any way. Just inform the researcher or a member of the ward team that you no longer wish to take part
- You do not have to give any reason for not wanting them to take part.

##### **What will the project involve?**

The researcher will observe both you and your relative during mealtimes to see what happens. She will do this observation during her normal working day and this should be un-intrusive. A maximum of 6 hours of observation will take place over a number of mealtimes. The researcher will also ask the nurses who care for your relative about how they support you and your relative during mealtimes. If your relative can communicate, the researcher will chat to them briefly about food and eating, you are welcome to be present during this time. This will last no more than 10 minutes.

You will be asked to complete a questionnaire about your beliefs and values of being a carer for your relative, and to complete a form detailing your demographics for example where you were

born, your cultural background, how much care you provide. This should take no more than 15 minutes. A ward nurse can help with this if you would like. You will also take part in interviews with the researcher to discuss in detail how you deal with your relatives eating behaviour. These interviews will last no longer than 30 minutes.

The interview will be tape recorded, transcribed (typed up) (you will remain anonymous) and sent to you for verification as to what was said. You can make comments and corrections or add things if you wish but you do not have to.

### **Are there any possible risks to our taking part?**

The researcher understands that this study may touch on some sensitive issues for carers when talking about their relative/loved one and their caring role. However, some carers may also find it beneficial to discuss their experiences. The researcher is highly skilled in working with carers. In the unlikely event that you do become upset in any way you must let the researcher know. The interview will be stopped and support will be provided

### **What are the possible benefits of our taking part?**

The researcher hopes that in taking part in this study, the information collected from you and the other participants will help to improve nurses understanding of the needs of carers of people with memory problems. The information you provide is very important as it will help inform and influence new and better ways of providing care.

If during the course of the observations undertaken by the researcher any unsafe or inadequate care is observed, the researcher will stop the research activity immediately, and address the situation in accordance with her professional guidelines as laid down by the Nursing and Midwifery Council and Trust guidelines.

### **Will my information stay confidential?**

Yes. All information collected about you during the course of the research will be kept strictly confidential. All identifiable information will be removed so that you cannot be recognised from it. This anonymous information will be collected, stored, handled and processed by the principle researcher.

### **What will happen to the results of the research study?**

The results will be shared with other health and social care organisations. They will also be presented at conferences and published in medical journals. If you wish to have a copy of the results sent to you, please let the principle researcher know. It will not be possible to identify individuals who have participated in the study.

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

The sponsor is University College Hospital London. The NHS Research Authority Research Committee has reviewed and approved this study.

If you have any questions or concerns please contact the principle researcher

Vicki Leah on: 07983450052

If there is a problem please contact

Patient Advice & Liaison Service

University College London Hospitals NHS Foundation Trust

Ground Floor  
University College Hospital  
235, Euston Road  
London  
NW1 2PQ  
**Tel: 0207 380 9975**

*Thank you for taking the time to read this information leaflet.*

## **Appendix 8: Patient Information Sheet**



Trust Logo

# **Defining the care needs of family caregivers of people with severe memory problems during mealtimes**

## **Patient Information Sheet**

We would like to invite you to take part in a research study.

### **What is the study about?**

I would like to find out how better to help your family provide care for you. I am interested in looking at what needs they may have when helping you to eat. This information will help healthcare staff improve the support nurses provide for family caregivers in the future.

### **If you take part:**

- I will ask you if you have any problems such as difficulties eating.
- With your permission, we will watch your mealtimes.
- We will collect information from your medical notes and from the people who care for you.

### **You do not have to take part, if you don't want to.**

You have 24 hours to decide if you want to take part. Please ask your staff nurse or ward sister if you want more time to make up your mind, or if you need to know more.

### **You can stop taking part at any time, just by telling me when you see me next or by telling a member of the ward team.**

This will not affect your care in any way.

If during the course of my observations of your mealtimes I see any unsafe or inadequate care I will stop the research immediately, and address the situation as laid down by my professional body the Nursing and Midwifery Council and the hospital's guidelines.

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

The sponsor for this study is University College Hospital London. The NHS Research Authority Research Committee has reviewed and approved this study.

**Any information I collect will be kept anonymous and private.**

However, in the unlikely event that we discover serious issues of concern regarding your wellbeing, I am required to break patient confidentiality and inform the medical or social care authorities.

Please let me know if you have any questions about this study. Ask Vicki Leah when you see her on the ward or call her on 07983450052 any time.

***Thank you for taking the time to read this information leaflet.***

## **Appendix 9: Personal Consultee Information Sheet**



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### **Defining the care needs of family caregivers of people with severe memory problems during mealtimes**

#### **Personal Consultee Information**

##### **Invitation**

I would like to invite your relative to take part in a research project but I understand that they are not able to understand, retain or weigh up the information given to them in order to make that decision. I would therefore like to ask you to consider if in your opinion your relative would like to take part in this study. Before you decide if you think they would like to participate, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please consider any previous wishes and feelings that your relative may have had regarding their participation in research. Ask any nurse on the ward if there is anything that is not clear or if you would like more information. You will have 24 hours to decide on whether you would both want to take part. Please let me know if you need longer.

##### **What is the purpose of the study?**

Many people with dementia experience difficulties with either eating very little or refusing to eat anything at all. Current research suggests that family members and carers of people with severe memory problems may find this challenging or upsetting at times. The researcher is interested in exploring in detail the way family caregivers support their relative to eat, what they do when this proves difficult and how this situation feels for them. This information will help us better understand how nurses can support family caregivers when people with dementia refuse to eat or eat very little and inform a model of care to improve the overall quality of care that people with dementia and their family caregivers currently receive.

##### **Why has my relative been invited to take part?**

Your relative has been invited to take part in this study because they have been identified as having memory problems.

##### **Do they have to take part?**

- No. It is up to you to decide whether or not your relative would want to take part in this study if they were able to decide for themselves.
- You should only agree for your relative to participate if you think they would not have refused to take part.
- If they do not take part, or they want to drop out of the study at anytime this will not affect the medical or nursing care that they receive in any way. Just inform the researcher of a member of the ward team that you no longer wish to take part
- You do not have to give any reason for not wanting them to take part.

### **What will the project involve?**

The researcher will observe both you and your relative during mealtimes to see what happens. She will do this observation during her normal working day and this should be un-intrusive. A maximum of 6 hours of observation will take place over a number of mealtimes. The researcher will also ask the nurses who care for your relative about how they support you and your relative during mealtimes. If your relative can communicate, the researcher will chat to them briefly about food and eating, you are welcome to be present during this time. This will last no more than 10 minutes.

You will be asked to fill in a form detailing your relative's demographics for example where they were born and their cultural background. This should take no more than 15 minutes. A ward nurse can help with this if you would like.

The researcher will also examine your relative's medical notes and document their past medical history, their functional and cognitive ability, how much they are eating and their weekly weight.

### **Are there any possible risks to our taking part?**

There is a slight risk that your relative may become uneasy if they feel they are being watched during mealtimes or asked questions they cannot answer. Everything possible will be done to avoid this. The researcher is an experienced nurse and will be observing mealtimes while carrying out her normal routine. Any interviews with your relative will be in the form of short chats rather than a question and answer session.

### **What are the possible benefits of my relative taking part?**

The researcher hopes that in taking part in this study, the information collected from your relative and the other participants will help to improve our understanding of the needs of carers of people with memory problems. The information you provide is very important as it will help inform and influence new and better ways of providing care.

### **Will our information stay confidential?**

Yes. All information collected about your relative during the course of the research will be kept strictly confidential. All identifiable information will be removed to ensure they cannot be recognised from it. This anonymous information will be collected, stored, handled and processed by the principle researcher.

### **What will happen to the results of the research study?**

The results will be shared with other health and social care organisations. They will also be presented at conferences and published in medical journals. If you wish to have a copy of the results sent to you, please let the principle researcher know. It will not be possible to identify individuals who have participated in the study.

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

The sponsor is Buckinghamshire New University. The NHS Research Authority Research Committee has reviewed and approved this study.

If you have any questions or concerns please contact the principle researcher,  
Vicki Leah on: 07983450052.

If there is a problem please contact

**Patient Advice & Liaison Service**

University College London Hospitals NHS Foundation Trust

Ground Floor  
University College Hospital  
235, Euston Road  
London  
NW1 2PQ  
**Tel: 0207 380 9975**

*Thank you for taking the time to read this information leaflet.*

## **Appendix 10: Family Caregiver Consent Form**



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### **Defining the care needs of family caregivers of people with severe memory problems during mealtimes?**

Name of Principle Investigator: Vicki Leah

Patient ID: \_\_\_\_\_

#### **Family Caregiver Consent Form**

I confirm that I have read and understood the information sheet (Version No. 1, 30.01.12) for the above project and have had the opportunity to ask questions.

I confirm that I have had sufficient time to consider whether or not I want to be included in the project.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I understand that some of the study information collected may be looked at by authorised and responsible personnel from The New Bucks University or from regulatory authorities to ensure that the project is being conducted properly.

I agree that my interview may be tape recorded and transcribed (typed up) and that this will be anonymised.

I agree that the information I give can be stored anonymously and used by the project team in developing an understanding of the health and social care needs of people with severe memory problems and their carers.

I agree to take part in this study

---

Name of Family Carer

---

Date

---

Signature

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

---

Name of Person taking / receiving  
consent

---

Date

---

Signature

## **Appendix 11: Patient Consent Form**



Trust Logo

### **Defining the care needs of family caregivers of people with severe memory problems during mealtimes?**

Name of Principle Investigator: Vicki Leah

Patient ID: \_\_\_\_\_

#### **Patient Consent Form**

**Please initial box**

1. I confirm that I have read and understood the information sheet (Version 1. 24.1.14) for the above named study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study.
3. I understand that my participation is voluntary and that I am free to withdraw at any time. If I do decide to withdraw I do not have to give a reason and my medical care and legal rights will not be affected.
4. I understand that relevant sections of my medical and social care records may be looked at by responsible individuals from the research team. I give permission for these individuals to have access to my records until I, or my carer, inform them otherwise.
5. I agree to take part in the above study.

---

Name & DOB of Patient\*

Date

Signature

\*If the patient is unable to sign the consent form, family carer to complete 'Family caregiver opinion form'

---

Name of Person  
taking/receiving consent

Date

Signature

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

[When completed, 1 for patient; 1 for project file; 1 (original) to be sent to GP].

## **Appendix 12: Family Caregiver Opinion Form**



Trust Logo

### **Defining the care needs of family caregivers of people with severe memory problems during mealtimes**

Name of Principle Investigator: Vicki Leah

Patient ID: \_\_\_\_\_

#### **Family caregiver opinion form**

**Please initial box**

I confirm that I have read and understand the information sheet (Version) for the above named study and I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I confirm that I have had sufficient time to consider whether or not I want my relative to be included in the study.

In my opinion, the person I care for, as named below, when they had capacity, would have agreed to join the proposed study

I understand that the participation of the person I care for is voluntary and that they are free to withdraw at any time. If they do decide to withdraw, or if I decide their withdrawal is appropriate and in their best interests, they / I do not have to give a reason and their medical care and my legal rights will not be affected.

In my opinion, the person I care for, as named below, when they had capacity, would have agreed to responsible individuals from the research team looking at relevant sections of their medical records.

I give permission for this access to health records until I inform them otherwise.

I understand that some of the study information collected may be looked at by authorised and responsible personnel from regulatory authorities to ensure that the project is being conducted properly.

I agree that the information my relative gives can be stored anonymously and

used by the project team in developing an understanding of the health and social care needs of people with severe memory problems and their carers.

I agree for the person I care for to take part in the study

---

Name of Carer

Date

Signature

---

Name & DOB of the person I care for

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

---

Name of Person taking / receiving consent

Date

Signature

**Appendix 13: Information Sheet to Patients and Family Caregivers not enrolled in Study**



Trust Logo

**Research project taking place on this ward**

While you are a patient on this ward a research project is taking place which aims to find out how to improve the way nurses support family caregivers of people living with dementia.

This research project has received ethical approval from the NHS Research Authority Research Committee.

The research is being carried out by Vicki Leah the consultant nurse for older people at University College Hospital London and PhD student at New Bucks University.

The research involves observing patients and families at mealtimes. Patients and families are only observed if they have agreed.

If during the course of the observations undertaken by the researcher any unsafe or inadequate care is observed, the researcher will stop the research activity immediately, and address the situation in accordance with her professional guidelines as laid down by the Nursing and Midwifery Council and Trust guidelines.

If you have any concerns please speak to the staff or Vicki.

Thank you for reading this.

Vicki Leah

Consultant Nurse Older People

07983450052

#### **Appendix 14: Study Poster**



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#### **Information to Visitors**



I am a University College Hospital London nurse and PhD student at New Bucks University. I am conducting research on the ward.

I will be observing the ward and writing things down about what mealtimes are like here.

If you feel unhappy about this please tell a member of staff.

I can speak to you individually about the research on the ward.

The staff can also let you know about the research. If you have any questions please ask a member of staff at any time.

## **Appendix 15: Family Caregiver Demographic Data Sheet**



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### **Family Caregiver Demographic Data**

Thank you for agreeing to take part in this research project. Your contribution will help towards increasing our understanding of family member's experience caring for relatives living with dementia.

Please answer the following questions

Name \_\_\_\_\_

Participant number \_\_\_\_\_

#### **Sex**

Male   Female

**Age** \_\_\_\_\_

Ethnicity: White British      British      European      East European

Black African      White African

#### **Religious beliefs:**

Christian      Muslim      Jewish      Sheik      Atheist

#### **Education level** (please circle the highest level of qualification)

GCSE   A levels   Certificate   1<sup>st</sup> degree      Masters      Doctorate

MVQ   other please state \_\_\_\_\_

**Occupation** \_\_\_\_\_ How many hours per week \_\_\_\_\_

What is your relationship with the patient? \_\_\_\_\_

How long have you been their main carer? \_\_\_\_\_

What form of care do you provide, for example all personal care, organisation of care or routine

---

Do you live with the patient?      Yes      No

Who provides you with informal support with your caring role, for example friends/family?

---

What formal support do you receive with your caring role, for example from paid carers, Admiral Nursing?

---

Do you think your relative is eating enough?      Yes      No      Not sure

Thank you once again for completing this form.

Please return in the addressed envelope provided to the ward clerk.

Vicki Leah  
Consultant Nurse  
Lead researcher  
07983450052

## Appendix 16: Patient Demographic Data Sheet



### Trust Logo Patient Demographic Data

Thank you for agreeing to take part in this research project. Your contribution will help towards increasing our understanding how people living with dementia experience care from their relatives.

Please answer the following questions

Name \_\_\_\_\_

Participant number \_\_\_\_\_

**Sex**

Male   Female

**Age** \_\_\_\_\_

**Ethnicity:** White British      British      European      East European

Black African      White African

**Religious beliefs:**

Christian   Muslim   Jewish   Sheik   Atheist   Other

**Education level** (please circle the highest level of qualification)

GCSE   A levels   Certificate   1<sup>st</sup> degree   Masters   Doctorate

NVQ   professional qualification   trade qualification

other please state \_\_\_\_\_

**Occupation/previous occupation** \_\_\_\_\_

Type of dementia   Alzheimer's   Multi infact   Lewy Body   Other \_\_\_\_\_

How long have you had the diagnosis? \_\_\_\_\_

Where do you live now?   Own home   Residential home   Nursing home   Sheltered Accommodation   Extra Care Housing   Other \_\_\_\_\_

**Other co-morbidities** \_\_\_\_\_

Thank you once again for completing this form.

Please return in the addressed envelope provided to the ward clerk.

Vicki Leah  
Consultant Nurse  
Principle Researcher  
07983450052



## Appendix 17: Beliefs about Caregiving Questionnaire



Trust Logo

### Beliefs about Caregiving

Thank you for agreeing to take part in this research study which is designed to examine ways in which family caregivers like you can be better supported by healthcare staff.

The study is being undertaken by Vicki Leah a consultant nurse for older people at University College Hospital London as part of her doctorate studies.

This questionnaire forms part of the study and explores your beliefs about care for your relative.

To what extent do you agree with each of the following statements?	Strongly agree	Agree	Disagree	Strongly disagree
1 Punishing my relative when he or she makes a mess is something I must do				
2 Letting my relative know who is boss is something I must do				
3 I must see my relatives bathroom habits are not offensive				
4 Making sure my relative follows the rules of proper behaviour is something I must do				
5 I have the responsibility to make sure my relative does not do anything to embarrass others				
6 “Taking the bull by the horns” with my relative is something I must do				
7 I have responsibility of confronting my relative with his or her mistakes				
8 I must allow situations to occur in order to teach my relative a lesson				
9 I must set up situations to test my relatives competence				
10 I have the responsibility of helping my relative to not embarrass themselves				
11Treating my relative like a child is something I must do for his or her own good				

12 I have the responsibility of checking that my relative takes a bath regularly				
13 I have responsibility for correcting my relatives mistakes				
14 "laying down the law" to my relative is something I must do				
15 I have responsibility for punishing my relative when he or she is deliberately aggressive				
16 I have responsibility of making my relative live with the mess he or she makes				
17 I must help my relative to do the things he or she is supposed to do				
18 I have responsibility of encouraging my relative to participate when interesting things are going on				
19 I must help my relative to keep his or her surroundings clean				
20 I have responsibility of making my relative's life comfortable				
21 I have responsibility of arranging my daily activities to accommodate my relatives social needs				
22 I have the responsibility of helping my relative enjoy life				
23 The transportation I provide must be acceptable to my relative				
24 I have the responsibility of providing the food my relative likes				
25 I must observe that my relative takes his or her medication as ordered				
26 I must evaluate my relatives safety at home				
27 I have the responsibility of arranging the household routine to make it easier for my relative				

Thank you for taking the time to complete this questionnaire it is very much appreciated.

## **Appendix 18: FAST Score**

### **FAST SCALE ADMINISTRATION**

The FAST scale is a functional scale designed to evaluate patients at the more moderate-severe phases of dementia when the MMSE no longer can reflect changes in a meaningful clinical way. In the early phases the patient may be able to participate in the FAST administration but usually the information should be collected from a caregiver or, in the case of nursing home care, the nursing home staff. The FAST scale has seven stages:

- 1 which is normal adult
- 2 which is normal older adult
- 3 which is early dementia
- 4 which is mild dementia
- 5 which is moderate dementia
- 6 which is moderately severe dementia
- 7 which is severe dementia

#### **FAST Functional Milestones.**

FAST stage 1 is the normal adult with no cognitive decline. FAST stage 2 is the normal older adult with very mild memory loss. Stage 3 is early dementia. Here memory loss becomes apparent to co-workers and family. The patient may be unable to remember names of persons just introduced to them. Stage 4 is mild dementia. Persons in this stage may have difficulty with finances, counting money, and traveling to new locations. Memory loss increases. The person's knowledge of current and recent events decreases. Stage 5 is moderate dementia. In this stage, the person needs more help to survive. They do not need assistance with toileting or eating, but do need help choosing clothing. The person displays increased difficulty with serial subtraction. The patient may not know the date and year or where they live. However, they do know who they are and the names of their family and friends. Stage 6 is moderately severe dementia. The person may begin to forget the names of family members or friends. The person requires more assistance with activities of daily living, such as bathing, toileting, and eating. Patients in this stage may develop delusions, hallucinations, or obsessions. Patients show increased anxiety and may become violent. The person in this stage begins to sleep during the day and stay awake at night. Stage 6 is severe dementia. In this stage, all speech is lost. Patients lose urinary and bowel control. They lose the ability to walk. Most become bedridden and die of sepsis or pneumonia.

## **Appendix 19 cont.**

### **Functional Assessment Staging (FAST)**

**Stage 1 -- Normal adult**

No functional decline.

**Stage 2 -- Normal older adult**

Personal awareness of some functional decline.

**Stage 3 -- Early Alzheimer's disease**

Noticeable deficits in demanding job situations.

**Stage 4 -- Mild Alzheimer's**

Requires assistance in complicated tasks such as handling finances, planning parties, etc.

**Stage 5 -- Moderate Alzheimer's**

Requires assistance in choosing proper attire.

**Stage 6 -- Moderately severe Alzheimer's**

Requires assistance dressing, bathing, and toileting. Experiences urinary and faecal incontinence.

**Stage 7 -- Severe Alzheimer's**

Speech ability declines to about a half-dozen intelligible words. Progressive loss of abilities to walk, sit up, smile, and hold head up (Reisberg et al., 1988).

**7A** – During the course of an average day or an intensive interview, no consistently meaningful verbal communication, only stereotypical phrases, or ability to speak is limited to 6 or fewer intelligible words.

**7B** – During the course of an average day or an intensive interview, ability to speak is limited to the use of a single intelligible word which the patient may repeat over and over.

**7C** - Ability to ambulate without personal assistance is lost.

**7D** - Cannot sit up without assistance (patient will fall over if there are no lateral arm rests on the chair).

**7E** - Loss of ability to smile.

**7F** - Loss of ability to hold head up independently.

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## Appendix 20: Montreal Cognitive Assessment Form

### MONTREAL COGNITIVE ASSESSMENT (MOCA)

Version 7.1 Original Version

NAME: \_\_\_\_\_  
 Education: \_\_\_\_\_ Date of birth: \_\_\_\_\_  
 Sex: \_\_\_\_\_ DATE: \_\_\_\_\_

VISUOSPATIAL / EXECUTIVE		Copy cube	Draw CLOCK (Ten past eleven) (3 points)			POINTS		
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
<b>NAMING</b>				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
<b>MEMORY</b> Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.	<input type="checkbox"/>	FACE	VELVET	CHURCH	DAISY	RED	No points	
1st trial	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
2nd trial	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
<b>ATTENTION</b> Read list of digits (1 digit/sec.).	Subject has to repeat them in the forward order <input type="checkbox"/> 2 <input type="checkbox"/> 1 <input type="checkbox"/> 8 <input type="checkbox"/> 5 <input type="checkbox"/> 4					<input type="checkbox"/>	<input type="checkbox"/> /2	
	Subject has to repeat them in the backward order <input type="checkbox"/> 7 <input type="checkbox"/> 4 <input type="checkbox"/> 2					<input type="checkbox"/>		
Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors <input type="checkbox"/> F B A C M N A A J K L B A F A K D E A A A J A M O F A A B							<input type="checkbox"/> /1	
Serial 7 subtraction starting at 100		<input type="checkbox"/> 93	<input type="checkbox"/> 86	<input type="checkbox"/> 79	<input type="checkbox"/> 72	<input type="checkbox"/> 65	<input type="checkbox"/> /3	
4 or 5 correct subtractions: <b>3 pts</b> , 2 or 3 correct: <b>2 pts</b> , 1 correct: <b>1 pt</b> , 0 correct: <b>0 pt</b>								
<b>LANGUAGE</b> Repeat: I only know that John is the one to help today. <input type="checkbox"/> The cat always hid under the couch when dogs were in the room. <input type="checkbox"/>							<input type="checkbox"/> /2	
Fluency / Name maximum number of words in one minute that begin with the letter F <input type="checkbox"/> (N ≥ 11 words)							<input type="checkbox"/> /1	
<b>ABSTRACTION</b>	Similarity between e.g. banana - orange = fruit <input type="checkbox"/> train - bicycle <input type="checkbox"/> watch - ruler						<input type="checkbox"/> /2	
<b>DELAYED RECALL</b>	Has to recall words <b>WITH NO CUE</b>	<input type="checkbox"/>	FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUED recall only
<b>Optional</b>	Category cue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	Multiple choice cue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
<b>ORIENTATION</b>	<input type="checkbox"/> Date	<input type="checkbox"/> Month	<input type="checkbox"/> Year	<input type="checkbox"/> Day	<input type="checkbox"/> Place	<input type="checkbox"/> City	<input type="checkbox"/> /6	
© Z.Nasreddine MD		www.mocatest.org			Normal ≥ 26 / 30	TOTAL <input type="checkbox"/> /30	Add 1 point if ≤ 12 yr edu	
Administered by: _____								

## **Appendix 22: Guide for Observations during Mealtimes**

### Guide for observations during mealtimes

Dyad identification Code \_\_\_\_\_

Description of patient's general condition and appearance including position from mealtime

Description of relatives positioning in relation to patient at mealtime

Events during observation

Time of event, verbal and non- verbal interactions between dyad and staff, recording of staff profession and grade

# **Blank raw data sheet**

**Date:** [REDACTED] **Time period:** [REDACTED] **Place:** [REDACTED]

**Total number of service users:**  **Number of staff:**  **Observer:**

## **Appendix 21: Dementia Care Mapping Data Sheet**

## **Appendix 22: Interview Guide**

### **Interview guide with family Caregivers**

Family caregivers often tell us that there are areas of caregiving for a family member that can be challenging or even difficult at times, mealtimes are an example for this. I would like to spend some time discussing this with you. Can you describe how you help your relative when it comes to eating?

Can you talk me through a typical mealtime?

What prompted you to act this way?

What do you feel you can do?

How does this feel?

What would be success for you?

What do you expect to happen?

What is really possible?

Asking probing questions, “can you tell me more about that?”

“Is this what they would have wanted?”

“How do you think they feel?”

“Is this what you would want for yourself?”

“How does this make you feel?”

Is there anything else you would like to say?

## **Appendix 23: Research ethics and Governance Approval Letter**



### **NRES Committee London - Queen Square**

HRA NRES Centre Manchester

Barlow House

3rd Floor

4 Minshull Street

Manchester

M1 3DZ

14 August 2015

Miss Vicki C A Leah  
Consultant Nurse Older People  
University College Hospital London  
250 Euston Road  
4th Floor East  
NW1 2PG

Dear Miss Leah

<b>Study title:</b>	An exploration of the relationship between family carers support for maintaining personhood in patients admitted to hospital with dementia and the eating behaviours of these patients Do positive interactions support patients to eat more, or do patients eat more when family caregivers exert pressure on them?
<b>REC reference:</b>	15/LO/0938
<b>Protocol number:</b>	N/A
<b>IRAS project ID:</b>	155182

Thank you for your email of 12 August 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Rachel Heron, [nrescommittee.london-queensquare@nhs.net](mailto:nrescommittee.london-queensquare@nhs.net). Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

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The sub-committee noted that the research team had conceded that the calculated sample size of 89 is the number per group and not, as they originally thought, the total number. So a sample of 178 participants would be needed altogether, divided equally between the two groups. The sub-committee was satisfied that this had been taken into consideration.

#### **Mental Capacity Act 2005**

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

#### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

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**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Ethical review of research sites**

##### **NHS sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

##### **Non-NHS sites**

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Cover letter]	V0.1	08 May 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity letter]	V.01	29 December 2014
GP/consultant information sheets or letters [letter to patients consultant ]	V0.1	15 December 2014
Interview schedules or topic guides for participants [interview schedual family and nursing]	V0.1	15 December 2014
Non-validated questionnaire [family caregiver demographics]	V0.1	11 January 2015
Non-validated questionnaire [Patient demographics]	V.01	29 December 2014
Non-validated questionnaire [nursing staff demographics ]	V0.1	19 December 2014
Other [Blank raw data sheet]		
Other [Behaviour category grid]		
Other [MoCA test]		
Other [UCH Food Record Chart 1]		
Other [Clarification re sponsor signature]		15 June 2015
Participant consent form [Nursing staff consent]	V0.1	15 December 2014
Participant consent form [personal consultee opinion form]	V0.1	23 April 2015
Participant consent form [patient consent]	V0.1	29 December 2014
Participant consent form [family caregiver consent form]	V0.1	29 December 2014
Participant consent form [Non-nursing consent form]	V.01	29 December 2014
Participant information sheet (PIS) [family caregiver info sheet]	V0.2	23 April 2015
Participant information sheet (PIS) [Family caregiver info sheet]	V0.3	10 August 2015
Participant information sheet (PIS) [Personal consultee info sheet]	V0.2	10 August 2015
Participant information sheet (PIS) [Non-nursing staff info sheet]	V0.2	10 August 2015
Participant information sheet (PIS) [Patient info sheet]	V0.2	10 August 2015

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Participant information sheet (PIS) [Nursing staff info sheet]	V0.2	10 August 2015
Participant information sheet (PIS) [Non-participant info sheet]	V0.2	10 August 2015
Participant information sheet (PIS) [Non-participant poster]	V0.2	10 August 2015
REC Application Form [REC_Form_10052015]		10 May 2015
Research protocol or project proposal [Research proposal]	V0.5	10 August 2015
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	.01	29 December 2014
Summary CV for student [supervisor CV]	V.1	12 February 2014
Summary CV for supervisor (student research) [supervisor CV]	V.1	06 May 2015
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Protocol flow chart]	V.01	29 December 2014
Validated questionnaire [Belief about care giving question]	V.01	29 December 2014

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### **After ethical review**

##### **Reporting requirements**

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### **User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

#### **HRA Training**

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

**15/LO/0938**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

A Research Ethics Committee established by the Health Research Authority

Yours sincerely



On behalf of  
Dr Yogi Amin  
Chair

Email: [nrescommittee.london-queensquare@nhs.net](mailto:nrescommittee.london-queensquare@nhs.net)

*Enclosures:*      *List of names and professions of members who were present at the meeting and those who submitted written comments*  
*"After ethical review – guidance for researchers" [SL-AR2]*

*Copy to:*      *Dr M Nakisa*  
*Dr Clara Kalu, University College Hospital London*

