

THE EFFECT OF CARE WORKER COMMUNICATION  
STYLE ON THE COMMUNICATIVE BEHAVIOUR OF  
CARE HOME RESIDENTS WITH DEMENTIA:

A MIXED METHODS STUDY

MIRIAM GRAY BSc. MSc.

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## **Abstract**

Previous research into communication between care workers and care home residents with dementia has not utilised the experience of healthcare professionals who work with people with dementia on a daily basis. Previous research mostly consists of observational studies and the assessment of care worker training programmes. No study has yet attempted to establish the efficacy of isolated communication strategies, recommended by healthcare professionals, and administered by care workers within a residential care setting. This thesis first presents the thematic analysis of 16 semi-structured interviews with healthcare professionals who have experience of working with people with dementia. The participants discuss the personal characteristics required in a healthcare professional to facilitate communication, the verbal and non-verbal strategies they use and the organisational factors which can impact the delivery of communication as desired.

Two of the recommended strategies, alpha commands and pacing an interaction, were then analysed experimentally. Three care worker-resident dyads were videoed during morning care routines in an ABAC design. Resident communicative behaviour was measured using an amended version of the Positive Response Schedule (PRS) (Perrin, 1997), the Resistiveness to Care Scale (RTC-DAT) (Mahoney et al., 1999) and compliance. It was found that the conditions containing a significantly higher percentage of alpha commands produced significantly higher PRS scores. This was shown within each dyad and across the dyads ( $r=+0.65$ ,  $p<0.05$ ). The results for the pacing condition were inconclusive as the residents responded quickly after instructions were given. This exploratory study found a significant effect of alpha commands on the communicative behaviour of care home residents with dementia. The implications for future research and care worker training are discussed.

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## **Preface**

Here in the UK and in other Western countries the average age of our population is increasing. People are now expected to live longer than ever before. This increase in the proportion of older people in our communities also brings an increase in the prevalence of people with age-related illnesses. One of these illnesses is dementia.

Dementia is a syndrome with many different biological and genetic causes. It is a degenerative illness where cognitive function, communicative ability and finally motor function gradually decline to death. It is an illness that is costly and prevalent and set to increase in the coming years.

Approximately a third of people with dementia live in residential care and approximately 60% of people living in residential care have a form of dementia.

These individuals are generally those at the more severe stages of dementia where their cognitive function has decreased to a point that makes it impossible for them to live independently. The care workers who staff these care homes are charged with the task of meeting their physical, emotional, social and spiritual needs, a task made more difficult by the communicative and behavioural symptoms of dementia.

Improvement in the care workers' ability to communicate with people with dementia, and therefore to meet their residents' needs, is crucial to the well-being of this growing population and the satisfaction of those who work with them.

This thesis contributes to the literature that pertains to communication with people with dementia. It researches the way in which care worker communication style can be changed to increase understanding between care workers and people with dementia and encourage the maintenance of communicative ability of care home residents.

This thesis is divided into seven chapters.

The first chapter describes the predicament of dementia care in the UK in the face of an ageing population. The symptoms and prevalence of dementia and its subtypes are described and the impact of dementia on communication. The role of residential care homes in the UK are outlined and the importance of improving communication practices for the quality of life of people with dementia. Lastly, some of the theories that seek to improve communication in healthcare contexts are then described and the definition of communication used throughout the thesis is given.

The second chapter presents the systematic search and review of the literature on the barriers and facilitators to communicating with people with dementia. In the previous chapter it was described how inquiries into this topic have changed over the last two decades. This evolution informs the systematic search strategy used to collect data for the review. The literature regarding observations of care worker communication style and their impact on the behaviour of care home residents with dementia and interventions that are aimed at increasing the quality and quantity of communication between people with dementia and formal care workers are reviewed. They are described in terms of their conclusions, the methodological quality and their efficacy in improving communication in this population. The gaps in the research are then highlighted for consideration in the rest of the thesis.

The third chapter describes how this thesis presents a unique contribution to the research in this field. It first presents research questions and the study characteristics required to fill the gaps in the literature and then goes on to discuss and propose a mixed-methods design by which these questions will be addressed.

The fourth chapter presents an interview study consisting of 16 semi-structured interviews with people experienced in communicating with people with dementia.

Participants were asked about the challenges of communicating with people with dementia, the things that helped or hindered communication, organisational factors impacting on communication and any training they had undertaken on this topic. Interviews were analysed thematically following established guidelines (Braun & Clarke, 2006) and the devised coding scheme is discussed in relation to the models of interpersonal communication described in the introduction and existing research described in the literature review.

Chapter five describes the process by which the strategies mentioned in the interview study were developed into two interventions. This experimental study is described and evaluated in chapter six. Chapter seven draws together the conclusions of the interview and experimental studies.

# **1. Introduction**

## **1.1 Chapter overview**

The average age of the world's population is increasing. With this ageing population comes an increase in the prevalence of age related illnesses such as dementia.

Dementia is an illness that has life changing effects both on the person with the illness and those who care for them. Its effects are biological, emotional, economic and social. This chapter explores the symptoms and prevalence of dementia and its subtypes and the impact of dementia on communication. The role of residential care homes in the UK are outlined and the importance of improving communication practices for the quality of life of people with dementia. Lastly, some of the theories that seek to improve communication in healthcare contexts are then described and the definition of communication used throughout the thesis is given.

## **1.2 The ageing population**

The world-wide community is currently experiencing a dramatic increase in the proportion of older people (those over 60 years). Advances in medical science have resulted in increased longevity so that the oldest old, those aged over 80 years, are the fastest growing age group in the world (United Nations, 2002). As the proportion of older people increases, so does the prevalence of illnesses that accompany old age. One of these illnesses is dementia. The growing population of people with dementia requires far-reaching economic and social adjustments (United Nations, 2002) and a commitment to research into the cause, cure and ongoing treatment and care of people with dementia.

## **1.3 Dementia**

Dementia is a syndrome, a collection of symptoms, which are caused by changes in the structure and chemical make-up of the brain, leading to the death of brain tissue. It is a degenerative illness where the primary feature is impairment in memory function, accompanied by other cognitive deficits such as difficulties with speech, reading, writing, attention, orientation and judgement. Dementia can be caused by various biological factors such as stroke or can have genetic elements, such as with Alzheimer's disease.

Because dementia is a syndrome that occurs mainly in older people it is commonly thought to be a natural consequence of ageing, however, this is not the case.

Dementia is most common in older people and it is estimated that one in 14 people over the age of 65 have late-onset dementia. But it is also found in those under the age of 65, approximately one in every 1,400 (Alzheimer's Society, 2012). This is

known as early-onset dementia. Most people are expected to live between three to nine years after diagnosis, yet this varies with the subtype of dementia and the characteristics of the individual (Luengo-Fernandez, Leal, & Gray, 2010). There are thought to be approximately 800,000 people living with dementia in the UK (Alzheimer's Society, 2012) but, due to the ageing population, the number is expected to rise to approximately 1,700,000 by 2051. Dementia is also one of the most costly health conditions. The calculated annual cost per person with dementia is £25, 472 (Albenese et al., 2007) with the total estimated at around £17.03 billion in 2005/2006, though other studies place the figure at around £23 billion (Alzheimer's Society, 2012). Compared to other conditions such as cancer, coronary heart disease (CHD) and stroke, dementia cost the UK twice as much as cancer and four times that of CHD and stroke in 2008 (Luengo-Fernandez et al., 2010). When these costs are weighed against the amount of funding released into research for these conditions there is a vast discrepancy. Of the £833 thousand dedicated to healthcare research in 2008 only 6% was dedicated to research into dementia.

The diagnosis of dementia, and especially the subtype of dementia, is far from straightforward. The Diagnostic and Statistical Manual of Mental Disorders (5<sup>th</sup> ed.) (DSM-5) (American Psychiatric Association, 2013) diagnoses dementia by the presence of multiple cognitive deficits. One of these deficits must be an impairment of memory accompanied by one or more of the following: language disturbance, impaired motor function, problems with orientation and difficulties with planning and sequencing. In addition, these cognitive deficits must each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of function.



However, because of the increasing drive for early diagnosis, many do not meet the second diagnostic criteria of significant impairment in social and occupational functioning and are often diagnosed before meeting both criteria. In addition to this, for some, dementia first manifests itself as behavioural and psychological symptoms such as personality change and depression before the characteristic memory impairments. Dementia is a progressive syndrome, meaning that symptoms increase in their severity over time. The course of this degeneration is different depending on the type of dementia and characteristics of the individual (Weiner & Lipton, 2012).

There are a variety of underlying causes of dementia symptoms, many of which are still not well understood. Each subtype of dementia varies in its preliminary symptoms and course. The communication difficulties with which this thesis is concerned present themselves differently in each subtype. What follows is an outline of the main subtypes of dementia.

## **1.4 Dementia subtypes**

### **1.4.1 Alzheimer's Disease**

Alzheimer's disease (AD) is the most common cause of dementia and is thought to account for 62% of all the people with dementia in the UK (Albenese et al., 2007). The term AD is sometimes used as a blanket term to cover all forms of dementia, however, a strict diagnosis of AD can only be given post-mortem by the presence of abnormal proteins called amyloid plaques and neurofibrillary tangles in the cerebral cortex and the hippocampus. It is the build-up of these deposits that is thought to cause the death of brain tissue. The presence of these structures has been found to be significantly higher in the brains of those who showed the AD behavioural

symptoms during their lifetime compared to those who have not exhibited these symptoms (Tomlinson, Blessed, & Roth, 1970). However, there are many studies that have discredited a direct causal link between the presence of these biological abnormalities and the classic AD symptoms (Baldwin & Capstick, 2007).

In the early stages of AD, behaviour changes may be very subtle. Often AD is not detected until later on as it is possible for the individual to mask the initial changes. Typically a person will begin to experience problems with recent memory, repeat themselves, or have difficulty finding the names of objects. It is possible for all of these symptoms to be attributed to other causes such as natural ageing or stress and so it is typical for people with AD to only seek help months, even years after the onset of symptoms. As the disease progresses the severity of the primary symptoms increase and they may experience other symptoms such as increased agitation or irritability. As memory declines the person with AD needs reminding to complete activities such as going to the toilet, getting dressed or eating and may also find themselves disorientated and unable to recognise people. In the later stages the disease affects motor ability and the person with AD becomes bedbound and unable to communicate.

The cause of AD is still unknown though it is thought to be a result of the complex interaction of a number of risk factors ranging from heredity to lifestyle choices. Research has found some genetic mutations, or markers, found to be associated with early-onset AD but only one to date that has been associated with the development of late-onset AD (Gatz, 2007).

#### **1.4.2 Vascular dementia**

Vascular dementia (VaD), or multi-infarct dementia, is thought to be the second most common cause of dementia after AD accounting for 27% of people with

dementia in the UK (Albenese et al., 2007). In this subtype there is evidence of multiple infarcts, or lesions, in the brain. As the dementia is thought to be brought on by this sudden cell death the onset of VaD is abrupt with a stepwise, rather than gradual, decrease in function. The deteriorating abilities depend upon the brain regions affected by the lesions and therefore the pattern of symptoms can vary. Apart from memory problems the most common symptoms are problems with executive function such as planning, attention and reasoning abilities (Budson & Kowall, 2011). People with VaD often show a preservation of personality but it is common for them to experience depression and have a history of hypertension and strokes.

#### **1.4.3 Dementia with Lewy Bodies**

Dementia with Lewy Bodies (DLB) shows similarities to both Parkinson's disease (PD) and AD but is a cause of dementia in its own right (Budson & Kowall, 2011). Approximately 4% of people with dementia in the UK have DLB (Albenese et al., 2007). DLB is thought to be caused by the presence of Lewy bodies. These are small spherical bodies containing the proteins ubiquitin and alpha-synuclein found in the substantia nigra but also in the cortical regions of the brain. DLB is characterised first by deficits in attention, executive and visuospatial function. Memory problems generally appear later as the disease progresses. The presence of recurrent, well-formed visual hallucinations and fluctuations in cognition and alertness are the core features that distinguish DLB from other forms of dementia, as well as the presence of Parkinsonism, the motor problems found in PD such as rigidity, bradykinesia which refers to slowness of movement and rest tremor.

#### **1.4.4 Frontotemporal dementia**

Frontotemporal dementia (FTD) is a progressive condition where atrophy is primarily located in the frontal and temporal areas of the brain. It is less common than the other dementia subtypes and is thought to occur in approximately 2% of all cases of dementia in the UK (Albenese et al., 2007). The three biological conditions, frontotemporal dementia, semantic dementia and primary progressive aphasia, have all come to be known under the umbrella term of frontotemporal dementia due to their similar symptomology and pathology (Budson & Kowall, 2011). The key difference between FTD and AD is the early occurrence of personality change, emotional blunting, the decrease of social skills, disinhibition and language problems such as fluent or non-fluent aphasia. In AD it is the memory problems that generally appear first whereas in FTD the memory problems typically appear later as the disease progresses. FTD is a common cause of early-onset dementia with a mean age of onset between 52-56 years (Miller et al., 1998). Patients often present with a lack of insight into their symptoms and show increased apathy and passivity as severity increases. They may also undergo dramatic changes in their beliefs and values (Miller et al., 2001). The life expectancy of a person diagnosed with FTD, especially those with the behavioural variant of FTD, is significantly lower than people with AD which, when coupled with the often early-onset of FTD, drastically reduces life expectancy (Roberson et al., 2005).

#### **1.4.5 Dementia due to multiple etiologies**

Although the diagnostic criteria stipulated in manuals such as the DSM-5 and the ICD-10 depict a straightforward process of diagnosing dementia, it is worth noting that simple diagnoses are rare. There are many other conditions that can cause the symptoms of dementia and the medical histories of patients often show a myriad of other medical conditions, such as cancer or diabetes, that take priority in diagnosis

and treatment. It is not uncommon for the different dementias to co-occur, such as AD and VaD, thought to occur in 10% of people with dementia in the UK (Albenese et al., 2007). In addition to this, the vast variability in symptoms, personal life histories and individual characteristics of each person with dementia call for caution when administering blanket diagnoses and treatments. Although there are common symptoms they will affect each person and interfere with their life and those of their care givers in unique ways. Illnesses such as dementia do not only affect the biology of a person but also their beliefs about themselves, their social roles and their relationships with others. The impact that dementia has on an individual will be determined by many other individual factors.

## **1.5 Dementia and communication**

Communication is one of the primary processes affected by dementia, though the difficulties experienced are due to a combination of cognitive deficits. In AD word finding difficulties are one of the first symptoms to appear. People with AD are mostly aware of their deficits and often express irritation and frustration at not being able to express very simple statements. The communication deficits in DLB typically begin with difficulties in attending to situations occurring in the environment making it increasingly difficult to engage in interaction and follow a conversation from beginning to end. In addition to this the slow reactions due to bradykinesia can stunt interaction, preventing it from flowing at a normal pace, and could result in care givers excluding them from communication due to the time it takes to interact. FTD is characterised by early problems with language in the form of fluent aphasia where fluent sentences are produced but the content is nonsensical, or non-fluent aphasia where any expression of language is severely impaired. Those with FTD are often

unaware of their deficits which can cause confusion and anger when messages are not understood by care givers. As dementia progresses all people with dementia experience the degeneration of communicative abilities until their ability to express or comprehend messages is no longer possible. What follows is a more in-depth summary of relevant research into the deficits of people with dementia, both in expression and comprehension.

### **1.5.1 Deficits of expression**

As with most research on dementia, research in communication is dominated by studies focused on AD. For people with AD most language problems stem from damaged semantic memory, the part of memory that enables a person to develop meaning and understanding from words and to apply previous knowledge and concepts to new information. Repeated tests of free association and confrontation naming have found that participants with AD show significant deficits in the self-directed search of semantic memory (Santo Pietro & Goldfarb, 1985; Troster, Salmon, McCullough, & Butters, 1989). Chertkow, Bub, and Seidenberg (1989) showed that superordinate category information, such as whether a food item is fruit or dairy, was preserved, yet the ability to distinguish between items within a category, such as an apple and an orange, was disrupted. Bayles, Tomoeda, and Trosset (1990), when using a confrontation naming task, found that people with AD tended to provide attributes of the object (e.g. long neck) rather than the name of the object (e.g. ostrich). These studies show that the deterioration in semantic memory begins with detailed semantic information, such as knowing the difference between an apple and a pear before progressing to the higher level categories such as the difference between fruit and meat. Bayles et al.'s study shows that people with dementia still associate the attributes of the object with the object itself but cannot find the name. Care givers may experience this as a problem when the

specificity of an object is an important factor in a situation, such as the difference between the refrigerator and the freezer or the computer and the television.

Ripich, Vertes, Whitehouse, Fulton, and Ekelman (1991) recognised the need to evaluate communication deficits in the context of interpersonal interaction. She, and her colleagues, found that participants with AD used fewer words per turn during the conversation, more nonverbal responses, fewer assertive statements and a greater number of unintelligible responses. In practice this would mean that people with dementia would have difficulty expressing their needs and wishes to their care givers with interactions becoming increasingly frustrating, both for the person with dementia and the care giver, as the illness progresses. This study also shows the way in which people with dementia can withdraw from conversation, offering less content in their answers and can mask misunderstanding or uncertainty with nonverbal and unassertive statements.

In addition, people with dementia do not seem as able to vary the form and content of their speech according to situational demands as found in healthy adults. Healthy adults would normally accommodate their speech to allow for presuppositions about the knowledge and ability of the listener. People with AD no longer seem to be sensitive to these situational factors (Kemper, Anagnopoulos, Lyons, & Heberlein, 1994). Combined with short term memory problems, this means that people with dementia may over explain or persevere on aspects of their life or care, recounting situations or experiences that others are already aware of, leading to impatience and irritation in care givers.

### **1.5.2 Deficits of comprehension**

All of the studies mentioned so far have focussed on the expressive ability of people with dementia. There is another group of research that investigates comprehension ability, the ability of people with dementia to understand messages being given to them.

One of these studies was conducted by Tomoeda, Bayles, & Boone (1990) who sought to examine the effects of speech rate and syntactic complexity on the comprehension of people with Alzheimer's disease (AD) in comparison to healthy controls when performing the Revised Token Task (McNeil & Prescott, 1978). They found that participants with AD performed less well overall compared to controls and that the syntactic complexity of the instructions significantly affected their performance. Speech rate had no significant effect; however, there was a near significant interaction between speech rate and complexity causing participants in the AD group to gain their lowest scores when responding to complex, fast instructions.

Two years following this the same authors (Bayles, Tomoeda, & Trosset, 1992) published a second study that aimed to determine the pattern of deficits that occur across the time course of the disease. This study involved a large subject group (152 AD patients and 60 control participants) and comprehensive psychometric testing including the Global Deterioration Scale (GDS) (Reisberg, Ferris, de Leon, & Crook, 1982) the Core Linguistic Battery, which involves measures of object naming, reading, writing and pantomime expression and recognition, among other measures such as picture description and the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975). They found that the score on all measures declined as GDS score increased but that there was great diversity within stages.



These studies show that the ability of people with dementia to comprehend spoken and written instructions and to recognise facial expressions in their conversational partners decreases as the disease progresses. This is especially so if the messages they are trying to understand are syntactically complicated. Yet the variability within stages found by Bayles et al. (1992) shows that the decline in these abilities are not predictable and the comprehension ability of a person with dementia cannot be assumed simply on the basis of a deterioration measurement.

### **1.5.3 Confusion, hallucinations and lack of orientation**

It is not only the expression and comprehension deficits that affect interaction between people with dementia and their care givers. People with dementia often suffer other psychiatric symptoms such as hallucinations, confusion and disorientation which can hinder communication. Research on the impact of these psychiatric symptoms on interaction is not a feature of communication literature, yet it is evident that these symptoms are a barrier the sharing of messages and experiences. For example, a care worker trying to communicate that the resident's dinner is ready is prevented by the resident's disorientation in time and place and their anxiety to get home and cook the dinner for their family.

## **1.6 Care home research**

Just over one third (36.5%) of people with dementia live in residential care rather than in the community (Luengo-Fernandez et al., 2010) with the proportion of those living in a care home rising with age. The cost of this care accounts for 41% of the overall costs of dementia each year (Alzheimer's Society, 2012). It is probable that in the future, with the growing numbers of people with dementia, care homes will be

used predominantly for the growing number of people with dementia rather than for physical disability alone (Gordon et al., 2014).

It is those who work in residential care who interact most with people with dementia. Unlike informal care settings where a care giver may only be caring for one person, for example their spouse or a parent, formal care workers have to adapt their communication style to the needs of over 40 people with dementia in one care setting. In a cohort study of the health status of people in residential care in the East Midlands, 62% of the sample had a diagnosis of dementia. In addition, 66% of the sample had some form of behavioural disturbance, mostly in the form of agitation, nervousness and irritability. A greater proportion of these had frequent symptoms rather than severe symptoms, the sort that would benefit from non-pharmacological management (Gordon et al., 2014). The cognitive deficits and behavioural symptoms of people living in residential care are often greater than those still living in the community as those living in residential care often have more severe dementia.

The cognitive deficits and behavioural symptoms of dementia result in communication difficulties for the person with dementia, both in expression and comprehension. These difficulties often mean that care workers are not able to understand the needs of those they care for and this lack of understanding has been seen to cause other behavioural symptoms such as disengagement, social withdrawal and verbal or physical aggression (Algase, 1996). These 'distressed behaviours' often lead to high staff turnover, burnout and increasing costs (Donaldson, Tarrier, & Burns, 1997) and can also interfere with the quality of care given to others (Balesteri, Grossberg, & Grossberg, 2000).

Over the last few years a number of initiatives have sought to improve the quality of life for people with dementia in residential care. The My Home Life initiative is a

national project which aims to improve the quality of life of older people in care homes through relationship-centred and evidence-based practice (Meyer & Owen, 2008). Their work is based on eight themes, developed by the National Care Homes Research and Development Forum who explored 'what residents want from care homes' and 'what practices are evidenced to work in care homes'. The themes identified were: managing transitions, maintaining identity, creating community, sharing decision-making, improving health and healthcare, supporting good end of life, keeping workforce fit for purpose and promoting a positive culture. These themes were thought to map onto the Senses Framework (Nolan, Brown, Davies, Nolan, & Keady, 2006) that emphasises the idea of community in residential care and the importance of the six senses: a sense of security, continuity, belonging, purpose, achievement and significance; both for the residents, family and friends and staff of the care homes. These initiatives have highlighted the importance of the psychosocial aspects of care to the quality of life of people with dementia in residential care contexts, including the role of the interaction between people with dementia and formal caregivers.

In more recent years the National Dementia strategy (Department for Health, 2009) has sought to discuss and improve the state of dementia services across the UK. One of the objectives of this strategy was 'Living well with dementia in care homes'. Two of the reasons presented for the need for change relate directly to communication between care staff and people with dementia. They cited evidence that over a six-hour period, a typical care home resident only spent two minutes interacting with staff or other residents when daily care tasks were excluded (Alzheimer's Society, 2008) and also that the quality of staff communication with people with dementia has a major impact on their quality of life (Commission for Social Care Inspection, 2008).

The high and increasing number of people with dementia in residential care, the high incidence of behavioural symptoms that require non-pharmacological intervention, the importance of the psychosocial aspects of care and the impact of staff communication on the quality of life of people with dementia all point to the importance of developing optimal communication between people with dementia and care home staff. This project focuses on communication between care workers and people with dementia. The models described below have all been developed for employment in health and social care contexts with implications for communication in residential care.

## **1.7 The psychosocial model of dementia**

### **1.7.1 Person-centred care**

In the past twenty years there has been a dramatic shift in the discourse related to the care and treatment of people with dementia. This change can be traced back to the work of Tom Kitwood and the advent of what came to be known as person-centred care. Until this point the dominating discourse in dementia research was rooted in the medical model and the common assumption that the symptoms displayed by those with dementia had a direct causal relationship to their neurological degeneration.

However, laboratory based papers failed to acknowledge the influence of the social context surrounding those with dementia. Kitwood pointed out that post-mortem examinations of dementia patients, episodes of catastrophic decline as well as the phenomenon of 'reminiscence', do not support the assumed linear relationship between neurological decline and dementia symptoms. In his 1993 paper, *Person and Process*

*in Dementia*, (Tom Kitwood, 1993) he postulated that the manifestation of a person's dementia relies on a number of factors of which neurological impairment is only one. He claimed that other factors; personality, biography, health status and social psychology, had repercussions both for the care of people with dementia and for the direction of research in this area. What was once simply the uncontrollable degeneration of brain cells had become a condition that could be slowed by factors that were malleable to those surrounding the person living with dementia. Consequently, there were now therapeutic opportunities for people with dementia and their carer givers.

Kitwood's theory of person-centred care changes the priorities of care contexts so that the patient or resident is at the heart of all tasks and decisions. It revolved around the idea of personhood. Personhood is described as "a standing or status that is bestowed on one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (Tom Kitwood, 1997, p. 8). Kitwood talks of the way in which the relational element of personhood is crucial. As it is bestowed by another it is in the domain of relationships and interaction that personhood can be fostered or damaged. Because of the relational nature of personhood, communication plays a vital role in preserving personhood and well-being in dementia care.

When describing the theory of person-centred care, Kitwood explores the idea of therapeutic communication between a care worker and a person with dementia. His theory of communication is based on the triadic unit in symbolic interactionism (Blumer, 1969) where one person makes an action, another responds to that action and the first person reflects on that response. Kitwood extended this triadic unit to include more detail:

- “P1 - a) an individual with a given temperament, constitution etc.  
 b) carrying his or her unique legacy from past experience  
 c) in a particular sentient state (referring here to mood, emotion, feeling)  
 d) defines the situation in a certain way and  
 e) having various assumptions (about others’ expectations, states etc.)  
 f) and with certain desires, intentions, expectations, etc.  
 - makes an action
- P2 - (a, b, c, d, e)  
 Interprets P1’s action and f)  
 -responds
- P1 - interprets P2’s response and  
 -reflects  
 checking in various ways whether the act he or she is trying to bring off with  
 P2 is likely to be successful.” (Baldwin & Capstick, 2007, p. 123)

This more detailed explanation of a unit of communication shows the many ways in which communication breakdown can take place, especially when one of the participants has a form of dementia. For example, a person with dementia may be in a very different sentient state and may define the situation in a way that is not openly obvious to the other participant. In addition to this, people with dementia are less able to make rational assumptions about the knowledge and abilities of the other participant (Kemper et al., 1994). Kitwood postulates that successful communication with a person with dementia requires greater resources from P2. He uses the analogy of a resourceful tennis coach maintaining a rally with a novice. The coach uses the contributions of the novice and, with creativity, returns a shot that enables the rally to continue. So the carer in an interaction must employ a therapeutic approach that facilitates the interpretation of meaning and shared understanding.

'Malignant social psychology' (Tom Kitwood, 1993) is another element of person-centred care theory which refers to the way in which the interaction process can go wrong and personhood can be undermined rather than encouraged in communication. Kitwood proposed that communication practices were a carer's response to a combination of the person with dementia's behaviour and old-age and cognitive-deficiency stereotypes. These practices consisted of: treachery, disempowerment, infantilisation, intimidations, labelling, stigmatisation, outpacing, invalidation, banishment and objectification. These communication practices in turn stimulate the person with dementia's behaviour in accordance with the stereotypes leading to a negative feedback loop where deficits are reinforced and any remaining abilities suffer from a lack of nurture and encouragement. For example, a care worker may pick out the clothes a person with dementia is to wear that day without asking their opinion. This could be called disempowerment or infantilisation based on the stereotype that the resident with dementia cannot choose appropriately for themselves. The resident learns from this interaction that their opinion does not matter and they are not able to make their own choices and are, therefore, less likely to attempt to offer an opinion in the future.

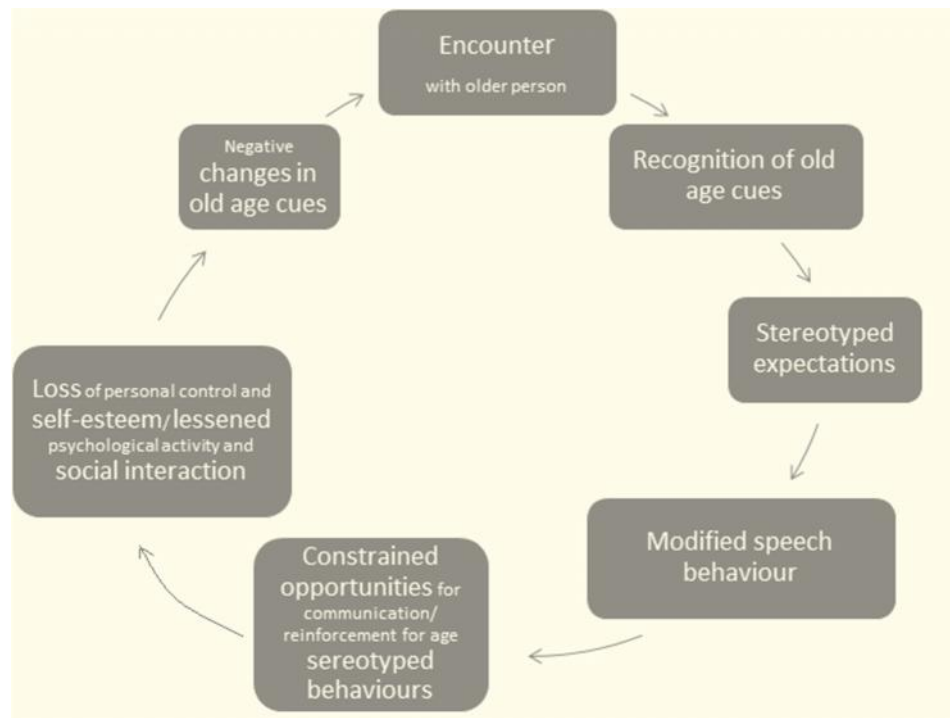
Person-centred care is the theory that underpins the practice in most care homes and is accepted by the National Institute for Health and Clinical Excellence (NICE) to be the guiding principles on which best-practice in dementia care is based (National Institute for Health and Clinical Excellence, 2012). As a result this theory not only provides a framework on which to base research initiatives but it is also informative as to the principles taught to care workers and the type of interventions that would be applicable in an environment that accepts these principles.

This theory, incorporating social psychology into a dialogue that until this point had been dominated by a medical discourse, opened the way for other models of communication in dementia.

### **1.7.2 The Communicative Predicament of Ageing Model and the Communication Enhancement Model**

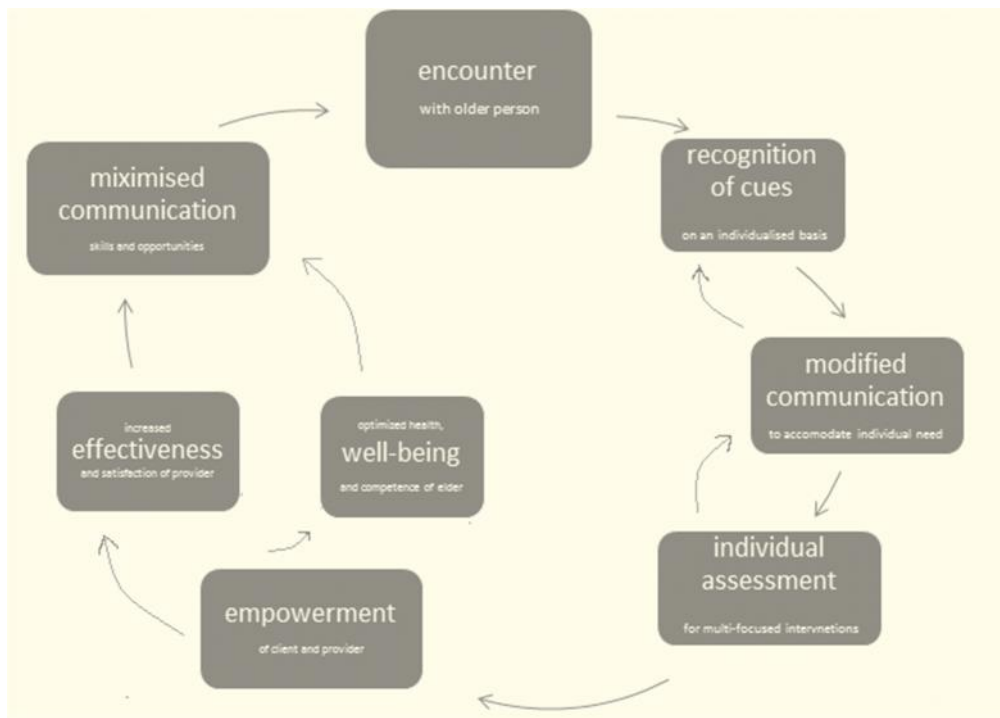
One of these models is the Communicative Predicament of Ageing Model (Hummert, Shaner, Garstka, & Henry, 1998). This model described the way in which older people have to overcome barriers experienced because of their ageing but also those imposed by their conversational partners. The model is presented in Figure 1. These barriers generally come in the form of old-age stereotypes and the resulting over-accommodated speech otherwise known as elderspeak or secondary baby talk. Speech modifications include slower speaking rate, exaggerated intonation, high pitch, increased volume, greater repetition, simpler vocabulary and reduced grammatical complexity (Caporael, 1981). Also mentioned in the literature is the inappropriate use of diminutives such as 'love' and 'dear', the avoidance of talk, restricted range of topics and a tendency to be dismissive of the older person's concerns (Kemper & Harden, 1999). These modifications can decrease the number of opportunities for the older person to participate in communication and also reduce satisfaction with the interaction. These interactions have also been found to impact the self-esteem and future performance of older people (Rodin & Langer, 1980) and so debilitate communicative abilities and reinforce stereotypes further. Although people with dementia often suffer from the deficits assumed in the old age stereotypes, it is still possible for communication to be over-accommodated and have the same negative impact on self-esteem and future performance.





**Figure 1. Communication predicament of ageing model, modified from Ryan, Giles, Bartolucci, and Henwood (1986)**

The Communication Enhancement Model addresses this predicament by, using a health promotion framework, employing educational interventions for health care professionals and patients both within the dyadic relationship and outside of it. The Communication Enhancement Model is displayed in Figure 2. Educational interventions are designed to increase understanding of ageing processes and new communicative skills for staff. These assist in the recognition of cues and the modification of communication on an individualised basis rather than reliance on stereotypes. The modified communication and assessment leads to the empowerment of individuals to participate in interaction and decision making rather than their exclusion. This successful communication leads to more positive expectations of future interactions.



**Figure 2. The Communication Enhancement Model, modified from Ryan et al. (1986)**

### **1.7.3 Need-driven dementia-compromised behaviour model**

Another communication theory often used in dementia research is the Need-driven dementia-compromised behaviour model (Algase, 1996). This claimed that all behaviour exhibited by people with dementia expresses a need, but the ability of the person to communicate that need has been compromised by their dementia and is therefore expressed in other ways such as shouting, aggression, wandering and resistance to care. By viewing these challenging or 'distressed' behaviours as the expression of a goal or need they are assigned meaning and can influence those caring for them. According to this model, need-driven dementia-compromised behaviour is the result of the interaction between background factors such as neurological and cognitive health and situational factors such as the physical and social environment. According to this model it is the responsibility of the care giver to attempt to interpret behaviour as a form of communication and to ensure that

any needs due to situational factors are met so that the person with dementia is not required to resort to their dementia compromised expressions for assistance.

The introduction of these models refocused research from the study of communicative decline to the examination of the environment surrounding those with dementia. Treatment for communicative disorders associated with dementia now became possible by altering the social situation surrounding them. The models described here have informed the design of this research project and the interpretation and discussion of results.

## **1.8 Operational definition of communication**

As this thesis focuses on communication between care workers and people with dementia it is important to define what is meant by the term communication when it is used. The Oxford English Dictionary defines “communication” as:

“The imparting or exchanging of information by speaking, writing, or using some other medium”

This includes the idea of “the successful conveying or sharing of ideas and feelings” and “social contact”. (Oxford English Dictionary, 2012)

The models described above, especially the Person-centred care model and the Need-driven dementia-compromised behaviour model portray a broad definition of communication that include non-verbal as well as verbal behaviour. The need-driven dementia-compromised model goes so far as to describe all challenging behaviour as a form of communication, including behaviour that is not intentionally expressed to another person, such as wandering.

In this thesis the definition of communication will not be as broad as this, as this would lead the research away from communication and towards a focus on all behaviour, a topic already studied extensively. The definition of communication in this thesis is restricted to the intentional conveyance or sharing of ideas or experience with another. Behaviour with no relational element will not be defined as communication. An example of this might be a person with dementia sitting in their chair with a facial expression indicating pain. However, if the person with dementia had an expression of pain on their face and attempted eye contact with another person or moved to hold the hand of another then this outward indication of an internal experience would become an intended communication of that internal experience to another.

## **1.9 Summary**

This chapter presented the symptoms, prevalence and cost of dementia in the UK. The subtypes of dementia and the varying ways the symptoms impact communicative ability were described, both in terms of laboratory research and how these effect communication in daily life. Four of the dominant theories of communication with older people or people with dementia were described before giving a definition of communication used throughout this thesis. The next chapter uses the theories and definitions described in this chapter to conduct a systematic search and narrative review of the research relating to the facilitators and barriers of communication between care workers and care home residents with dementia in care homes. This focus on the facilitators and barriers of communication will indicate the evidence-base for optimal communication between care workers and

people with dementia and highlight the gaps in the literature and the identification of research questions for the thesis.

## **2. Systematic search and narrative review of the literature on the barriers and facilitators to communicating with care home residents with dementia**

### **2.1 Chapter overview**

This chapter presents the systematic search and review of the literature on the barriers and facilitators to communicating with people with dementia. The previous chapter presented the background of communication research in previous decades, including how inquiries into this topic changed from a biomedical to a psychosocial focus in the last 40 years. This evolution informs the systematic search strategy used to identify literature for the review. The literature regarding observations that identify factors affecting interaction with this subject group and interventions designed to increase the quality and quantity of communication between people with dementia and formal care workers are reviewed in terms of methodological quality and efficacy.

## **2.2 Review protocol**

The introduction of the models such as person-centred care, the communicative predicament of ageing model, the communicative enhancement model and the need-driven dementia-compromised behaviour model of communication changed the direction of research into appropriate dementia care and highlighted the role of communication in the promotion of well-being for people with dementia. Focus was no longer on the course of communicative decline and instead turned to the examination of the social environment surrounding those with dementia. The possibility of facilitating communication and removing barriers, and even maintaining communicative abilities further into the illness, became possible through the intervention and education of health care professionals and carers. As a consequence of this change in theoretical framework, the research corpus on this topic is relatively new with few methodologically sound investigations. This shaped the review question and the criteria guiding the exclusion and inclusion of papers such as the inclusion of qualitative and observational work.

### **2.2.1 Review question and inclusion criteria**

This review aimed to identify and evaluate the research into the barriers and facilitators of communication with people with dementia and any strategies or interventions that aimed to improve interaction with this population. By evaluating these studies it was possible to identify the gaps in the corpus and this informed the direction of the studies presented in the proceeding chapters.

The review sought to answer the following questions:

- 1. On an interpersonal level, what elements of caregiver communication have been observed to facilitate or hinder interaction between professional care givers and people with dementia?**
- 2. In what ways has communication with people with dementia been modified by professional care givers in formal care contexts?**
- 3. How effective are these modifications in encouraging positive interactive behaviour with people with dementia?**

The review included studies that fulfilled the following criteria:

#### ***2.2.1.1 Population***

- Only studies of residential care home or nursing home residents diagnosed with dementia interacting with healthcare professional were included.
  - Studies that focussed on interaction with informal care givers such as family or friends were excluded due to evidence that certain forms of communication found to be acceptable when coming from a family member or friend may provoke different reactions when coming from a healthcare professional (Small, Perry, & Lewis, 2005) and therefore would not be generalizable to a formal healthcare setting.
- Diagnosis or separation of participants with different subtypes of dementia, e.g. AD or FTD, was not an issue when considering inclusion or exclusion.
  - This was because the variance found even within these subtypes or stages of severity was so great that consideration of subtypes would not improve the homogeneity of the population sufficiently to merit the exclusion of other data sources (Bayles et al., 1992).



- Studies where the sample was a mixed population were included if the proportion or ratio of people with dementia is documented and the results of the dementia group were reported separately.
- Some studies also included the diagnosis of (mild) cognitive impairment (CI) instead of dementia. As the diagnosis of dementia is still a controversial issue in the literature and CI is thought to be the precursor to dementia, these studies were also included.

#### ***2.2.1.2 Interventions and comparators***

- Observational studies and experimental studies were included in the review but were restricted to those that observe elements of interpersonal discourse between formal caregivers and people with dementia.
- Studies were only included if the participants being observed or delivering an intervention were professional caregivers.
- Only studies where data were collected in a residential care setting were included.
- Possible comparators were a 'usual communication' condition where communication was not altered from what would normally take place, a control group who received no intervention, a waiting list control group or a baseline measure. In observation studies the comparator would be a situation where the naturally occurring incident under study did not occur.
- Multi-component interventions, such as staff training interventions, had to include at least one element related to communication and was only incorporated if the study provided information as to what this element involved.

### **2.2.1.3 Outcomes**

- To meet the inclusion criteria a study had to include at least one measure of resident communicative behaviour.
  - Other reviews had included communication interventions where outcome measures were restricted to care worker satisfaction or levels of resident depression. These measures would not constitute a measurement of resident communicative behaviour.
- Possible measures of resident communicative behaviour included quantity and coherence of residents' utterances, measures of challenging behaviour, measures of positive affect, cooperative/appropriate responses, initiation of interaction or topic and frequency of communication breakdown.
  - Quality of life measures for this population often included elements of these. Studies using these outcome measures were only used if communicative behaviour measures were reported separately. Surrogate outcome measures of resident depression or anxiety were only considered when a study reported on the main outcome measures also.
- For qualitative studies, the interactional behaviour of formal caregivers and people with dementia had to be a key element or theme in the analysis.

### **2.2.1.4 Study design**

- Studies of quasi-experimental, case study and observational design including those with qualitative methodology were included as it was anticipated there would be few randomised controlled trials or controlled trials due to the relatively recent development of this field.

### ***2.2.1.5 Language***

- Only studies published in the English language were included as acquiring a translator for the purpose of this review was not possible.

### ***2.2.1.6 Publication type/status***

- Relevant studies appearing in peer-reviewed journals, reports and book chapters were included in the review. Other grey literature was not included due to uncertainty over the validity of sources.

## **2.2.2 Search strategy**

### ***2.2.2.1 Data sources***

The following online databases were searched over the period of November 2010:

PsychInfo, EMBASE, Medline, AgeInfo, Web of Knowledge and CINAHL. The publication dates of search results was set at the default for each of the databases.

Some relevant journals: American Journal of Alzheimer's Disease and Other Dementias, The Scandinavian Journal of Caring Sciences, Research in Nursing and Health, The Gerontologist and Research and Theory for Nursing Practice: An International Journal, were searched by hand as well as the reference lists of relevant papers and book chapters.

### ***2.2.2.2 Study selection***

Table 1 presents the search terms used for searching the online databases and the MeSH terms onto which these were mapped. Different databases resulted in different MeSH terms but the terms presented in the table were always selected when identified by the databases.

**Table 1. Search terms, MeSH terms and subheadings used in online search of databases**

<b>Search term</b>	<b>MeSH</b>	<b>Subheadings</b>
Dementia	Lewy bodies disease, semantic dementia, vascular dementia, senile dementia, frontal variant frontotemporal dementia, multi-infarct dementia	
Alzheimer's disease	Alzheimer's disease, cognitive impairment	disease management, rehabilitation, therapy
Communication	Augmentative communication, communication barriers non-verbal communication, interpersonal communication, conversation, oral communication, communication aids for the disabled, communication barriers, communication methods, health communication, persuasive communication, communication skills, social influences	
Interaction	Interpersonal interaction, social interaction	
Residential care	institutionalisation, long term care, nursing home, residential facilities, homes for the aged, caregivers	Ethics, methods, psychology, standards
Nonpharmacological	complementary therapies, stress/psychological, interventions, treatment, disease management	

Table 2 presents an example search of PsychInfo and how the search terms were combined. The same combinations were used for each database searched.

**Table 2. Example search of PsychInfo**

Search no.	Search term	Results
1	exp Dementia/ or exp Senile Dementia/ or exp Semantic Dementia/ or dementia.mp. or exp Dementia with Lewy Bodies/ or exp Vascular Dementia/	62941
2	exp Alzheimer's Disease/ or exp dementia/ or exp cognitive impairment	70777
3	1 or 2	80429
4	exp Communication Skills Training/ or exp Communication Barriers/ or exp Communication/ or exp Oral Communication/ or exp Verbal Communication/ or exp Augmentative Communication/ or exp Interpersonal Communication/ or exp Persuasive Communication/ or exp Nonverbal Communication/ or exp Communication Skills/	187266
5	exp Interpersonal Interaction/ or exp Social Interaction/	266999
6	4 or 5	393569
7	exp Residential Care Institutions/	30915
8	3 and 6 and 7	1738

Studies were identified first through the reading of titles to identify those on the appropriate topic. After reading the abstracts, full text copies of papers that fulfilled the inclusion criteria were obtained. For those abstracts that did not include the information needed to fulfil the inclusion criteria, full text copies were obtained and the appropriate information extracted before deciding on inclusion.

Table 3 presents the search results from the different online databases and the number of papers that were included in the literature review.

**Table 3. Inclusion of papers obtained through online search**

Database	Search results	Papers included
EMBASE	80	4
Medline	345	5
PsychInfo	1738	9
Web of Science	54	0
CINHAL	18	0

After duplicate papers were discarded 12 papers fulfilling the inclusion criteria were identified through online databases. Two further studies were identified through hand searching of specific journals and searching the references of relevant papers. Fourteen studies were included in the final review. Figure 3 shows the process by which papers were excluded from the review.

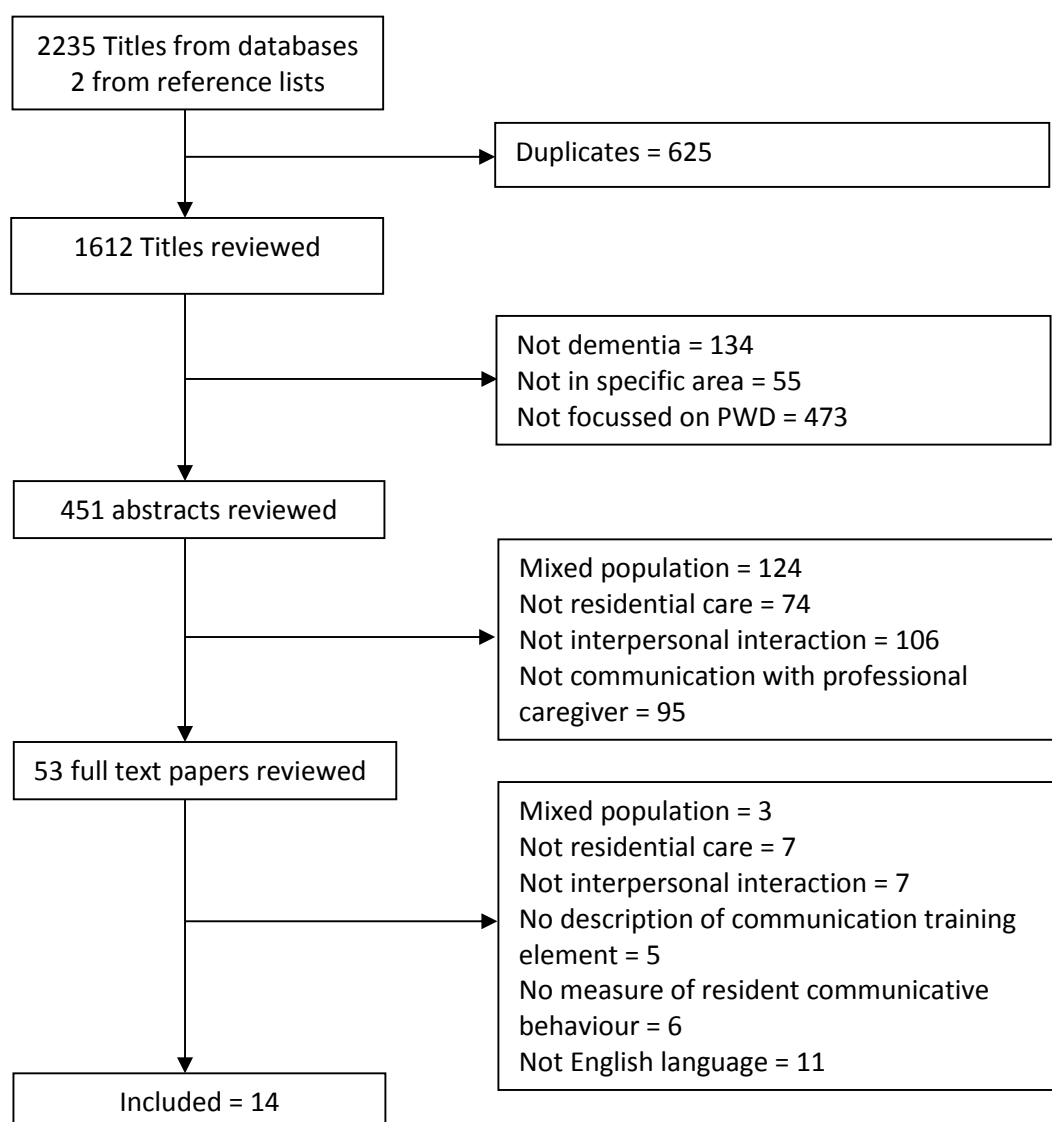


Figure 3. Diagram of Literature Review

## **2. 3 Narrative Review**

The remaining 14 studies pertained to the barriers and facilitators of communication between people with dementia and healthcare care workers in residential care homes. The studies identified in the search were divided into three broad categories: 1) observation of care worker communication style, 2) staff training interventions, 3) therapeutic interventions.

### **2.3.1 Observation of care worker communication style**

Across the literature there are two ways in which the style of speech used by care workers has been observed in order to determine the response it generates in care home residents with dementia. One of these styles referred to in the previous chapter is elderspeak. Kemper and Harden (1999) found that the exaggerated prosody and slow speaking rate found in elderspeak triggered negative self-assessments of competence in healthy older adults and negative assessments of the speaker. Three studies have been carried out that observed the effect of elderspeak on the behaviour of people with dementia in a residential care setting.

All three studies were conducted by the same group of authors (Cunningham & Williams, 2007; Herman & Williams, 2009; Williams & Herman, 2011). The first was a case study examining the response of one care home resident with dementia to elderspeak by measuring instances of resistance to care behaviours as described by Mahoney et al. (1999). Resistant behaviours or 'resistiveness to care' are a group of behaviours that indicate the unwillingness of an individual to cooperate with the person administering their care. They include clenching, crying, hitting/kicking, screaming and threatening. They counted instances of elderspeak in videos using the Elderspeak Scale constructed by the authors and instances of resistive

behaviours measured using the Resistiveness to Care Scale (RTC-DAT) (Mahoney et al., 1999). They analysed four videos and found that there were significant positive correlations between RTC-DAT scores and rates of elderspeak. The second study (Herman & Williams, 2009) sought to show the direction of causality between elderspeak and RTC-DAT behaviours. They used the same method, this time analysing 80 interactions during activities of care featuring 52 members of staff and 20 residents throughout the day. This time, increases in resident RTC-DAT behaviours were noted and the researcher then looked back seven seconds in the recording to determine the style of caregiver communication at the time. They calculated the frequencies of staff communication-resident behaviour state combinations and the frequencies of the alternative hypothesis that nursing staff communication style was caused by resident behaviour. They found that residents were twice as likely to exhibit RTC-DAT behaviour when staff used elderspeak. It was also found that residents' neutral behaviour was highly associated with a staff member's use of elderspeak. However, it was suggested that this was mainly because elderspeak was often present in the initial stages of an interaction before the resident had displayed any particular behaviour. A third study (Williams & Herman, 2011) used the same observational methodology to analyse the effect of one element of elderspeak known as emotional tone on the RTC-DAT behaviour of care home residents with dementia. An imbalance in emotional tone across the dimensions of care, respect and control had already been documented as a feature of elderspeak (Hummert & Ryan, 1996). This study sought to establish whether emotional tone was also correlated with incidences of resistance to care. Volunteers rated the care worker in each recoding using the Emotional Tone rating Scale (ETRS) which consisted of five-point Likert scales across 12 items, four belonging each to the dimensions of care, respect and control. Again, the RTC-DAT scale was used to code



levels of resident resistance to care in each video. They found that the use of controlling emotional tone had a significant positive correlation with RTC-DAT scores.

These three studies have all found that the communication style of care workers, specifically the use of elderspeak, negatively affected the behaviour of care home residents with dementia. Resistant behaviour was twice as likely to occur when care workers used elderspeak, and one of its features, a controlling emotional tone, was found to have a positive correlation with resistant behaviour. This suggests that this style of communication, while often used to placate or encourage cooperation from residents, instead produces uncooperative behaviour. It must be noted that all three of these studies were conducted by the same research team, used the same data and participants and the strength of the statistical calculations were weakened by the rarity of RTC-DAT behaviours in the recordings. It is a danger in such a specialised field, and in contexts in which it is notoriously difficult to collect data, that the same conclusions can be a product of the repeated analysis of a small data set. Problems with the original videos, such as lack of control over time of day, are replicated in the proceeding studies and make generalisation more problematic. However, these studies had well documented procedures for the reliability of coding and analysis. In addition to this, the use of the Elderspeak scale and the ETRS, and their demonstrated inter-observer reliability and internal consistency in previous literature, shows that these complex and often indefinable communication styles can be quantified.

The other communication factor investigated in the literature was the phrasing of instructions and whether these resulted in cooperative or uncooperative behaviour with people with dementia. Christenson, Buchanan, Houlihan, and Wanzek (2011) analysed 27 recorded interactions between 11 nursing staff and 11 residents with

dementia during care activities such as washing and dressing. They aimed to identify the different types of instructions, or commands, used by nursing staff and to calculate the percentage of commands which resulted in compliance or non-compliance by the residents. They devised a coding system of commands used in nurse-resident interactions based on work carried out on adult-child interactions (Forehand, 1977). In the coding system they included 9 different command types, most of which could be divided into either alpha commands, where an action or verbal response is appropriate and feasible, e.g. 'Lift your right arm', or beta commands, where compliance may be difficult due to vagueness, indirectness or forced compliance, e.g. 'move over.' By calculating the frequencies and percentages of each command that resulted in each response type they found that alpha commands resulted in greater compliance as opposed to beta commands. Most importantly, of the command types used most regularly in care activities; interview alpha e.g. 'Do you want a glass of water?', regular alpha e.g. 'Stand up', indirect beta e.g. 'Here's your glasses' and interview beta 'What?', only interview alpha and regular alpha were among the top five command types with the highest levels of compliance.

This study showed the way in which care workers may favour interaction styles that do not lead to the maximal level of understanding and cooperation from care home residents with dementia. The suggested changes to the types of commands used in daily care activities are a practical and manageable way to increase compliance and something that could be easily taught to care home staff. The main weakness of this study, a weakness shared by all of the studies reviewed so far, is that the conclusions on the impact of caregiver communication style on the communicative behaviour of people with dementia are restricted by the observational, rather than experimental design. Therefore, it is difficult to infer the direction of causality. Future research

can build on these observations by controlling the presence of elderspeak or the phrasing of instructions in a number of conditions to further establish the causality of resident communicative behaviour.

### **2.3.2 Staff training interventions**

One way in which care giver communication style has been modified is through the employment and evaluation of care giver communication training programmes.

These studies use experimental methodology, strengthening claims that changes in resident behaviour are due to the communication changes in staff. The interventions included in this review contained at least one element of training in communication strategies with people with dementia.

McCallion, Toseland, Lacey, and Banks (1999) evaluated the Nursing Assistant Communication Skills Program (NACSP), a training program designed to help nursing assistants interact more effectively with care home residents with dementia. The training involved five group sessions interspersed with individual sessions that served to reinforce and apply the concepts learnt in the group sessions. The teaching sessions covered issues such as the impact of age and dementia on communication, the use of memory aids and a three-step communication-based approach to dealing with challenging behaviours. These sessions were preceded by follow-up visits once a month for three months. To determine the effectiveness of the intervention the researchers measured the care staff's knowledge of dementia (Knowledge of Alzheimer's Test, KAT) and their knowledge of general behaviour management issues (Penn State Mental Health Questionnaire, MHQ). They also assessed staff turnover rates. From the residents they collected information on depression (Cornell Scale for Depression in Dementia, CSDD), agitation (Cohen-Mansfield Agitation Inventory, CMAI) and made general observations of dementia behaviour (Multidimensional

Observation Scale for Elderly Subjects, MOSES). They employed a nested partial crossover design where one unit from each setting was randomly assigned to the intervention group and the other to the waiting control (WC) condition who would receive the training after completion of data collection from the first group. The outcome measures from the WC group after their training were then compared with the intervention group. Outcome measures were taken at baseline, then three, six and nine months post-intervention. They found that, for residents in the NACSP condition, there was a significant decrease in residents' agitation scores after three months and a significant decrease in depression scores after six months when compared to the WC condition. When the WC group then underwent the intervention they also found a significant decrease in resident depression scores and significant decreases in the physical aggression and verbal aggression subscales of the CMAI after six months.

The training of staff in the impact of dementia on communication, the use of memory aids and a communication based approach to challenging behaviour was seen to reduce agitation, depression and aggression in the residents. This is a relatively strong study due to the presence of a control group and the large sample size: 88 nursing assistants and 105 residents with dementia. One criticism of this study was the way in which all resident outcome measures were informant-based, relying on the observation of staff who were not blind to their involvement in an intervention and may be biased towards the intervention having an effect. It must also be noted that in another study (Magai, Cohen, & Gomberg, 2002), real-time observation-based measures of wellbeing were found to be more sensitive to change than measures based on the retrospective observations of nursing staff.

The second study that reports a staff training intervention does not meet the inclusion criteria of the review. However, the subsequent analyses of the data from this intervention do meet the inclusion criteria. Therefore, the original study is reported in this review to inform the following reanalyses of the original data. In this staff training intervention (Burgio et al., 2000) a memory book and communication skills training program for care staff was evaluated in five nursing homes in the USA. The memory books provided were a laminated book containing biographical information, photographs of people they knew, their daily routine and instructions on activities of daily living. The general communication skills training aimed to train care workers in the skills later measured by the Communication Skills Checklist (CSC) which assessed the frequency of specific instructions, one-step instructions, positive statements, biographical statements, responses to behavioural disturbances and the use of general distraction techniques. All care workers received this training in a two-hour training session. Accompanying this intervention was a staff supervisory and motivational system that offered feedback and rewards to staff who achieved high percentages on the CSC and their self-monitoring forms (Burgio et al., 2002). Results of the intervention were taken from scores averaged across the first four weeks post-intervention and weeks five to eight post-intervention. They found that there was a significant increase in communication skills measured by the CSC including an increase in the use of positive statements and one-step statements and a decrease in the use of multi-step instructions. There was also an increase in the amount of staff speech directed to residents.

This study on its own does not fulfil the criteria for inclusion in this review as it uses a mixed sample of residents where the outcomes of residents with dementia are not recorded separately, and the measures of resident communicative behaviour were so rare that this analysis was not completed. However, it can be concluded that the

training undertaken resulted in an increase of staff communicative behaviour.

Another paper (Dijkstra, Bourgeois, Burgio, & Allen, 2002) used the participants with dementia and the intervention from this study and added a control group of participants not exposed to the intervention. Twenty-one nursing assistants were assigned to the intervention group and 19 to the control group. Each nursing assistant had between one and four residents assigned to them, 33 residents to the intervention and 33 to the control group. This study aimed to assess the benefits of the intervention by analysing the communicative ability of residents and staff in structured interviews before and after training. Out of the 33 residents with dementia in each condition 11 were judged to have early-stage dementia, 11 mid-stage and 11 late-stage dementia according to MMSE scores. It was found that, in comparison to the control group the intervention group showed increases in coherence, the use of unique words and decreases in indefinite words. Nursing assistants used more facilitators, encouragements and cues than the control group. The greatest improvements were seen in residents with late-stage dementia.

The addition of this paper is crucial to the evaluation of the training program devised by Burgio et al. (2000). It shows that an intervention combining education in the use of memory books and communication skills increases the communicative abilities of care home residents with dementia and their care workers in comparison to a no treatment control group. Although the participants were not randomly assigned to their experimental groups, this study had many strengths such as the use of a control group, a comparatively large sample size, the possibility of comparing results from participants from different stages of dementia and clear evidence of effects on resident and staff communication without having to rely on retrospective reports from staff.

Wells, Dawson, Sidani, Craig, and Pringle (2000) analysed the effect of abilities-focused training for care workers on care home residents with dementia. They used a repeated measures design with one group trained in abilities focused care and a second group who received no training. The training consisted of five sessions covering the effects of dementia on social abilities and self-care abilities and evidence-based interventions within these topics. Data on resident and care worker interaction behaviours, resident level of agitation and function and care worker stress and perceived ease of care giving were collected by researcher observation at baseline, three months post training and six months post training. They found residents from the experimental group exhibited significantly more interactional behaviour, were found to be more relaxed and displayed more attending behaviour and less agitation than the control group. The experimental group also showed a consistent decline in their levels of socially inappropriate behaviour over time. Care givers were found to use increased levels of interactive behaviour, however, despite these changes in resident and care giver behaviour, there were no significant changes in measures of care giver stress and ease of caring.

This study was one of the studies that were conducted and reported to a higher level of quality. Participants in the control group were matched to those in the experimental group by gender, age and severity of dementia. Researchers collecting data and participants were blind to the allocation of experimental or control groups. The follow-up period lasted six months, longer than most other studies of this nature. It can be inferred from this study that change in caregiver behaviour does affect that of the person with dementia, however, as with their results on overall and social function, it may take time, maybe as much as six months, to see the effects of an intervention on the behaviour of residents.

Magai et al. (2002) conducted a randomised controlled trial to assess the effect of a training program that trained care workers to be sensitive to the nonverbal emotional signals of people with dementia. Using three nursing homes randomised to different groups they trained the staff of one nursing home in nonverbal sensitivity. The training consisted of ten one hour sessions covering basic emotions, selective perception of emotion, personal emotional triggers, facial, vocal and bodily indications of emotion, emotional cues, practice sessions in recognizing emotional cues and a discussion on the effects of emotion communication and training in emotion validation skills. The second group acted as a placebo and participated in an equal number of training sessions so that any positive outcome in the nonverbal sensitivity group could be distinguished from the effect of simply investing in the development of care staff. The second group received education in types of dementia, behavioural changes caused by dementia, symptoms and their course over time, current treatment and diagnostic strategies, films showing interview and evaluation techniques and practice in the administration of dementia screening scales. The waiting list control (WC) group did not participate in either training but were offered the nonverbal sensitivity training after data collection for all groups was completed. The researchers collected data on the residents' frequency of delusions and hallucinations, ratings of depression and anxiety and also their levels of positive and negative affect expressed during a semi-structured interview. Caregivers were also asked to complete a brief symptom inventory measuring their own symptoms of depression, anxiety and somatic symptoms. The researchers found that, although there was no significant change in residents' symptomatology there was a significant increase in resident positive affect in the nonverbal sensitivity group compared to the other two groups whose levels remained the same. This showed that training staff in the recognition of residents' nonverbal expressions of emotion increased the



incidence of residents' expression of positive affect. It was found, however, that this increase in positive affect began to decrease soon after the completion of training and converged with the levels of the other groups after 12 weeks. They also found that staff's negative symptoms declined in the two training groups. This result, combined with the results of informal interviewing following the training suggest that staff wellbeing increased because they felt they were being invested in and had acquired new skills and knowledge that would improve the quality of care that they gave.

This study concluded that training care staff to recognise the nonverbal expression of emotion in residents with dementia can increase the communication of positive affect in people with dementia. However, for these improvements to remain effective, it had to be followed up with refresher sessions. They also concluded that, as the observation method discriminated between the groups when the informant-based measures did not it was suggested that observation instruments may be more sensitive to change than the informant-based measures. One criticism of this study is that the caregivers' implementation of the training was not assessed so it was not known in what way the training was put into practice. This lack of assessment also means that it is not known whether the fading of positive affect in the residents after the training was due to the failure to maintain the implementation of the training or the ineffectiveness of continued implementation.

Although the four staff training interventions described here vary in implementation and assessment there are some common themes. Firstly, all of the studies show increases in the care workers' use of the strategies they are trained in post-intervention. This shows that care workers can be trained to use certain communication strategies and implement them with obvious benefits to interaction,

resident wellbeing and care worker wellbeing. Three of the four interventions educated the care workers in the effects of dementia on communication and behaviour and it may be that this grounding in the abilities of a person with dementia and the reasons behind their behaviour enable care workers to see past prejudices and stereotypes to the needs of the person with whom they are interacting. Besides this commonality the other elements of the training varied, covering approaches to challenging behaviour, the use of memory aids, evidence-based physiological practices and sensitivity to emotional cues. However, all showed improvements in the behaviour they were measuring, whether it be global measures of agitation and depression or detailed identification of unique or indefinite words in a conversation.

One theme running through all of the studies was the benefit of residents with dementia being exposed to a communication-enhancing environment over a long period of time. McCallion et al. (1999) found that resident depression scores did not decrease until six months after the intervention. Despite the relative immediacy of improvement in resident communicative ability in Dijkstra et al.'s study they mention the possibility of even greater benefits over time. Wells et al. found that interactional behaviour, agitation and attention improved quickly but the reduction in socially inappropriate behaviour was a feature only seen later in follow-up. Yet it is the study by Magai et al. that brings forth the question of the maintenance of such an environment. This study found that the benefits faded after 12 weeks. This may have been due to the communication changes in staff not being maintained as in other studies with refresher sessions (McCallion et al., 1999) or staff motivational systems (Burgio et al., 2002).

Although these interventions show some of the factors which may facilitate communication between care workers and care home residents with dementia, the composite nature of these interventions means that it is not possible to know which elements of the interventions are effective in improving interaction. Future research could attempt to use some of these education sessions in isolation to distinguish the effectual strategies from those that are not effective.

### **2.3.3 Therapeutic interventions**

This section of the review refers to other interventions to improve care worker-resident interaction that do not include staff training. Only two types of intervention were found that fulfilled the inclusion criteria, individualised communication prescriptions and music therapeutic care (MTC).

One study (Acton, Yauk, Hopkins, & Mayhew, 2007) presented an intervention to improve communication between nursing staff and care home residents with dementia in which an individualised communication prescription was developed and administered to ten care home residents with dementia. The researchers developed each prescription by analysing video and audio recordings of a 15 minute interview between participants with dementia and an advanced practice nurse. Data were transcribed from the recordings and techniques such as the use of open-ended or closed questions, allowing time to respond, minimal cues and supportive statements were noted. The responses of the person with dementia were analysed to see which techniques facilitated or blocked communication for the participant. Using the techniques that were associated with increased communication, an individualised communication prescription was formulated for each participant. The prescription was used in a second interview with a research nurse. Total number of words, average words per topic, percentage of topics initiated by participants and total

number of topics needed to sustain the conversation for 15 minutes were calculated from transcripts of the interviews. The coding of all interviews was reviewed in consensus meetings until consensus reached 100%. The authors found that although there was no increase in the average total number of words uttered by the residents in the second interview the average number of words per topic significantly increased from the first interview. The average number of topics introduced by the residents also significantly increased and the number of topics required to maintain the conversations significantly decreased. In addition to this they found that when participants were divided into three groups according to the severity of their cognitive impairment it was the group with the lowest MMSE scores who showed the largest increases in communicative behaviour in the second interview.

Despite the small sample size and the different interviewers for the two interviews the effect of employing the individualised communication prescriptions is promising, especially for those with severe dementia. The development of a replicable protocol for developing these individualised communication strategies and the means for teaching these strategies to formal care givers would be a direction for future research. It would have been interesting to note the extent to which each prescription was individualised and whether most participants required similar accommodations. It would also be interesting to know whether long term exposure to these communication prescriptions result in long term changes in resident communicative ability and quality of life.

The other type of intervention documented in the research is known as music therapeutic care (MTC). Götell and colleagues published three studies, all analysing the same video data but analysing different concepts within it (Gotell, Brown, & Ekman, 2002; Gotell, Brown, & Ekman, 2003; Gotell, Brown & Ekman, 2009). They

wanted to examine the influence of using music during a normal care routine on people with dementia. They used three conditions carried out in a repeated measures design; normal care, background music, where music that had been chosen or enjoyed by the resident were played in the background during the care routine, and caregiver singing where the care worker was encouraged to sing old folk songs or children's songs. Nine resident-care worker dyads were recorded during morning care activities with a different condition each day. Only two of the three papers were included in this review as the other analysed the data according to body awareness and posture which was outside of the remit of this review.

Their first paper (Gotell et al., 2002) analysed the verbal communication between the residents and their care workers in the three separate conditions. To analyse the video data they used a phenomenologic-hermeneutic qualitative analysis of the dialogue. The normal care condition was described by the title "Caregivers' toil to create a comprehensible situation for the patients" where the care workers were seen to strive for cooperation from the residents. In the background music condition the dominant theme was "The creation, in cooperation, of an understood context" where the care workers did not have to strive as much for the cooperation of the residents. The caregiver singing condition was characterized as "Musical mutuality in a comprehensible context" where the care worker, and often the resident singing seemed to remove the need for explanation of the care task. Their second paper (Gotell et al., 2009) aimed to describe the way in which emotion and mood were expressed during music therapeutic care. Each video was transcribed according to the mood and emotional states that residents and staff expressed. Themes were then generated for each condition. The normal care condition was characterized as "Disjoined vitality" as the forced cheerfulness of the care worker did not equal that of the resident. The theme from the background music condition was "Mutual

vitality infused with playfulness” and often involved cheerful and sometime cheeky interactions between the dyad. In the singing condition, characterized by attitudes of “Mutual vitality infused with sincerity” there were expressions of openness and even vulnerability.

Another similar study (Hammar, Emami, Engstrom, & Gotell, 2011) used a two-condition, repeated measures design comparing usual morning care with an MTC condition similar to the singing intervention described above. Twelve residents with dementia and ten care workers were recorded once a week for four weeks carrying out ‘usual’ morning care. Care workers were then trained in MTC where they learned songs with accompanying body movements. Participants were observed once a week for four weeks using MTC. Videotapes were analysed using qualitative content analysis. As in the previous study normal care was described as disjointed, incongruous, confused and sometimes aggressive. But the MTC condition was characterized as active response, mutual relaxation and well-being. Eye contact also appeared to be important in this study as levels of eye-contact dropped when there was a lack of cooperation. The authors claimed that singing became a form of communication between the dyads.

Gotell, Thunborg, Soderlund, and Heideken (2012) examined the effect of care worker singing on person transfer situations, where caregivers assist residents with dementia to transfer from one setting to another. They sought to determine care workers’ experience of the intervention by interviewing nine care workers. Care workers were asked to talk about their experiences with the intervention and interviews were transcribed and analysed using qualitative content analysis. The coding scheme devised consisted of one category, “Reciprocally spirited movements and disposition”; and four subcategories, “Improved mutual transfer ability”,

“Enhanced mutual verbal and nonverbal communication”, “Caregivers’ new experiences, emotions and moods”, and “Singing can be both straightforward and challenging”. It was reported by the care workers that care worker singing seemed to facilitate the transfer process making movement easier. The majority of care workers reported that the residents showed more independence so that less physical effort was needed on behalf of the care worker. During the singing condition most of the verbal communication consisted of singing so that fewer commands and less repetition were needed and gesture seemed to be enough to communicate. Care workers also commented on the increased expression of personality in the people with dementia with an increased use of humour, smiles and speech.

Taken together these four papers describe very different styles of interaction in the different conditions. In the usual conditions the care workers are described as labouring to instil cheerfulness and understanding into the interaction in stark contrast to the passive, disjointed and sometimes uncooperative responses of the residents. However, when music was introduced, the interactions were more reciprocal and the care workers seemed less burdened with the responsibility of the interaction and gave way to greater expression in the residents. In conditions that involved signing, caregivers used very few words that were not sung as part of a song, yet residents showed an intuitive ability to cooperate with the care worker to complete activities and often joined in the singing, exercising the use of preserved abilities, even in residents who were normally silent.

The qualitative nature of these studies mean that results cannot be easily compared with the results of the care worker training interventions or the studies observing speech modification, however, the analyses portray the cooperative atmosphere of the interactions when music is introduced and the mutual understanding that singing

provided. Future research could repeat such studies using quantitative measures and analysis to demonstrate the objective efficacy of this intervention and make results more comparable to other research in this area.

#### **2.3.4 Discussion**

This narrative review has examined the literature pertaining to the barriers and facilitators of communication between people with dementia and formal caregivers in residential care homes. The studies identified in the search were divided into three broad categories: 1) observation of care worker communication, 2) staff training interventions, 3) therapeutic interventions. From the studies reviewed it can be seen that there is variety in the methodology used to research this topic, qualitative, quantitative, observational and experimental. Yet by reviewing the literature it is possible to glimpse the beginnings of a coherent picture of how care worker communication styles do effect the communicative behaviour of people with dementia and can be altered to improve interaction in residential care contexts.

The studies featuring the observation of care worker communication style have all found that the communication style of care workers, specifically the use of elderspeak and certain command types, affected the behaviour of care home residents with dementia. Resistant behaviour was twice as likely to occur when care workers used elderspeak, and one of its features, a controlling emotional tone, was found to have a positive correlation with resistant behaviour. Christenson et al. (2011) also found that the use of alpha commands, where instructions are precise and possible for the resident to fulfil were more likely to be complied with than commands that were vague. They also found that the command types most often used by care workers were generally not the command types that would elicit the most cooperative behaviour from residents with dementia. These studies suggest



that the communication styles often used to placate or encourage cooperation from residents instead produce uncooperative behaviour. All four staff training interventions included in the review varied in content, implementation and assessment yet all demonstrated that care workers can be trained to alter their communication techniques. All interventions demonstrated improvements in the resident behaviour they were measuring from long term changes in depression and agitation to immediate changes in the use of unique or indefinite words in interaction. In addition to this, all of these studies either demonstrated or hypothesised the possible benefit for residents when dwelling in a communication-enhancing environment over a longer period of time. Although only two therapeutic interventions met the criteria of this review, both showed promise as methods that could improve care worker-resident interaction. The use of an individualised communication prescription increased the residents' use of their communicative abilities, especially for those with severe dementia, and MTC shows signs of promoting a calm, cooperative environment for both staff and residents.

It is clear that the research on this topic cannot be described as being of the best methodological quality, for example none of the quantitative studies could be described as randomised controlled trials and even those with comparatively large sample sizes would not fulfil the requirements of power calculations seeking to establish the needed sample size to conclude the presence or absence of effect. Yet this is not unexpected in a field that is relatively new, with labour intensive methodology and in such a challenging setting.

### **2.3.5 Challenges of care home research with people with dementia**

Nursing homes are often reluctant to be involved in research and there are often feelings of scepticism, mistrust and threat about researchers coming from their 'ivory

towers' of academia into the 'real world' of the care home (Cleary, 2004). Reticence about being involved in research may be due to concerns about the welfare of the residents and the potential costs related to disruption of routines and increased demands on staff time. There is also the added difficulty of the ethical issues surrounding the involvement of participants without the mental capacity to give informed consent and the added time and effort required to find an appropriate consultee to give consent for involvement in the study (Cleary, 2004). In addition to this, many in the population are frail with the health of participants often becoming unstable during the course of the research leading to drop-out due to hospitalisation, relocation or mortality.

Because of the difficulties associated with obtaining data within this setting and population it is not surprising that many of the studies reviewed here are reanalyses of datasets used in other studies. Many of these studies are analyses of videos from the same dataset (Cunningham & Williams, 2007; Herman & Williams, 2009; Williams & Herman, 2011). Some studies are different analyses of the same intervention (Burgio et al., 2000; Dijkstra et al., 2002) so use the same setting and participants. In addition, Gotell et al. (2009) use the same video data as Gotell et al. (2002). Secondary analysis of datasets can lead to problems such as the inability to control variables in the original data, such as time of day in Cunningham and Williams (2007). This also means that most of the corpus, although from different studies, may only be based on a few minutes of footage or data from a small number of participants.

Another by-product of research in care homes is the difficulty of collecting data or continuing follow up over a longer period of time. Few of the studies in the review looked at the longer term effects of interventions. Only two studies, (McCallion et

al., 1999; Wells et al., 2000) collected data up to 6 months post intervention. Magai et al. (2002) collected data 3 months after the intervention finished. The MTC studies seemed to assume the instant effect of their intervention (Acton et al., 2007; Gotell et al., 2002; Gotell et al., 2009; Gotell et al., 2012; Hammar et al., 2011) and an instant reversion back to original resident communication following cessation of the treatment, though this was never tested. Although some authors did suggest that exposure to a communication therapeutic environment over a longer period of time may result in greater benefits for the participants (Acton et al., 2007; Burgio et al., 2000; Wells et al., 2000), this was not demonstrated in the designs of the studies.

### **2.3.6 Other limitations**

In addition to this, many interventions combined different interventions into one training intervention making it impossible to know which components of the training are actively benefitting residents and staff (Burgio et al., 2000; Dijkstra et al., 2002; McCallion et al., 1999; Wells et al., 2000). Many of these studies also used measures that were not adequate assessments of resident behaviour. Some measures, such as those of aggression, the RTC-DAT scale, use of restraints or medication, or negative affect were insensitive to change due to their rarity (Herman & Williams, 2009; Magai et al., 2002; McCallion et al., 1999). In one case, outcomes related to resident behaviour were not included in the results because of the rarity of the measured behaviour (Burgio et al., 2000). Many of the measures used were also informant-based, relying on the presence, memory and objectivity of care staff. These informant-based measures were not found to be as sensitive to change as observational measures used in the same study (Magai et al., 2002).

### **2.3.7 Research gaps identified in the review**

This review of the work so far undertaken researching the facilitators and barriers to communication between care workers and care home residents with dementia has highlighted four gaps in the literature.

Firstly it is pertinent that all studies in this review involve the application of ideas and interventions devised by academicians. Although one study (Gotell et al., 2012) interviewed care workers on their experiences of an intervention, there are no studies which seek to document the opinions or experiences of care workers on the facilitators and barriers to communication with people with dementia. It is important that this well of knowledge is not disregarded (Perkins, Whitworth, & Lesser, 1998). Future research would do well to capitalise on this knowledge base for the benefit of devising and executing not only evidence-based interventions but interventions that are acceptable for care workers and feasible for execution in day-to-day care.

Secondly, the care worker training interventions were a combination of many elements and taught care workers to use multiple strategies. Although all of these training interventions benefitted residents and care workers it is not known which elements were effectual in facilitating interactive behaviour and which were not. Future research should analyse some of these elements in isolation to determine their effectiveness before utilising them in a combined training intervention.

Thirdly, the studies that did investigate the effect of isolated communication styles, such as elderspeak, vocal tone or command type, were only descriptive rather than experimental in design. This restricted the results to correlations rather than causal conclusions. Researchers in the future could seek to directly manipulate the variable

of care worker communication style to establish causality between care worker communication style and resident behaviour.

Finally, many of the studies included in the review did not use adequate assessments of resident behaviour. Some measures, such as those of aggression or the RTC-DAT scale were insensitive to change (Herman & Williams, 2009; Magai et al., 2002; McCallion et al., 1999) or were not included in the results at all (Burgio et al., 2000) due to their rarity. Also, many of the measures used were reliant on the retrospective memory of care staff, measures found to be less sensitive to change than real-time observational instruments (Magai et al., 2002). Future research should use other, more sensitive measures of resident communication that record more frequently occurring behaviour and can be measured through real-time observation.

### **2.3.8 Conclusion**

Although many different research designs and outcome measures have been used across the literature in this field it can be concluded that the communicative behaviour of both care workers and people with dementia in residential care can be improved. Some of the general findings show that the use of elderspeak causes resistance to care, as does the use of a controlling tone and certain types of command use. Training staff in communication techniques has been shown to reduce rates of resident depression and aggression and to increase levels of communicative behaviour in residents with dementia however it is not known which of the many techniques taught produced this change. Individualised communication prescriptions and MTC also seem to be promising interventions yet more research is required and the knowledge of those who are in daily contact with people with dementia should be incorporated into the dialogue.

## **2.4 Summary**

This chapter has presented the systematic search and narrative review of research relating to the facilitators and barriers to communication between care workers and care home residents with dementia. Results of studies that involved the observation of speech characteristics, staff training interventions and other therapeutic interventions were discussed in terms of methodological quality and efficacy. Gaps in the literature were identified for further study. The next chapter will present the research questions and goals for this thesis and the methodology by which these questions will be answered.

## **3. Methodology**

### **3.1 Chapter Overview**

Following the review of the literature, this chapter describes how this thesis presents a unique contribution to research in this field. It presents the research questions, epistemological considerations and the rationale for a mixed-methods design.

## 3.2 Research Questions

In the previous chapter the literature pertaining to the facilitators and barriers of communication between care workers and care home residents with dementia was reviewed. It highlighted the following omissions:

- The voice of those who work with dementia on a regular basis was noticeably absent from the dialogue. There may be factors crucial to the care of people with dementia which have not yet been considered by researchers.
- Studies rarely used a direct measure of resident behaviour and instead relied on the retrospective report of care workers.
- Many studies were observational rather than experimental; therefore direction of causality between care worker communication style and the communicative behaviour of people with dementia could not be established.
- Some of the interventions involved training care workers in a multi-component package of communication techniques; it is not possible to isolate the 'active ingredients' in increasing positive communicative behaviour.

These omissions were considered in the construction of the research questions and research design. Based on these criticisms, this thesis will address the following research question:

**How does care worker communication style affect the communicative behaviour of care home residents?**

This overarching question will be answered by addressing the following:



1. According to health care professionals, what are the facilitators and barriers to communicating with care home residents with dementia?
2. Can the effectiveness of the facilitators suggested by health care professionals be demonstrated in an experimental context?

In answering these questions this thesis also aimed to address some of the methodological weaknesses of previous research by:

- Utilising the expertise of practitioners who care for and communicate with people with dementia on a regular basis;
- Including an experimental component to establish a causal relationship between care worker communication style and resident communicative behaviour;
- Testing communication techniques individually to assess their effectiveness in isolation from other strategies;
- Including measures of resident behaviour that do not rely on care workers' retrospective report.

### **3.3 Paradigms and Epistemology**

In order to design a research study it is first important to establish the paradigm and therefore the epistemological assumptions from which the research methodology springs. The epistemological perspective of this thesis is now described before explaining the methodology through which the research questions were answered. A paradigm has been defined by Saks and Allsop (2007) as 'an overarching philosophical or ideological stance, a system of beliefs about the nature of the world,

and ultimately, when applied in the research setting, the assumptive base from which we go about producing knowledge' (Saks & Allsop, 2007, p. 17). The paradigm to which a researcher holds will determine their understanding of ontology, their theory of reality, and epistemology, their theory of knowledge. In the social sciences the prevailing dialogue has been between the positivist paradigm, leading to quantitative research, and the interpretivist/constructivist paradigm, leading to qualitative research methods. In recent years a new understanding called critical realism, sometimes hailed as 'the third paradigm', has become more widely accepted. A brief description of each paradigm is given before discussing the reasons for utilising critical realism as the philosophical standpoint for this thesis.

### **3.3.1 Positivist paradigm**

The concept of positivism in the social sciences emerged in the early 19<sup>th</sup> century.

The assumption central to the positivistic understanding is that reality is defined by what can be experienced through the senses and can be measured objectively.

Within the social sciences the researcher aims to follow the basic premises of scientific enquiry in the social world and therefore assumes that it is possible to collect and interpret social facts objectively, produce laws and models of behaviour from those social facts and view them as neutral and unbiased (Saks & Allsop, 2007).

The main aims of the quantitative methods that spring from this paradigm are to measure behaviour, known as quantification, and construct models that predict that behaviour, known as determinism. There is also an emphasis on the reliability of research which is achieved by eliminating or reducing bias, often through the process of randomisation and researcher blinding. If the results of a piece of research are reliable it is also thought that they can be generalisable to the rest of the population.

However, there are some criticisms to this approach. It has often been argued that the processes of categorisation and generalisation so common in quantitative research do not take into account the individual's experience and the social and historical context in which this experience is embedded. The complexity of reasons *why* an intervention will lead to certain results cannot be answered by methods that only register whether a significant change has taken place. Accessing the perceptions and subjective understandings of participants can only be achieved through use of qualitative methods. The interpersonally complex research questions posed in this thesis place great value on the role of social context and the beliefs and attitudes underlying communication. The first question, involving the views of formal care givers, requires the acknowledgment of personal opinion and experience for the purpose of identifying important factors and generating theory that can be tested. These phenomena would be best identified using research methods that accept the importance of personal experience and seek to identify the underlying factors behind observed behaviour.

### **3.3.2 Interpretivist/Constructivist paradigm**

The interpretive paradigm emerged in the social sciences in the 1960s and 1970s. This paradigm challenged the assumptions of the positivist tradition. To the constructivist, reality is socially constructed by individuals based on the meanings that are interpreted from events. (Rubin & Rubin, 2012) say that interpretive research aims to explore what events mean to the research participants and how they understand what has happened to them. Because of the focus on social context research mainly takes place in a naturalistic setting. In this way the research is valid as it identifies the perspectives of the participants, but it is not generalisable as it emphasises the unique experiences of the participants through the subjective interpretation of the researcher. Conducting research from an interpretive paradigm

allows the research to be more flexible. Instead of simply testing pre-existing hypotheses which only allow the recording of data pertinent to the hypotheses, research in this paradigm can begin to discern other factors and patterns that do not yet belong to any hypothesis. As Saks says “This is a valuable approach because so often the cost of attempting to generalise is that we do not see and investigate those aspects of a process that do not fit our presuppositions about a particular phenomenon” (Saks & Allsop, 2007, p. 26).

There are criticisms to this paradigm. Firstly, the ontological perspective that reality is socially constructed creates problems when researching physical conditions such as dementia. Secondly, when considering the effectiveness and relevance of research, it can be seen that the inability to generalise findings to the rest of a population is a disadvantage. This thesis, while acknowledging the uniqueness of the individual experience of the person with dementia and the care giver, also acknowledges the common symptoms experienced by every person with dementia and seeks to identify generalizable strategies that can improve communication for the majority of this population. This paradigm would not allow a social construction such as interpersonal communication to be generalised from one formal caregiver-person with dementia dyad to another.

### **3.3.3 Critical realism**

Critical realism was designed first to be a challenge to positivism but also holds criticisms for constructivism. The role of science for the critical realist can be summarised in the words of Denemark, Ekstrom, Jakobsen, and Karlsson (2002), “Scientific work is instead to investigate and identify relationships and non-relationships, respectively, between what we experience, what actually happens, and the underlying mechanisms that produce the events in the world.” (from

Alvesson and Skoldberg, 2009, p.40). Critical realism argues that both positivism and constructivism are too superficial. According to critical realists positivism disregards the unobserved phenomena that produce observable data, whereas the interpretive paradigm does not capture the phenomena that are of real interest, the mechanisms that lie beyond individual interpretation. Like positivism, critical realism does hold that independent, objective knowledge exists; however, the nature of this knowledge will depend on the social context and the questions raised when looking at the world. Like constructivists, critical realists also emphasise that there are social constructions but that these should be regarded in an objective manner.

Ontologically they acknowledge the reality of a phenomenon if it causes an effect. In this respect nonmaterial things, such as ideas and discourses, can still be real in that they change human behaviour. Unlike the positivists, causality does not take the form of easily predictable patterns with inevitable conclusions. Although causal explanations are the ideal, these relationships are seen to be complex. There is a sense that a critical realist can never know the full complexities of a causal relationship but it is still the duty of the researcher to attempt to gain as full a picture of the underlying mechanisms as possible.

It is argued that critical realism makes grand claims about their ability to decide upon objective reality. But, in the context of health research, where the empirical model of physical illness and the interpretivist approach of the experience of the individual combine, it is the most pragmatic approach. This approach acknowledges the importance of individual experience and opinions concerning interaction and also the objective measurement of behaviour when exposed to different communication styles. It also allows the possibility of tentative generalisation.

A critical realist stance was adopted in this study in order to examine the underlying processes that mediate the effect of care worker communication style on the communicative behaviour of care home residents with dementia. In adopting the critical realist approach there was no definitive research methodology as it holds that both material and social constructions are objectively real and useful in exploring the underlying mechanisms of observed phenomena. The methods most appropriate for researching communication between these populations depended upon the research questions.

### **3.4 Mixed methods design**

On considering the research gap it was pertinent that the questions required both qualitative and quantitative methodology. Therefore, this thesis utilised a mixed-methods approach that combined both qualitative and quantitative methods.

#### **3.4.1 Definition**

Creswell and Plano Clark (2011) defined mixed-methods research in the following way:

“In mixed methods, the researcher:

- Collects and analyses persuasively and rigorously both qualitative and quantitative data (based on research questions);
- Mixes (or integrates or links) the two forms of data concurrently by combining them (or merging them), sequentially by having one build on the other, or embedding one within the other;
- Gives priority to one or to both forms of data (in terms of what the research emphasises);

- Uses these procedures in a single study or in multiple phases of a program of study;
- Frames these procedures within philosophical worldviews and theoretical lenses; and
- Combines the procedures into specific research designs that direct the plan for conducting the study.” (Creswell & Plano Clark, 2011, p. 5)

### **3.4.2 Choice of methods**

Creswell then goes on to explain the different types of mixed method design. These are categorised based on the way in which the data types are emphasised, how they relate temporally and the point at which the data are synthesised. Each type is utilised according to the method which best answers the research questions. The research questions addressed in this thesis are best answered through an exploratory mixed methods design, a design best used when the variables to be considered are not yet known (Creswell & Plano Clark, 2011). The exploratory design is a two phase design where the first qualitative phase helps to inform or develop a second quantitative phase. The first phase of this thesis used qualitative methods, gathering knowledge from healthcare professionals to identify important variables which were then analysed in more detail in the second quantitative phase of the thesis.

## **3.5 Research Proposal**

From the research questions and methods stated a two stage research design was proposed in which the research questions were addressed in the following ways:

1. According to health and social care professionals, what are the facilitators and barriers to communicating with care home residents with dementia?

This first question was addressed by conducting interviews with healthcare professional who were involved in the daily care of people with dementia. This incorporated their voice into the dialogue and identified the facilitators, or communication strategies, that could be analysed in the second phase.

2. Can the effectiveness of the facilitators suggested by care workers be demonstrated in an experimental context?

This second question was addressed by building on the results of the interview study. Chapter five describes the process where two of the strategies identified in the interview study were selected for further analysis. Chapter six describes the effects of these two strategies in separate conditions using an experimental design and measuring both care worker and resident interactional behaviour using real-time observations by a researcher.

### **3.6 Summary**

This chapter described the research questions and the way in which this thesis proposes to fill the gaps in the literature highlighted by the review in chapter two. The reasons for taking a critical realist paradigm was then described, followed by a description of the mixed-methods approach and the proposal for a two phase thesis. This is composed of an interview study enquiring into the facilitators and barriers to communicating with people with dementia, and an experimental study examining the effect of certain communication strategies on the communicative behaviour of care home residents with dementia. The next chapter describes the collection,



analysis, results and discussion of 16 semi-structured interviews with healthcare professionals.

## **4. Expert views on the facilitators and barriers of communication with people with dementia: An interview study**

### **4.1 Chapter overview**

This chapter presents an interview study consisting of 16 semi-structured interviews with people experienced in communicating with people with dementia. Participants were asked about the challenges of communicating with people with dementia, the factors that helped or hindered communication, the organisational factors impacting communication and any training they had undertaken on this topic. Interviews were analysed thematically following established guidelines (Braun & Clarke, 2006) and the devised coding scheme is discussed in relation to the models of interpersonal communication described in the introduction and existing research described in the literature review.

## **4.2 Rationale and Aims**

As stated in the previous chapter, the aim of this research was to determine the effect of care worker communication style on the communicative behaviour of care home residents. As a result of the literature review, it became evident that there were no published studies that determined how those who work with people with dementia best communicate with members of this population. People whose work involves communication with people with dementia have expertise born of experience. Also, those who work in health care are those to whom any communication interventions would be aimed. By gaining the knowledge and opinions of those who work with people with dementia it would be possible to construct communication interventions that are not only based on experience, but are feasible for implementation in health care contexts.

**The aims of the study were:**

- 1. To ask people who work with people with dementia what they believe are the components of good or bad quality communication with this population.**
- 2. To set communication in the wider context of residential care and what factors may contribute to a care worker's use of good quality communication.**
- 3. To identify a selection of practical and simple ways in which care workers' communication style could be manipulated in the experimental stage of the research.**

Semi-structured interviews were chosen as the best way to meet these aims. The purpose of this study is to know what healthcare professionals deem to be 'best

practice' in communication, and also the reasons why they may not be able to function in this way at all times. A technique such as naturalistic observation, although demonstrating communication in practice, would not convey the reasoning behind their choice of communication technique. Semi-structured interviews allow participants to expound on their beliefs and attitudes on a topic, incorporating both the ideal and the factors that interfere with the actualisation of that ideal.

## **4.3 Method**

### **4.3.1 Participants**

In depth, semi-structured interviews were conducted with 16 healthcare professionals who work or have previously worked with people with dementia on a daily basis.

#### ***4.3.1.1 Care workers***

Eight of the 16 interviews were conducted with care workers employed by two participating care homes in the Midlands. The care homes were a purposive sample selected for:

- A previous willingness to be involved in research. This was so that the care home managers and staff were more accustomed to the presence and aims of researchers and would be accustomed to the processes of recruitment and consent and speaking about their work.
- A reputation for delivering dementia care of the highest quality. This was judged through the report of healthcare professionals whose work involves accessing care homes and reports from the Care Quality Commission (CQC). It was thought that, as the research question aimed to discover the

components of effective communication, it was most probable that this would be found in care homes that have a good reputation. The author was concerned with 'best practice' as viewed by those who are judged to give the best quality of care, therefore purposive sampling was appropriate for this study (Pratt, 2009).

The inclusion criteria for care workers were that they were:

- Experienced (more than six months working with people with dementia).

This was to ensure that participants were not new to care work. Other research studies in this field have also used this criteria e.g.(Wang, Hsieh, & Wang, 2013).

- English speaking.
- Willing to talk about the different techniques they use to encourage or facilitate communication with people with dementia.

#### ***4.3.1.2 Other healthcare professionals***

Another eight interviews were conducted with professionals from other healthcare contexts who also work with people with dementia on a daily basis. It was thought that the inclusion of interviewees from other backgrounds such as medicine, nursing and the allied healthcare professions would add richness to the dialogue through the introduction of beliefs and attitudes from other disciplines, making results more comprehensive. Again, the inclusion criteria for these healthcare professionals was that they were:

- Experienced (working longer than 6 months with people with dementia),
- English speaking,

- Willing to talk about the different techniques they use to encourage or facilitate communication with people with dementia.

#### **4.3.2 Recruitment**

The care workers were recruited via care home managers. Managers were asked to consider care workers in their employ who met the inclusion criteria. These care workers were then asked by the manager whether they wished to be involved in the research. Those who were willing were introduced to the researcher. They were asked to read through an information sheet with the researcher and were asked to sign a consent form. Recruitment of the other eight healthcare professionals took place through established contacts within the university. Originally, three contacts known to be experienced in dementia care and interested in dementia research were emailed and a date and time for an interview fixed. As with the care workers, on the day of the interview they were asked to read through an information sheet with the researcher and sign a consent form. During the interviews, participants were asked if they knew of any other healthcare professionals who met the inclusion criteria and would be interested in taking part in the research. These contacts were then emailed and asked if they would be willing to participate. The settings for all interviews were the workplaces of the interviewees. All interviews took place between the researcher and the interviewee only and in a private room where speech could not be overheard by any third party. Ten healthcare professionals from other healthcare backgrounds were contacted inviting them to take part in the study. Eight consented to being interviewed.

Recruitment for the study ceased when no new information was being imparted during the interviews, otherwise known as saturation (Glaser & Strauss, 1967).

### **4.3.3 Procedure**

Before beginning the interview, participants were informed of the purpose of the study and given the opportunity to go through an information sheet with the researcher. This information sheet can be seen in appendix 1. Participants were also given the researcher's contact details. On agreeing to take part they were asked to sign a consent form and assigned a participant number. The only file containing details of the names of participants and the corresponding participant numbers is kept on an encrypted data stick and stored in accordance with the Data Protection Act (1998). All participants were anonymised and assured that any identifying information in the data would be removed on transcription. Participants were informed that they could withdraw from the study at any time and that their data could be destroyed if requested. The interviewees were also given the option to be informed of the results of the study, and offered a copy of their transcript and the final paper as advised by Elliott, Fischer, and Rennie (1999). Interviews were conducted in the participants' place of work and lasted between 15 minutes and one hour.

### **4.3.4 Theoretical Position**

When devising an interview schedule, interviewing participants and analysing results there were a number of different methodologies that could have been chosen. The reasoning behind the choice of thematic analysis over other theoretical positions such as Grounded Theory (Glaser & Strauss, 1967) Interpretative Phenomenological Analysis (Smith, Flowers, & Larkin, 2009), Discourse Analysis (Holt, 2011), Critical Discourse Analysis (Fairclough, 1955) and Conversational Analysis (Banister, Burman, Parker, Taylor, & Tindall, 1994) were as follows.

The methodology used for this study required flexibility in epistemological approach. This was due to a preconceived topic and the knowledge of pre-existing theories such as the person-centred approach (Baldwin & Capstick, 2007), the communication predicament of aging model (Ryan, Meredith, MacLean, & Orange, 1995) and the communication enhancement model (Harwood, 2007). For this reason methods such as Grounded Theory (Glaser & Strauss, 1967), where the aim is to discern the 'main concern' of a population and build questions and theory from the data, were not appropriate. On embarking on this interview study the interviews themselves were not to determine the 'concern' which was to be investigated as the topic had already been chosen. Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) was also thought to be inappropriate for similar reasons as well as the fact that it was developed for the close examination of prominent life events and is mostly concerned with meaning-making processes. The topic under investigation in this research, that of day-to-day communication in dementia care contexts, would not lend itself to this methodology.

The research question to be answered in this study was concerned with the explicit data resulting from the interviews rather than the process of the interview itself. Discourse analysis, critical discourse analysis and conversational analysis were considered as methods of analysis, however, these theoretical approaches concern themselves with the interview process rather than the outcome. They look at causal relationships of behaviour between the interlocutors within the interview and are concerned with patterns of interaction and concepts such as persuasion, power and encouragement. The appropriate theoretical approach for this study was one that is concerned with the outcome of the interviews rather than the process and whose results are of a more explicit than implicit nature. Thematic analysis (Braun & Clarke, 2006) is a flexible and practical method for qualitatively analysing themes occurring



within data. Its aim is to organise and describe the data in as greater detail as is required by the research question and could, if needed, be used to interpret aspects of the research topic. This made thematic analysis an appropriate method for answering the research questions as it was useful in examining the content of the interviews rather than the interpersonal processes between the interviewer and interviewee.

#### **4.3.5 Development of the interview schedule**

A semi-structured interview schedule was developed drawing on advice from experts in interviewing techniques (Banister et al., 1994; Bell, 2010; Guendouzi & Muller, 2006). The interview schedule consisted of questions referring to:

- Basic information about the participant, allowing him/her to become accustomed to the interview
- The challenges faced by care workers when communicating with people with dementia
- The strategies that may facilitate communication
- The factors that may hinder successful interaction
- Questions about communication training
- The impact of organisational structures within their place of work on communication with people with dementia

The author devised a set of 14 questions with the aim of constructing a comprehensive picture of the factors impacting the success of an interaction with a person with dementia. The original questions were informed by the researcher's previous experience of the challenges faced when interacting with people with dementia and some of the factors identified in the literature referring to speech, challenging behaviour and staff training. The questions were then evaluated, revised

and rephrased over a number of meetings with supervisors. Questions were evaluated on the basis of their open-endedness, relevance to the topic of communication, comprehensiveness, conversational nature and their fit within the flow of an interview. The final schedule included 11 questions with additional probes and prompts. Two pilot interviews were carried out as advised by Tong, Sainsbury, and Craig (2007). The participants in the pilots were two female support workers who worked on a geriatric ward. The purpose of these pilot interviews was to ensure the comprehensiveness and flow of the schedule. These pilot interviews resulted in the addition of some prompts and probes and the rephrasing of some questions. The full interview schedule for care workers can be found in appendix 2. The interview schedule was amended to accommodate differences in job role and background for the participants from other professions. The amended interview schedule for healthcare professionals can be found in appendix 3. All interviews were recorded using a digital recorder.

The interviews were transcribed using a simple orthographic technique recommended in the literature (Banister et al., 1994). The simplicity of this method of transcription was chosen over the more detailed multi-level techniques. This was because the research question could be answered through a simple analysis of the content of the speech rather than focusing on the subtext communicated through intonation and body language. Therefore the more elaborate transcription techniques were seen as excessive for this study. Consequently, the themes generated are of a more semantic and explicit nature. Strong emphasis, indicated by underlining, and laughter, indicated in brackets [laughter], was retained to aid in the understanding of humour, sarcasm and the implied importance of certain concepts.

#### **4.3.6 Analysis Process**

Interviews were analysed thematically using the 6-phases recommended in published guidelines (Braun & Clarke, 2006) depicted in Figure 4. The data set is defined as; the sections of the overall data corpus that relate to communication between professionals and people with dementia. A theme was defined as; a recurring concept that appears, either within a data item or across items, that articulates something important in relation to the research question. Although the semi-structured interview was guided towards certain aspects of communication such as challenges, strategies and training, the guidance of these questions was designed to elicit a thorough conversation on the topic rather than to establish a deductive framework for the generation of themes at the analysis stage. As a consequence of this, themes were generated from a realist paradigm using an inductive, 'bottom up', approach as no pre-existing coding framework was devised. However, it is acknowledged that some themes were expected to correspond to the questions constructed by the interviewer before-hand and were influenced by the researcher's interests and background knowledge.

Familiarisation with the data occurred through repeated listening to the interview recordings, during transcription and repeated reading of the transcripts. An example of a transcript can be seen in appendix 4. During analysis the software package NVivo9 was used to order and simplify the coding process. See appendix 5 for a screen shot of analysis using NVivo. Initial coding was extensive and inclusive and later refined down to a concise coding scheme with overarching themes and sub-themes. The internal homogeneity of the themes was largely managed by the main researcher. See appendix 6 for all the coded extracts for one sub-theme. The external homogeneity (Patton, 1990) was a discursive process involving the researcher plus two other researchers who advised and questioned

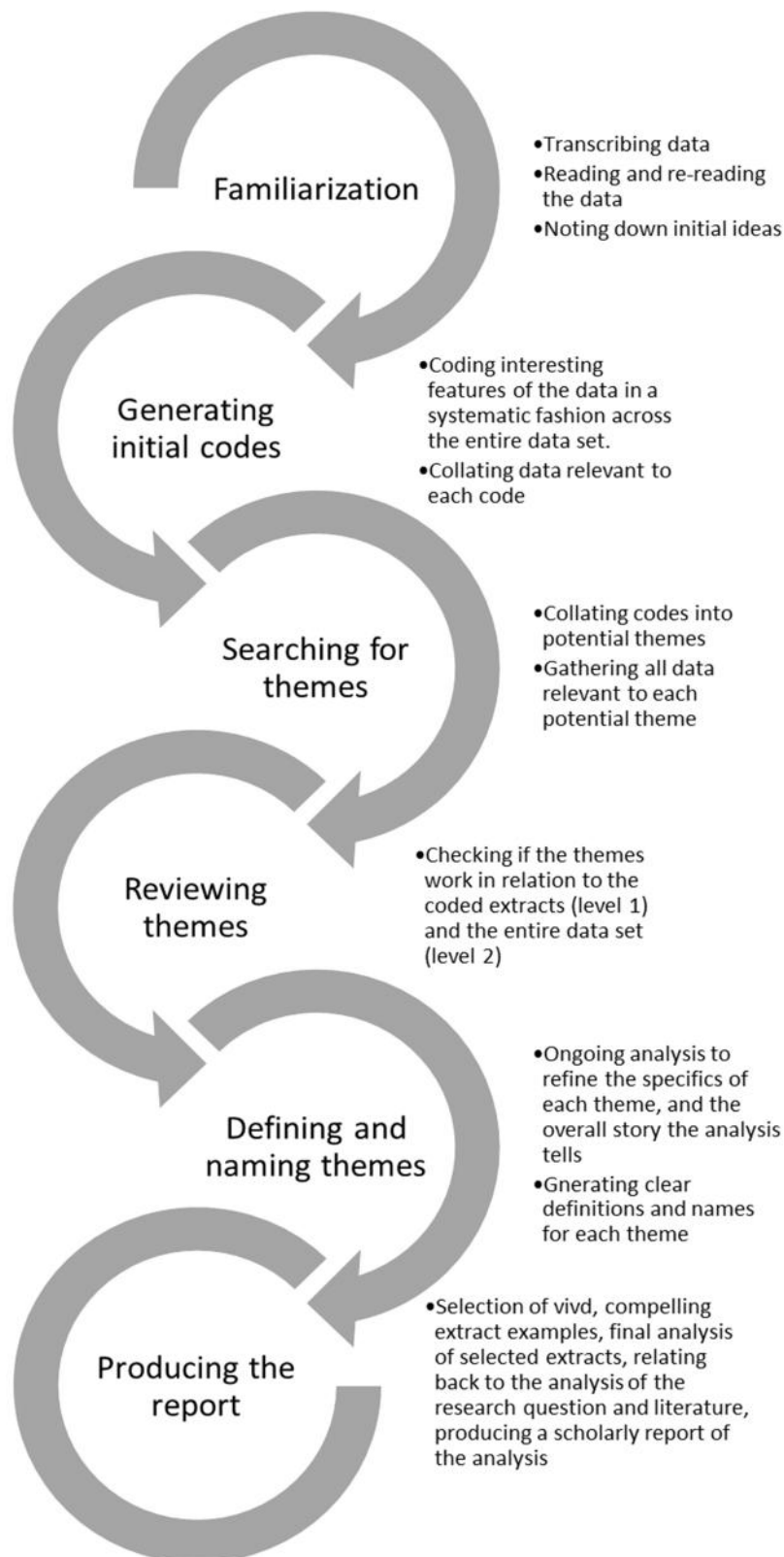


Figure 4. Six phases of thematic analysis, modified from Braun & Clarke (2006)

the definitions and positions of individual codes within the overall framework. The process of refining the codes and themes was thoroughly documented with different versions of the coding scheme developed before deciding on a 'best fit' for the data. See appendix 7 for three iterations of the coding scheme.

#### **4.3.7 Reflexivity**

Throughout the interview, transcription, coding and write-up processes it was acknowledged by the researcher that the gathering and interpretation of data is a reflexive exercise through which meanings are constructed rather than discovered (Mauthner & Doucet, 2003). It is therefore important to communicate the author's background and previous experience of dementia and care work as relevant to the research question.

I am a 26 year old female PhD student from a working class background. I have had much previous experience of dementia due to two family members being diagnosed with Alzheimer's disease and spending time in care homes. Later, I spent three years working as a care worker and a further two years as a rehabilitation support worker in a community based rehabilitation hospital, mainly working with elderly patients. Because of these experiences I reflected on the way in which I may be inclined to only include themes that corresponded to my own experiences and to discount data that does not describe care work as I experienced it. I also reflected on my academic background in psychology which provided a strong grounding in quantitative research methods, now being challenged through the use of qualitative methods. Because of this it was difficult to reject the concept of a detached and 'neutral' researcher and the assumed value of numerical data. In addition to this, during my time as a care worker, I had rigorous training in person-centred care approaches and as part of my studies had also undertaken extensive reading into this

model. Any interpretation of data will have been influenced by my partiality to this paradigm. Throughout the data collection and analysis I kept a reflective diary to record the way in which my experiences and beliefs impacted the interview and analysis process. A section of this reflective diary can be seen in appendix 8.

Ethical approval of this research was granted by the Institute of Work, Health and Organisations, University of Nottingham Ethics Committee.

#### **4.3.8 Response rate and demographics**

Of the care homes approached one home provided six interviewees; five care workers and one activities co-ordinator, and the other three care workers. Care workers had varying degrees of experience with people with dementia. None of the care workers who were asked to participate in the study declined. Another eight interviews were conducted with participants from other healthcare disciplines who regularly work with people with dementia. Two who were emailed and invited to participate did not respond to the invitation.

The interviewees' profession, gender and years of experience working with dementia can be seen in the table 4. Experience ranged from 6 months to 54 years.

**Table 4. Participants' profession, gender and years of experience**

<b>Participant no.</b>	<b>Job title</b>	<b>Gender</b>	<b>Experience in care</b>
01	Mental Health Nurse (retired)	Female	54 years
02	Care worker	Female	1 year 6 months
03	Care worker	Female	7 years
04	Care worker	Female	1 year 6 months
05	Care worker	Male	7 years
06	Care worker	Female	3 years
07	Activities Co-ordinator	Female	3 years (in this role)
08	Care worker	Female	1 year 8 months
09	Care worker	Female	6 months
10	Care worker	Female	7 months
11	Occupational Therapist	Male	26 years
12	Consultant Clinical Psychologist	Male	12 years
13	Speech and Language Therapist	Female	12 years
14	Consultant Geriatrician	Male	16 years
15	Professor and Director of a university Centre for Quality Aging	Male	30 years
16	Falls Clinical Specialist (Occupational Therapy)	Female	7 years (in this role)

#### **4.4 Results**

Through thematic analysis, a coding scheme was devised encompassing the participants' views on the importance of good communication and the factors that were thought to facilitate and hinder interaction between healthcare professionals and people with dementia. The complete coding scheme can be seen in Figure 5.

## **1. Attributes of care worker to facilitate communication**

- a. Skilful development of relationships
  - i. Individualised approach (*based on info from family and care plans, experience with the individual, situational differences*)
  - ii. Initiating and using opportunities for interaction (*task-orientedness, ADLs, finding other ways to communicate other than talking*)
  - iii. Showing respect for personhood (*care worker values including respect for the residents, politeness, choice, protecting them from their deficits*)
  - iv. Engaging with resident's reality (*seeing things from the resident's perspective, setting aside own rules of communication, validation/reality orientation*)
  - v. Fluidity of personal and professional boundaries (*sharing personal information, having a professional role*)
- b. Personal characteristics
  - i. Tolerance (*patience and tolerance of challenging behaviour*)
  - ii. Sensitivity to residents' responses and mood (*attending to micro-behaviours that indicate their mood state*)
  - iii. Honesty and tact (*being open and honest with residents, withholding the full truth*)
- c. Knowledge and understanding of dementia
  - i. Realistic expectations (*not expecting residents to understand things that are no longer possible and attempting communication despite problems*)
  - ii. Cognitive deficits (*feelings of frustration, acceptance, accommodation*)
  - iii. Age related physical decline (*co-morbidity*)
  - iv. Challenging behaviours (*agitation, aggression, vocalisation, wandering*)

## **2. Strategies to facilitate communication**

- a. Verbal
  - i. Language (*choice of words and topic, simplification, infantilisation*)
  - ii. Speech characteristics and vocal tone (*volume, speed, pitch, vocal tone*)
  - iii. Explanation of actions (*explaining each step, over-explanation*)
  - iv. Repetition (*the necessity of repetition/rephrasing*)
  - v. Questioning (*to discern what is trying to be communicated, test questions*)
- b. Non-verbal
  - i. Eye contact (*interpersonal communication, power, withdrawal*)
  - ii. Touch (*affection, gaining attention, guiding, comfort*)
  - iii. Communication aids, demonstration and gestures (*picture cards, pointing*)
  - iv. Facial expression (*smiles*)
- c. Pacing (*matching speed of verbal/non-verbal behaviour to that of the resident*)
- d. Disengagement (*knowing when to withdraw and/or hand the situation to another person*)
- e. Distraction and rewards (*positive and negative uses*)

## **3. Organisational factors**

- a. Culture, leadership and management (*importance of ethos and the role of manager*)
- b. Staff training (*effectiveness and components of good training*)
- c. Staffing establishment and workload (*how the home is staffed, numbers and time pressures*)

## **4. Physical characteristics of the home (noise, navigation)**

**Figure 5. Coding scheme from thematic analysis of interviews**



#### **4.4.1 The importance of communication**

In exploring participants' opinions of the facilitators and barriers to communication with people with dementia all participants spoke of the importance of communication with those they cared for and the impact that the success or failure of communication had on their energy levels, emotions, job satisfaction and self-esteem.

Most participants commented on the way in which communicating with people with dementia required high levels of intense concentration, empathy and creativity.

Care workers said that these demands often left them feeling physically, intellectually and emotionally drained so that such activity could only be sustained over a certain period of time. This tiredness did not seem to depend on the success or failure of interactions but was a result of the use of personal resources in order to communicate at all.

Most participants spoke of the impact of unsuccessful communication. The most common experience was frustration. This frustration stemmed from different sources such as an empathetic reaction to the frustration of the person with dementia, frustration at their own inability and confusion and sometimes their frustration at knowing that they had neither the time nor the energy to attend adequately to an interaction.

Participants also commented on the positive impact of successful communication as bringing great joy and relief. Unexpected communication from a resident who was not often interactive seemed to be an especially emotional and beautiful experience.

*"Communication with elderly people with dementia, it's a wonderful thing.*

*It's a wonderful thing. It's a lovely thing."*

*(Participant 01)*

Some spoke of the way in which the success or failure of an interaction impacted their perceived ability to fulfil their job role and, at times, their self-esteem. As stated above many felt great pride in being *the person* who was able to interact and meet the needs of an individual. However, unsuccessful communication sometimes lead to participants speaking of themselves as defeated or labelling themselves as failures.

A few participants spoke with anger of instances of poor communication. They spoke of being 'angry', 'horrified', 'disgusted' and 'heart-broken' when they saw or heard about what they judged to be abusive, neglectful or patronising behaviour, mostly as case-studies in training sessions or broadcasted through the media.

These comments emphasise the way in which professionals view communication as a concept embedded in good quality care and highlights the consequences of their ability to communicate effectively with those they work for. Having established the importance of this topic for professionals working with people with dementia we will now examine the attributes that a good communicator was thought to possess, the practical verbal and non-verbal strategies thought to facilitate communication and the organisational and environmental factors influencing communication.

#### **4.4.2 Theme1: The attributes of a professional to facilitate communication**

A number of themes centred on the personal attributes of professionals that facilitate communication. The concepts spoken of in these themes were mostly non-practical and related to the attitudes, ethics and principles of professionals good at communicating with people with dementia. They have been grouped into three categories: (a) the skilful development of relationships, (b) personal characteristics and (c) knowledge and understanding of dementia.

#### **4.4.2.1 Theme 1a: Skilful development of relationships**

In this theme the participants described a cycle where they would seek to learn as much as possible about the person with dementia in order to improve their communication, which in turn would further their knowledge and understanding of the resident so that they could further enhance their interaction.

Every participant spoke of the importance of forming relationships with the people they cared for. Communication was thought to be crucial to forming and maintaining a relationship where the person with dementia could feel safe and comfortable. These safe, communicative relationships were developed through the use of certain attitudes and skills.

##### **4.4.2.1.1 Individualised Approach**

All participants spoke of the importance of individualising both care and communication. This point was often referred to passionately. Participants stated that when communication was conducted on an individualised basis this contributed to building up a rapport with the residents. For example, one care worker spoke of the way in which he used a certain kind of humour for some residents, but had to moderate his humour for others.

*“There was a woman here, she’s died now, but every morning she had the Sun and I used to say “Oh, can I look at page three?” And she used to say “Oh no, you’re not looking at that!” And we used to laugh about that, joking like...But others wouldn’t.”*

*(Participant 05)*

Participants reported individualising their communication based on two categories of information. Firstly, their personal experience of the individual and the way in which the person with dementia had responded to them in the past. Secondly, background information from sources such as residents' notes and talking to relatives and colleagues. Information included diagnosis and impairments, previous occupation, personality, preferences, hobbies, interests, family and routines. All of these informed the way in which a healthcare professional communicated and the content of conversation. Communication that had been individualised according to this knowledge was reported to prevent agitation, and thereby aided the building of rapport and the completion of care tasks.

*"...but you have to look at the patient and know something about their background...and that can give you a real insight into who they are and then you can develop your communication skills for that individual."*

*(Participant 02)*

The participants stated that communication also changed with situational differences. The care workers, especially, commented on the way in which the needs of people with dementia changed rapidly, even over the course of an hour, and that communication had to change rapidly in response to these changes.

*"They can get up with a smile on their face and then they can come in the lounge and see something or somebody that they don't like or they get confused and then suddenly they're all withdrawn....So it is very quick."*

*(Participant 03)*

#### **4.4.2.1.2 Initiating and using opportunities for interaction**

Initiating and using all opportunities for interaction, sometimes called 'embedded' communication, was an approach referred to by participants that contributed to the

forming of relationships. It was believed to be a philosophy that should underlie every activity that took place within a healthcare context and was the responsibility of every person in the home including staff, volunteers, visitors and management. Many of the participants talked about the negative consequences of a 'task-oriented' care system where completing the job list and staying to schedule were of greater priority than catering for the emotional and relational needs of the residents. The participants argued that communication satisfied social and emotional needs that were just as important as the more physical requirements. Participants sought to combat the task-oriented system by utilising activities of daily living (ADLs) as opportunities for interaction. They stated that ADLs should be treated as a means to the end goal of meeting emotional and relational needs rather than an end in themselves.

*"A lot of [communication] will be going on during, throughout personal care when you're getting people up and ready 'cause it's an ideal time to be talking to someone 'cause you've got that one on one interaction...So in a morning is an ideal opportunity."*

*(Participant 09)*

The participants also emphasised the importance of initiating opportunities for communication outside of ADLs. Participants described the creativity required on the part of the staff member at these times. Yet they also stressed that interaction need not be difficult or time consuming and that short moments of connection with individuals were the building blocks that contributed to a warm, meaningful interpersonal dynamic.

*"I used to cut up scraps of material and let them hold it and say, 'What colour is that?'...and out of the blue somebody who doesn't speak, by feeling that material will just say 'red!'"*

*(Participant 01)*

Many participants spoke of how they continued to make an effort with those in the last stages of dementia as there was still a possibility of 'getting through' or receiving a surprise response.

*"Sometimes you feel you're speaking to yourself because you don't see much of a reaction to you. But I think it's better, you're trying at least, you never know how much they can hear."*

*(Participant 03)*

#### **4.4.2.1.3 Showing respect for personhood**

Most of the participants expressed the view that building relationships with people with dementia could only be accomplished by communicating with respect, thereby acknowledging the personhood of that individual. Many participants, while talking about communication, referred to the importance of seeing people with dementia as fellow human beings. The attempt at interaction was seen as a way in which a healthcare professional could express their belief in the personhood of the person with dementia.

*"That's a person you have in front of you. No matter what stage of life they're in, acknowledge that they're still a person and talk to them. Communicating is the most important thing in life."*

*(Participant 01)*

Not initiating interaction with a person with dementia or talking over them to another colleague was seen as impolite, disrespectful and ultimately damaging for the person with dementia.

*“...if you come up to a patient and you talk to your junior doctor but you do not talk with the patient you are denying them their personhood, it’s discourteous.”*

*(Participant 14)*

One of the ways in which respect was thought to be communicated within interaction was through general politeness and manners. Participants believed that, not only were you giving the person with dementia what they deserved, but that politeness would act as a kind of lubricant that would ‘oil the cogs’ of an interaction, prevent insult and increase cooperation.

Another way in which respect could be communicated was by giving opportunities for choice. Participants described how, when done skilfully, choice enabled the individual to keep a sense of control over their day-to-day lives. Participants spoke of asking permission and offering choice even in circumstances where the task to be completed was essential so that a resident’s sense of dignity and agency could be maintained.

*““I’ll cut your meat up for you shall I cut your potatoes for you too?” You ask, although you know you need to do it, you ask.”*

*(Participant 01)*

In addition to this, participants believed that respect could be shown through a form of communication that did not expose the deficits of the person with dementia, either to themselves or to others.

*“...we can provide a place of safety, inter-personally. And that’s partly got to be built over time. That you know this is a safe person who won’t ask you lots of questions and make you answer, and won’t make you feel bad.”*

*(Participant 13)*

A few participants talked about the emotional effort and attention that is required to keep a respectful demeanour towards all residents in their care over the course of a shift and the effects of tiredness.

*“If you can have the energy to maintain an attitude of interest and respect it can get you a long way but at the end of a... [shift] I’m shattered... I’m physically and emotionally tired...think what happens when you become tired, you become less tolerant. You tend to do things quicker. You might become more irritable and abrupt.”*

*(Participant 14)*

#### **4.4.2.1.4 Engaging with residents’ reality**

One of the greatest hindrances to communicating with people with dementia and developing a therapeutic relationship was the sense that they lived in a different version of reality. The ability to engage with the alternative reality of the person with dementia was therefore seen as an important concept when attempting to communicate. Throughout the dialogue on this theme participants emphasised the importance of setting aside their own psychosocial rules and norms and attempting to step into the reality experienced by the person with dementia. According to the participants, the first thing this required was empathy; the ability to understand the situation from the resident’s perspective and to be compassionate in response.



*“And what do you say to somebody who comes in and says, “I’ve got to go home ‘cause the kids are coming home from school” and their son’s just left, 64 year old bloke...you can’t say “Oh they’ve grown up and left.” ‘Cause I know what I would feel like.”*

*(Participant 05)*

There were many discussions about the positives and negatives of validation therapy; where all behaviour is respected and acknowledged as valid communication, despite its relation to reality, and reality orientation; where people with dementia are respectfully and consistently re-orientated to time and place. All participants agreed that healthcare professionals should have a ‘tool-box’ of different approaches and skills that can be used at appropriate times depending on their knowledge of the person and what would be least distressing. No participant advocated the pure implementation of one approach or philosophy.

*“We used to have a very elderly gentleman here who’d been a city bus driver for years and he wanted to get up at 4 o’clock because he had to go and do the early shift...he responded better to a clear, “Well actually you don’t do that anymore...so why don’t we just go and have a cup of tea and an early breakfast and you can read the paper.” “Oh well thank you very much, what a lovely idea I forgot I was retired.” Yet somebody else, it could actually provoke a very negative reaction so you need to use a variety of different techniques.”*

*(Participant 07)*

All participants who commented on this theme did agree that ‘playing along’ with delusions was sometimes necessary when considering the underlying emotional needs, such as sadness or fear, communicated through those delusions. This playing

along involved serving residents a second breakfast, comforting a woman who thought her children had died or momentarily filling the role of mother or sister if that was how the participant had been labelled in reality of the person with dementia.

*"I think the best response to somebody who is terrified and wants to be protected by a parental figure is to fulfil that role in that moment and resolve that need."*

*(Participant 12)*

One participant described how the same degeneration of brain tissue that causes dysphasia also leads to strange, alternative connections in the brain. This often results in conversation which seems illogical but, when viewed in a different light, can be poetic, symbolic and sometimes profound.

*"The interaction feels like being in a Beckett play... There is something about being able to tolerate the absurd... they're often quite weird conversations but I think they can be still quite meaningful conversations in an emotional and psychological sense."*

*(Participant 11)*

#### **4.4.2.1.5 Fluidity of personal and professional boundaries**

This topic was a controversial issue with many participants expressing different opinions on the extent to which a professional can communicate with residents about personal issues or maintain professional boundaries. Some participants commented on physical contact and their nervousness about giving a hug or holding a hand because of worries of being inappropriate. Yet they also spoke of the alternative, of an environment where residents were isolated from all genuine human contact because of 'professional boundaries'.

*"If I imagine myself being consigned to a ward where I wasn't allowed to make physical contact with another human being outside of very invasive personal care - that just sounds like hell."*

*(Participant 12)*

On the subject of sharing personal experiences, some participants were of the view that it was acceptable to speak to residents about their personal life but it was important to have a limit on the nature of topics. Many stated that they would never share anything which may burden the person with dementia or make them feel they could not respect or rely on the professional with whom they were interacting. Another participant spoke of the way in which sharing personal experiences allowed people with dementia to regain some of the status they felt they had lost by going into residential care.

*"I will hear people talking about their kids and getting advice from the old folks and you think well that's really nice. That's a bit normative. Here we are, here's the wise older person."*

*(Participant 11)*

Many participants spoke of having a work persona that was different to the version of the self that was expressed at home or outside the workplace. For example, this professional role may include their level of patience and tolerance, the topics of conversation and the way in which they were called 'nurse'.

*“It’s your job role. It’s totally different communication to what I am at home...Yes, you just put yourself into these different positions and different situations and it’s like you totally swap. I wish I was more patient at home.*

*[laughter]”*

*(Interview 03)*

Most participants stated that there was an important balance to hold between fulfilling a work role and being a human being who attempts to build and maintain a caring relationship with another human being. Some stated that it was impossible not to become attached to residents that they care for every day and that it would be unprofessional if there was no attachment.

*“But we’re doing personal care for God’s sake. We’re doing things to people that in any other walk of life you’d be jailed for... If they don’t trust you and they don’t have that bit of a [joke] with you it’s gonna be a very embarrassing job for them and an embarrassing job for you.”*

*(Participant 05)*

#### **4.4.2.2 Theme 1b: Personal characteristics**

Characteristics of the professional themselves were also thought to affect communication. This could be something externally evident such as age or gender, or internal factors such as personality and past experiences of people with dementia. So not only is each resident different but also each dyad. However, there were some qualities that participants said every carer should possess in every interaction.

##### **4.4.2.2.1 Tolerance**

Tolerance was thought to be a personal characteristic that facilitated communication with people with dementia and was nurtured by a professional in their clinical practice. Most often it was referred to as 'patience' but described circumstances where participants had to tolerate challenging behaviour, or other symptoms of dementia such as confusion and attention deficits exhibited by residents. A lack of tolerance would result in an interaction that could rebuke and humiliate the person with dementia or provoke further agitation making interaction more difficult.

*"You just think, 'oh she should be behaving that way' but you just have to go with the flow in a way and try to understand. That's the important bit. Be patient."*

*(Interview 03)*

#### **4.4.2.2.2 Sensitivity to residents' responses and mood**

Sensitivity to a resident's responses and mood was thought to be a necessary characteristic of a healthcare professional and an attribute that facilitated interaction. Sensitivity to the small attempts at communication or the minute reactions to stimuli was thought by some to be an innate ability. However some saw it as a skill, developed over time. It was seen by others as a therapeutic mind-set, used during working hours, which embodied openness to communication in all its varieties.

*"It's less about what the person's abilities are and more about what the people around that person, what their abilities are, to enable them to effectively process what's trying to be communicated."*

*(Participant 12)*

Participants suggested that the body language of a person with dementia, rather than their vocal behaviour, communicated their needs more eloquently.

*“I think body language with a lot of them is a big indicator.... If they’re [vocalising] something it doesn’t necessarily mean that that’s what they’re trying to say. It can be completely contradictory.”*

*(Participant 09)*

Because of this, it was quite common for care workers to use the words ‘listen’, ‘observe’ and ‘look’ interchangeably. Micro-reactions such as facial expression, movement of fingers, feet, gaze and posture were all believed to be possible indications of that person’s needs, preferences or mood. Some participants commented that the ability to interpret micro-behaviours increase with experience as overlooking these can sometimes lead to distressing situations.

*“I think we developed this capacity because very often we were sat with people who at any moment might hit us... and there’s nothing like that for providing you with a really good incentive for actually watching people extremely closely and trying to process what’s going on with them.”*

*(Participant 11)*

This level of attentiveness was also said to be important when a participant was attempting to communicate a message to a person with dementia. It was by attending to micro-reactions that the healthcare professional could discern at what point the communication was broken and, therefore, how to proceed.

#### **4.4.2.2.3 Honesty and tact**

Honesty and the topic of being truthful with people with dementia was another controversial topic for the participants. One participant was adamant about the importance of being truthful and open with the residents for two reasons. Firstly, because being honest was seen as ethical, no matter the circumstance. Secondly, despite memory deficits, the person with dementia could associate that person with

dishonesty, impacting the relationship and quality of communication with that person in the future.

*“Things I don’t do, I never lie to them. Never ever... If you lie to them they’re very good at remembering that. Very good.”*

*(Participant 05)*

Another opinion expressed by some participants was that, although the truth was important, telling the whole truth was often unhelpful. Tact was important, especially when concerned with sensitive information such as the death of a loved one. Participants mentioned side-stepping elements of an interaction to prevent the necessity of disclosing distressing information. Information that would only be forgotten and would have to be imparted again causing repeated distress.

*“If someone is looking for their husband... you can’t exactly say “Oh your husband is dead” or whatever, so you just, you side track a little bit and ask them what their husband’s name is and things.”*

*(Participant 09)*

One participant described a situation in which the full disclosure of their job role, and therefore their power, would have inhibited communication and caused further agitation for the person with dementia, rather than the feeling of being understood.

*“What I’ll try and communicate is; I’m interested and I understand what they’re feeling and I haven’t really got an agenda of my own... Which is slightly deceptive, kind of... I am posing as a non-member of staff. But the alternative, I just always know where that’s gonna go which is no good for anyone.”*

*(Participant 11)*

This 'telling the truth but not the whole truth' approach was only mentioned in relation to sensitive situations as a method of engaging with the resident's experience without causing distress. Situations where dishonesty was used to keep a resident quiet, such as telling them that they would be going home soon, was thought to damage the relationship between the healthcare professional and the person with dementia and be detrimental to communication over the long-term.

#### ***4.4.2.3 Theme 1c: Knowledge and understanding of dementia***

In order to be a good communicator, some participants reported the need to have a good knowledge of dementia and how the syndrome affects the individual.

##### **4.4.2.3.1 Realistic Expectations**

Many participants commented on the importance of having realistic expectations of what can be achieved through communication with people with dementia. There were two kinds of expectations that needed to be modified in order to maximise the potential of interactions.

Firstly, it was believed to be important to modify the expectation of what was possible to convey to the person with dementia based on knowledge of their abilities. Participants stated that, before initiating a conversation, it should be considered whether it were possible for the person with dementia to conceptualise what was being expressed. For example, it is improbable for the person with severe dementia to understand that they will be travelling to the clinic to see the doctor a week on Wednesday. The complicated 'there and then' concepts may cause frustration and confusion during the interaction. Furthermore, it may result in increased anxiety in the short term and then be forgotten, only to be imparted again



later. However, interaction motivated by the desire to involve, comfort or entertain the person with dementia in the 'here and now' was seen to be more beneficial.

Secondly, it was thought to be important to modify the expectations of how a normal interaction would occur. For example, in normal conversation interest is often shown by asking questions requiring factual answers. A person with dementia would not be able to do this easily and therefore it was proposed that interest and engagement must be shown in other ways, such as commenting on a stimulus that is clearly visible in the present.

*"If you had a picture of a guard from the Tower of London and I said to you "Who is he? What is he?" That's prompting you to access factual information... generally, people can feel tested and can find that quite aversive. But if you were just generally curious with that person, "Wow that's a really strange hat he's wearing isn't it?", then people, from a position of strength, can volunteer their own opinions."*

*(Participant 12)*

No matter how the communication took place all participants agreed that the disability of the person with dementia should only lead to the modification of communication style rather than the prevention of interaction.

#### **4.4.2.3.2 Cognitive Deficits**

All participants spoke of the way in which a healthcare professional needed to know and understand the cognitive deficits associated with dementia in order to communicate effectively.

Participants listed many of the cognitive deficits symptomatic of dementia and spoke of how these impacted communication. These deficits included: short-term memory

loss, attention deficits, confusion, dysphasia, unpredictability, loss of judgement and the degenerative nature of the syndrome. Participants mentioned individual strategies used to accommodate for these deficits. These are described in the next overarching theme. Participants also spoke of a philosophical approach to these deficits, separate to the strategies they used.

One of the feelings most commonly expressed by the participants when describing the impact of cognitive deficits on communication was the feeling of frustration. This frustration stemmed from not being able to adequately communicate a concept to a person with dementia or not being able to understand the communicative attempts of the person with dementia.

*"I think the frustration that they experience when they're trying to get something across is, it's sometimes horrendous to witness, you feel like quite a failure if you can't get through."*

*(Participant 07)*

Participants spoke of the need to accept these deficits and the challenges they pose to communication. They spoke about patiently accommodating to, or 'absorbing', the deficits themselves rather than allowing them to negatively affect the emotions of either of the interlocutors.

*"I sponse accepting the fact that repetition is a necessary part of working with people who've got memory problems. Because you've explained it today doesn't mean you won't have to explain it tomorrow, or in five minutes."*

*(Participant 12)*

Participants said that they responded to feelings of frustration by recognising that the deficits were part of their dementia, and therefore, were part of the reason that

they were in residential care. Participants spoke of the consequences of forgetting about these cognitive deficits and the futility of trying to reason with a person with dementia, giving them complex instructions or getting irritated when they ask the same question repeatedly.

*“...on the one hand we assume that they’re incompetent and on the other hand...we argue with them as if they are competent. And then we’re very confused, hurt and annoyed when it doesn’t help.”*

*(Participant 12)*

In addition to this, some also commented that the extent of dysphasia was often wrongly used to determine the extent of other cognitive deficits, such as the mental capacity of the person with dementia to make decisions. This assumption of correlation between verbal ability and judgement was thought to lead to anger, embarrassment or the premature removal of independence from a person with dementia.

*“We have a chap in at the moment who is very dysphasic so you would think he hadn’t got capacity but actually the closer attention you pay... it’s clear that actually he’s understanding a lot more than his dysphasia would suggest.”*

*(Participant 11)*

#### **4.4.2.3.3 Age related physical decline**

In order to communicate well with a person with dementia it was thought to be important for a professional to be aware of other age-related issues that can also affect communication. Auditory and visual deficits were referred to most often, yet other participants mentioned their residents having had strokes or infections in addition to their dementia which further hindered communication.

*“I think what is very difficult working with older people is just the volume and the intensity of the difficulties. Every other patient is deaf, every fifth patient can’t see very well, every second patient is immobile... one in seven are distractible.”*

*(Participant 14)*

Another issue raised by some participants was the co-morbidity of depression with dementia. This made communication very difficult as it further reduced engagement and cooperation in care activities and made some participants uncomfortable in initiating communication.

*“Many of these people are depressed too...if you’re trying to engage them in activities... quite often they will say they don’t want to do it, maybe every time.”*

*(Participant 15)*

#### **4.4.2.3.4 Challenging Behaviours**

Participants also reported that an understanding of the challenging behaviour which often accompanies dementia was important when interacting.

The majority of comments about challenging behaviour referred to agitation.

Agitation, where a resident with dementia was in a heightened state of arousal or anxiety, was seen as a barrier to communication. Some commented on the way in which the communication style of the care worker could trigger or exacerbate agitation, but equally, communication style was also said to calm a person with dementia in an agitated state. Most participants spoke of the importance of not assuming that agitation was simply a symptom of dementia caused by degeneration of brain cells. The fact that each resident had different factors that made them anxious or agitated was a concept emphasised in many interviews.

*“We’ve got one particular lady where if she becomes upset or anxious we find that if we take her to her room, she has a cup of tea, sit and chat with her, she’ll calm down. She’ll probably want a little time on her own and then she’s ready to come back and join the community group. However, some residents, if they work themselves into a real stew... there’s sometimes... no pacification techniques and sometimes we just have to withdraw and allow them to settle in their own time.”*

*(Participant 07)*

Similar to agitation, aggression was seen as always having a cause, even if that cause was unknown or incomprehensible to the healthcare professional. Many of the comments about aggression, such as punching, scratching or shouting, were stated in an off-hand way, as if they were an accepted part of the job. However, all comments were made with sympathy for the person with dementia. Some participants professed the view that all aggression was a form of communication and that this behaviour was their final resort in their attempts to have their needs heard. It was reported that, if requirements could be communicated, understood and met before residents had to resort to aggression, instances of such behaviour could be substantially reduced.

*“People with marked expressive language problems who’ve ended up in our services because they got physically aggressive, through finding other ways to communicate, they’ve ended up being placed back into much less restrictive care environments.”*

*(Participant 12)*

Vocalisations such as shouting, screaming or repetitive sounds were considered to be a form of communication. It was thought by participants that vocalisations were

sometimes prompted by lack of stimulation and were an attempt by people with dementia to meet their own need for noise.

Wandering was also mentioned as a behaviour which some called challenging.

However, most participants made it clear that, although wandering often made communication more difficult and sometimes interrupted the smooth management of the care home, there was no reason to intervene as long as the resident was safe.

As with other challenging behaviours, wandering was attributed to self-stimulation, especially when the person with dementia once led a busy and active lifestyle.

Restricting such activity was said to cause agitation and therefore hinder interaction even more than the wandering.

*“Here’s somebody who ran three businesses and has always been a control freak, a perfectionist, was constantly busy... They never took holidays really, did go away but they were always on their Blackberry and now they’re in a care home and they’re pacing. I wonder why?”*

*(Participant 13)*

Another issue mentioned by one participant was that those who displayed challenging behaviour were often given more attention and time from care workers than those who did not. Concerns were raised that other residents may be just as distressed, or have just as many needs, but may not be able to communicate them. Some people with dementia become more withdrawn and isolated as the illness progresses and it is this group, some participants said, who should receive more attention.

*"I think often we focus on the challenging behaviour...I think it's much more challenging that we've got somebody who's slowly withdrawing for whatever reason and communicating less and less. That almost goes unnoticed."*

*(Participant 16)*

#### **4.4.3 Theme 2: Strategies to facilitate communication**

As well as the attributes that a healthcare professional should possess in order to facilitate communication, the participants also gave insights into the practical strategies that they used to increase the effectiveness of their communication.

##### ***4.4.3.1 Theme 2a: Verbal strategies***

All participants spoke about the way in which they did or did not modify their speech in order to maximise the likelihood that the person with dementia could understand and respond.

##### **4.4.3.1.1 Language**

The most prevalent opinion was that sentences should be simpler and shorter. It was reported that people with dementia were not able to process longer, more complicated sentences and so making speech pithier and more straight-forward would allow even those with severe dementia to process and respond to incoming information.

*“You might give an instruction like, ‘Stand up’ instead of, ‘Hello, John it’s really nice to see you. Isn’t the weather lovely today? Do you fancy having a stand up and going for a walk with me?’”*

*(Participant 16)*

It was also reported that language should steer clear of concepts that are more difficult to comprehend. Abstract ideas, such as choices about events taking place in the future, were thought to be especially difficult. Participants stated that giving simple, concrete choices could enable a person with dementia to process the choice offered to them, and therefore a sense of control and agency over their care could be maintained for longer.



*“I would have to say, not ‘where would you like to eat?’ That would make them confused because ‘where’ is an abstract term. But I might say, ‘Would you like to eat in your room or would you like to eat in the dining room?’”*

*(Participant 15)*

The participants often commented that any alteration of language was dependent on the individual person they were caring for and the severity of their dementia. The use of certain vocabulary would depend on whether that person would use that word in day-to-day conversation before they were diagnosed. Participants also commented on the importance of being open to changing the complexity of language in response to the severity of an individual’s dementia. The same participants also cautioned against assuming a person’s level of communication based on their diagnosis because some people with dementia may retain their abilities well into the illness.

*“Everyone’s got different levels of education and different ways of speaking and also I think there’s a generation thing sometimes and you have to get to know that person, observe them and go at their level ‘cause otherwise you’re not going to get anywhere.”*

*(Participant 07)*

Following on from this point, many participants noted that simplification of language for people with dementia could have negative connotations, especially when language was simplified to a greater extent than needed. One professional reported, with humour, an instance where the simplicity of their language was greeted with the severe reprimand of, “Do you think I’m stupid or something?” This illustrated the problem highlighted by some participants that there was a very fine line between

simplifying language to aid in comprehension and speaking to a resident in a patronising manner.

*“Well it can be difficult because, the rules of communicating with someone with aphasia, first rule is simplify. Now, if you’re simplifying speech there’s not an awful long way between that and infantilizing.”*

*(Participant 14)*

#### **4.4.3.1.2 Speech Characteristics**

Opinions on the topic of whether speech should change when talking to people with dementia were rather contentious. Just over a third of participants, when asked, stated that they did not change the way they spoke when talking to people with dementia. However, many participants later gave some examples of how they might modify their speech in certain circumstances.

Participants who discussed speech modification often mentioned volume, speed and pitch. Most participants said that you should always speak softly and clearly when speaking to people with dementia and that raising the voice caused distress and confusion and made comprehension more difficult. The other prominent opinion on this topic was that speech should occur at a much slower pace when talking to people with dementia. It was reported by many that speaking fast caused confusion and distress and put greater pressure on a person with dementia’s processing abilities.

*“To me it’s very like someone trying to speak French to me. That if they speak too fast I won’t be able to follow them, that they need to give me time to process, to actually work out what my response needs to be. So the whole pace of communication needs to be different.”*

*(Participant 11)*

Some participants mentioned the pitch of speech. It was difficult to separate this concept from vocal tone and many participants talked about these concepts interchangeably. There was an underlying assumption that people with dementia, even in the very late stages, were still able to understand the emotional, paralinguistic elements of speech. One participant commented that even if he were being spoken to in another language he would still be able to tell if his conversational partner was being hostile, attentive or respectful. Based on this assumption, many participants said it was important to try and impart warmth, cheerfulness, calm, respect and a non-judgemental attitude through their tone of voice during interactions. This was especially important given that the mood of people with dementia often reflected that of those caring for them. It was therefore important to keep vocal tone positive and to guard against negativity such as tiredness, panic or impatience creeping into the voice.

*“But you do sense that...particularly if there’s a safety issue...There’s almost a rise in panic. So trying to keep your voice quite calm and steady rather than...the pitch goes up as people are panicking...which just engenders more agitation and the person’s more likely to swipe out at somebody if they feel that.”*

*(Participant 16)*

Finally, many participants indicated the way in which vocal tone could be patronising. Although examples of patronising tone were often accompanied by patronising words some professionals noted that altering vocal tone can make otherwise respectful words infantilising. Furthermore, some said this could be done subconsciously, especially if a person with dementia was presenting in a very passive or childlike way.

*“Special voices...you certainly shouldn’t speak to them as though they’re a child...you can’t belittle them or make them feel like children...they’re adults, irrespective of whether they’ve got dementia. They’ve been there, they’ve seen everything haven’t they. You don’t start standing there and saying “Right, this is what’s going to happen.” And saying it in a special voice is absolutely drastic.”*

*(Participant 07)*

#### **4.4.3.1.3 Explanation of Actions**

Many participants commented that, when carrying out a care procedure, it was important to explain their actions and their purpose. Most of the references to this topic were in the context of activities such as undressing, toileting, washing or applying lotions. If these actions were misunderstood it would be distressing for the resident. Participants stated that explanation was crucial to establish the understanding and cooperation of the person with dementia and to reassure them of the propriety of an action that could otherwise be perceived as indecent.

One participant gave another rationale for explaining their actions. She thought that by continually talking to the resident she kept her attention on the resident and prevented the interaction from becoming cold and clinical. Speaking to the resident constantly reminded her of the personhood of the resident she was caring for.

*“While you’re washing them you tell people what you’re doing so, “I’m gonna wash your hands next, I’m gonna put some soap on the flannel” rather than saying, “I went out to the cinema with my boyfriend last night” and totally ignoring the bit of meat in the bed.”*

*(Participant 14)*

However, the opinion was also expressed that it was possible to over explain actions. One participant gave an example of a resident becoming distressed over a care activity and the care worker over explaining in an attempt to calm them. But, instead of reassuring them, the participant said that the constant talking over stimulated the resident and compounded the situation.

*“I think too much communication. I think if you’re looking at people particularly with quite advanced dementia, there’s too much going on, the over-stimulation of lots and lots of chatter and almost meaningless communication. ‘Cause it can be quite detrimental to people because they don’t know what’s going on.”*

*(Participant 16)*

#### **4.4.3.1.4 Repetition**

Repetition seemed a controversial facilitator of communication. When mentioned positively it was set amongst a list of other techniques such as rephrasing, slowing speech and simplifying sentences. When these comments were taken in context it seemed that the term ‘repetition’ was often used synonymously with the concept of rephrasing and that it would be rare for repetition to be verbatim. When repetition was mentioned separately from these other strategies it was mostly in a negative light, as a half-hearted effort at communicating due to a lack of creativity and imagination.

*“Repeating and shouting is the worst thing you do because they get agitated, agitated because it’s just bouncing, bouncing and it’s going nowhere.”*

*(Participant 03)*

#### 4.4.3.1.5 Questioning

Questioning was a strategy discussed by most participants as a way for healthcare professionals to better understand the communicative behaviour of people with dementia. Participants commented that often communicative problems such as aphasia prevented people with dementia from making straight forward requests for assistance. Therefore, care givers sometimes had to engage in a '20 questions' type game to discern the needs of an individual. The questions suggested by participants were most often closed questions, only requiring simple yes/no answers from a resident. However, some participants said that even these simple answers can be problematic.

*"With each resident you get an inkling of what they're trying to say, but you have to have a start place 'is it in the room?' and then sometimes they go 'yeah' and then when it comes to it it's actually a car outside, but you have to start somewhere haven't you?"*

*(Participant 05)*

Some participants used the strategy of asking questions to bring a person with dementia out of their distressing delusions or hallucinations. One participant used the example of a male resident who used to become very tense and roam the corridors with clenched fists. The participant said that he would ask the man why his fists were clenched and the resident would often look at his hands as if surprised, relax his hands and calm down.

In contrast, some participants made the point that it was important not to ask what were called 'test questions' that require the use of impaired memory or executive function. It was thought that the posing of these types of questions only caused confusion and embarrassment for the person attempting to answer.

*"I've said it before but questions are really obvious. People still ask, 'Can you remember the name of our daughter?'" "Err, no...And now I feel really bad 'cause I can't."*

*(Participant 13)*

#### **4.4.3.2 Theme 2b: Non-verbal strategies**

Nearly all participants emphasised the importance of non-verbal communication because of the deteriorating verbal abilities of people with dementia. Some participants commented on how 'actions speak louder than words'. There were a number of non-verbal elements mentioned.

##### **4.4.3.2.1 Eye contact**

Eye contact was portrayed as an important facilitator of two-way communication in a context where the person with dementia was no longer able to converse verbally. The majority of comments on this topic indicated that eye contact was an important means by which a person with dementia could communicate emotion to a healthcare professional. This emphasised the importance of meeting the gaze of a person with dementia when it was offered.

*"I think when you look into somebody's eyes you sometimes see someone trapped in a body, which is so sad. And you can see in their eyes this bewildering world that they're in."*

*(Participant 16)*

The care workers mentioned the way in which making eye contact was an opportunity to overcome power imbalance by being on the same level as the person with dementia. Eye contact was often discussed in the same sentence as the

concept of sitting or kneeling so that the heads of the two people communicating were at an equal height.

Many participants claimed that eye contact could prevent withdrawal by engaging and maintaining the attention of the person with dementia. Some also said that, by attending to the gaze of a person with dementia, it could be determined how orientated and attentive the resident was at that moment.

*“They just drift, in the half of the sentence they just drift away...all of a sudden the eye connection isn’t there...And then they come back and they make some eye connection.”*

*(Participant 01)*

#### **4.4.3.2.2 Touch**

Many participants spoke of touch as an important factor in interaction with people with dementia. Physical contact with other people was thought by many to be a fundamental human need that often went unmet in long-term, residential care. Many commented that one of the possible reasons for this is the culture of litigation and a care worker’s fear that they may be sued or suspected of malpractice.

*“Contact is amazingly important. There was a school of thought at one time that you shouldn’t be too touchy feely but to be honest a lot of the residents do respond greatly to love, cuddles, hugs, holding their hand.”*

*(Participant 07)*

Participants described a number of things that could be communicated through touch. It was thought to be a way of initiating interaction with a resident and maintaining their attention throughout a conversation. It was also used to calm or comfort a person with dementia when they were in distress. Other participants



mentioned the importance of physical contact to aid in guiding a person with dementia, especially when verbal instructions were not being understood.

*“Does ‘two steps backwards’, does ‘stepping sideways’, does that mean anything to that person? And wouldn’t you be better to actually stand next to that person and nudge them to where that person needs to be?”*

*(Participant 16)*

Touch was also thought to be of great importance to those with severe dementia who had very little communicative ability remaining. The stimulation of touch, such as during washing, brushing their hair, hand massage and nail care, was perceived to be one of the final ways in which care, attention and affection could be communicated to an individual when other channels of communication had gone.

#### **4.4.3.2.3 Communication Aids, Demonstration and Gesture**

Participants commented on many ways in which visual communication was used, both for when healthcare professionals wished to communicate with people with dementia and for when people with dementia wished to communicate with a healthcare professional.

Many participants reported using picture books that contained pictures and symbols relating to food, drink and care activities. The use of pictures was thought to be important especially when difficult procedures, such as a vaccination, needed to be explained. Pictures were also used to assist people with dementia communicating with healthcare professionals. For example some used emotion pictures so that people with dementia could tell a carer if they were feeling happy, sad or in pain.

*“We have like, picture books and little diary things and so if they need to communicate what they’re needing you can show them the pictures and see what they point to”*

*(Participant 02)*

Gesture, such as pointing and demonstration was also thought to be important and had the benefit of not requiring additional equipment. One method of demonstration mentioned by a few participants involved initiating the movement for the individual which stimulated a reflexive memory for the person with dementia so that they could continue independently. This type of demonstration was used in repetitive activities such as eating and washing.

*“You put the flannel in their hands and you bring it up to their face gently and you wash and before you get to the other side you take your hand away and let them do it. So they’ll do it, not remembering but the reflex is there.”*

*(Participant 01)*

Other communication aids that were mentioned included memory boards which displayed photographs of residents’ family members and personal information. The use of calendars was also mentioned to remind residents of the date and future events. Although the care workers interviewed had no complaints about the strategies and aids that they used to facilitate communication, the interviewees from other professions sometimes commented on the absence of communication aids from residential care homes and the way in which these could be utilised more.

#### **4.4.3.2.4 Facial Expression**

Facial expression was mentioned by participants, mainly in conjunction with vocal tone and the expression of a healthcare professional’s mood. When participants

described a cheerful, positive or calm tone of voice this was mostly accompanied with a comment on carrying that tone through to facial expression. One participant said it was not possible to have a cheerful tone of voice without a smile. One participant spoke of consciously mirroring the facial expression of the person they were caring for in order to validate their expressions and empathise with them.

*"I do my best to understand the characteristics of that individual so there are some people where I would not speak necessarily, I would smile. Some people where I mirror their actions or I caricature something back to them."*  
(Participant 12)

#### **4.4.3.3 Theme 2c: Pacing**

Pacing was a concept mentioned by many participants. It combined the slowing of speech with the slowing of any interaction or task that needed to be completed. Some participants mentioned the way in which rushing a person with dementia caused confusion and distress. But working and interacting at a slower pace and matching speed with that of the person with dementia, created a calmer, more interactive and cooperative environment.

The main reason given for pacing was that, as dementia progressed, it became more difficult for a resident to interpret incoming information, formulate a response and then express that response. Many participants commented that, in a job that had time pressures or long working hours, it often seemed easier to complete a task, or even a sentence, for a person with dementia rather than wait for them to do it themselves. However, this led to misunderstanding, confusion and the denial of a resident's personhood. Instead, participants claimed the fundamental importance of

waiting for a response, even if this involved uncomfortable silence and less efficient task completion.

*“There might be a 3 or 4 second delay before they’re able to...give you a response to a question. It’s a long time when you’re waiting. I’ve seen people literally saying “Would you like a cup of tea? Cup of tea? No, ok fine” and away they go and then you hear the person say, “Yes” but by that time they’re gone.”*

*(Participant 12)*

#### **4.4.3.4 Theme 2d: Disengagement**

Healthcare professionals referred to the importance of knowing when to persevere with an interaction and when to disengage from an interaction with a person with dementia. This was thought to be important especially when residents were agitated or aggressive.

*“Sometimes you just have to see that your input is only going to escalate the situation.”*

*(Participant 07)*

Participants also noted that different residents reacted in various ways to healthcare professionals at certain times. Some care workers suggested that family members could sometimes communicate with residents when professional care workers were unable to. A number of possible reasons were given for this. For example; the relative may have a greater knowledge of the abilities and background of the person with dementia, or the person with dementia may trust the relative to a greater extent and therefore be more attentive. Others said that simply changing the

healthcare professional attempting to communicate can aid in interacting with a person with dementia.

Some participants commented on the emotional impact of having to disengage from an interaction, or having to hand over to another carer. Many said that, although they knew it was due to dementia, care workers can still take it personally and find the experience disheartening. However, they stated the importance of remembering that it was for the good of the person with dementia to find the best person to communicate at that particular time.

*“But I think, it’s just within us isn’t it. If you see someone upset you want to be that person to try and comfort them. But I think sometimes you just need to step back from it a bit. Not admit defeat, but allow someone else to take your place. Someone else could do it a bit better than you.”*

*(Participant 09)*

#### **4.4.3.5 2e: Distraction and rewards**

Many participants commented on using an ‘end goal’ when having to complete a task that the person with dementia did not like. This gave the person with dementia something to look forward to once the present disagreeable task was completed. For example, one care worker spoke about assisting a resident who did not enjoy getting washed and dressed. She would use the ‘end goal’ of breakfast to motivate the person with dementia and to explain the need to complete the task.

Another strategy that the participants described was distraction. Some talked of distraction in a negative way and said that it should not be used as a strategy. One participant recalled a time when a confused resident was repeatedly asking for their

family. Instead of engaging with the resident, a care worker offered them a cup of tea. However, other participants spoke of distraction as a positive strategy where residents were able to transfer their attention from negative thoughts to more positive preoccupations. A few participants gave examples such as talking about family, sitting down with a box of photos and memories or even the use of humour in a potentially embarrassing situation such as incontinence.

*“We had a woman here who used to smoke like hell and I used to say “Oh you’ve had a fall of soot!” And she would laugh and the tension would be gone and... in the time it would take her to stop laughing, it would all be cleaned up and done.”*

*(Participant 05)*

#### **4.4.4 Theme 3: Organisational factors**

All participants commented on the way in which their ability or inclination to communicate with people with dementia was affected by the way in which their work place was managed, the training that they received and the way in which their work place was staffed.

*“They would love to be able to comfort that lady...part of it will be that they don’t know how to respond to her and part of it might be that they don’t have the numbers to respond with sufficient intensity. Part of it might be that the leadership is making them tidy the linen cupboard rather than sit with a distressed lady.”*

*(Participant 14)*

#### **4.4.4.1 Theme 3a: Culture, leadership and management**

When speaking of the role that work place culture plays in communication, some participants described the way in which many healthcare contexts were still bio-medical in their outlook. It was believed that this created an environment in which staff were task-focussed and care was administered on the basis of a conveyor belt rather than personalised care. It was said that in a bio-medical care system one size was thought to fit all. Therefore, there was little need to get to know or engage with an individual so a healthcare professional's time and energy was more likely to be invested in tasks rather than interacting with the residents.

*“And again I think the ethos of how the home is run...The tasks for the day. Is it changing beds, baths and things? Is that the task because we can be so task-oriented. Where's the care and compassion in that?”*

*(Participant 16)*

In contrast to a bio-medical culture, participants felt that an environment should be fostered where the structures and schedules of the care home were less of a priority than person and relationship focussed care.

Many participants felt that managers played a crucial role in the establishment of such a culture. For example, some spoke of being encouraged by managers to sit and talk to residents or being rebuked if they were not spending enough time doing this. Others talked of being well trained in communication techniques through the insistence of managers and one participant spoke of being given the creative and emotional resources, by her manager, in order to feel able to form friendships with those she cared for.

Others commented that the main way in which managers encouraged such an environment was leading by example. Some said that in certain healthcare contexts

the role of the manager was far removed from that of the care worker and that it was common for those making decisions about the running of a care home or ward to have little experience of caring for people with dementia. This was especially believed to be the case where a care home was owned by a large, for-profit company. Many participants said that environments with the best person-centred, relationship-centred and therefore communication-centred ethos were those in which managers took a hands-on, frontline leadership role.

*"If you're working with people who have companies that have 300 nursing homes you can't ever get anything done 'cause you go to the manager and they go to their manager and they go to the area manager and then...3 months later they say "No." But here you can knock on the door and if you put up a case for something you'll get it in a few days."*

*(Participant 05)*

The importance of an ethos that prioritises communication was further emphasised when participants spoke about the impact of communication training. Some professionals commented that no amount of training would be effective unless the culture within the home was conducive to putting that training into practice once they return to their work environment.

*"Training in and of itself is helpful but inadequate because it's the culture that leads to an application of what's been learned that's most significant."*

*(Participant 12)*



#### **4.4.4.2 Theme 3b: Staff training**

When asked about communication training, some participants felt that they did not require any further training in the area of communicating with people with dementia. However, others felt the training they had received was inadequate and had not met their needs as healthcare professionals working with people with dementia. One participant said that he and other colleagues disagreed with some of the concepts taught in the training sessions they had attended and had felt patronised by the course.

*"I watched a video...There was this old woman in her room listening to her music and this bloody nurse came in...She switched the music off! I said "You know if that'd been me I would have kicked her." If I was...really into the music and this bloody bitch walked in and turned the music off to ask me if I wanted a cup of tea with sugar in...And that was a good example of communication!"*

*(Participant 05)*

One of the most dominant views expressed by participants referred to the way in which present training structures rely too heavily on classroom learning and not enough on transferring those theoretical concepts into the work place. Some participants even went so far as saying that communication skills are impossible to learn in the classroom context and can only be learnt through practice.

*"Didactic classroom training doesn't work. Full stop...These are practical skills...you couldn't learn tennis from a book. You actually have to get out there and hit a ball, a hundred balls. So these are practical skills that you need experience in."*

*(Participant 14)*

There were many suggestions about the content of training sessions. Training in philosophies of care such as Dementia Care Mapping and Butterfly training were mentioned by some as well as receiving input from fields such as neurology and speech and language therapy. However, the point emphasised by most participants was that training needed to encourage empathy with those they cared for. It was suggested that this could involve watching video clips, role play or using case studies. But the motivation should be to engage emotionally with residents and their situation. To substantiate this point many of the care workers describing effective training spoke of sessions that had moved them emotionally.

*“Because it punched, it was a real physical feeling in your stomach. My heart broke and I thought, that could be me. And I think that’s the thing. It’s getting people to think about what it’s like from their point of view.”*

*(Participant 16)*

#### **4.4.4.3 Theme 3c: Staffing establishment and workload**

Most participants said that it took much longer to care for and communicate with a person with dementia than it would a person without dementia. The staffing ratio, therefore, was an important topic for participants. Although most participants stated that the place in which they worked was, in general, very well staffed, some commented that at times there were not enough staff to care for residents to the standard that they wished. Professionals stated that it was the nature of the job for a care worker to be looking after many people at one time and that workload pressures can sometimes prevent genuine engagement with residents. Some participants commented that this was sometimes due to being overworked and not

having the personal resources, such as patience and openness, needed to communicate effectively with residents with dementia.

*“Unfortunately with the place being busy and you feel like there isn’t enough staff and people get tired...Sort of understaffed in a way...[care workers] forget to do their job well...they’ve got problems and then you find that they don’t communicate as well as they should, because they’re just tired.”*

*(Participant 03)*

#### **4.4.5 Theme 4: Physical characteristics of the home**

Three-quarters of participants mentioned the physical characteristics of the care home as an important element in communication.

Most participants commented on the level of noise as an environmental factor that directly impacts communication with people with dementia. Often the term ‘noise’ was used interchangeably with the words ‘distraction’ or ‘over-stimulation’, yet these other terms also included visual stimulation. This auditory and visual noise was the result of television, radios, other people in the room, or even brightly patterned furnishings. Participants stated that this auditory and visual ‘noise’ was detrimental to successful communication with people with dementia who were easily confused and distracted. Participants implied that over-stimulation of residents had a causal link with agitation and the inability to concentrate on an interaction with a healthcare professional. However, some participants also stated that removing all stimulation from the environment would be detrimental to the residents. This problem was often overcome by having a variety of environments with different levels of stimulation in each.

*“We’ve had individuals who are clearly distressed in very noisy, very chaotic environments so the common sense approach is to put them in... a very quiet, calm environment but that is often as aversive for those individuals as the chaotic environment... find an ambient environment that provides the right level of stimulation but without overwhelming that person.”*

*(Participant 12)*

Some participants often spoke of their wish to have a quieter area where they could bring residents so they could talk without having to take residents to their own private rooms which could be some distance from the main lounge.

In addition, some spoke of the impact of having enough space for people with dementia to wander, explore, and choose their company. Some participants mentioned a recent expansion of their care home gardens and the way in which this had improved their ability to manage residents’ agitation as after ‘a couple of laps’ residents were reported to be calmer and more able to interact.

The last environmental issue referred to by the participants was the concept of a navigable environment where certain places were sign-posted using words, pictures or colour codes. This was thought to be helpful as it reduced complicated explanations and increased the likelihood that people with dementia could make their own way to locations.

*“I would still consider this to be communication in a sense of, making...an environment navigable for a person so that if they need something like the toilet or access to a drink it’s actually possible to do that independently.”*

*(Participant 12)*

## **4.5 Discussion**

### **4.5.1 Summary of results**

To the author's knowledge, this is the first study that interviewed healthcare professionals who work with people with dementia to ascertain what they believed were the facilitators or barriers to communication with this population. Eight care workers and eight healthcare professionals in other roles were interviewed. Transcripts were analysed using thematic analysis and a coding scheme was devised. This study identified four overarching themes from the data: The personal skills and attributes of a healthcare professional required to facilitate communication, the practical strategies used by healthcare professionals to facilitate communication, the organisational factors that affect the employment of those skills and strategies and the environmental factors that interfere with the efficacy of communication skills and strategies.

Participants spoke of the personal attributes required by a healthcare professional to facilitate communication with a person with dementia. The first set of attributes referred to skills that enabled the development of relationships with those they cared for. It was thought that a healthcare professional should have the skills to: a) approach each resident as an individual; seeking to know as much as possible about their personality, preferences and abilities, b) use every opportunity to interact with those they care for; using personal care activities as quality time but also making additional opportunities, c) show respect for personhood; by using communication as a vehicle for showing respect, d) be able to engage with the subjective reality of the person with dementia; by letting go of facts and addressing the emotional reality behind communication attempts, e) address the complexity of personal and

professional boundaries; by knowing when the sharing of personal information would be of benefit to the resident.

Another set of attributes believed to facilitate communication referred to the character of a healthcare professional. Tolerance was said to be crucial in coping with challenging behaviour. Sensitivity to the resident's responses and mood by attending to minute body language was also seen as important when attempting to interact; and honesty was thought to be important when used with tact.

A comprehensive understanding of dementia was believed to be essential to facilitate communication. This involved having realistic expectations of an interaction, accepting and accommodating for the impact of cognitive deficits on interaction and also the general effect of old age on a person's communicative abilities. Participants also thought it was important to regard challenging behaviour as the communication of an unmet need from a person whose abilities have been compromised by their illness.

Participants referred to many strategies that they used to facilitate communication with people with dementia. Some of these were verbal; such as modifying language complexity, keeping speech quiet and calm, explaining activities as they took place, repeating instructions and using simple questions to establish the meaning behind resident initiated interaction. Other strategies were non-verbal; such as the use of eye-contact, facial expression, touch or communication aids such as pictures and gesture to elaborate on verbal communication. Participants also stated the importance of pacing an activity at a speed suitable to the resident, knowing when to disengage from an interaction and the use of distraction or rewards when completing a task disagreeable to the person with dementia.

Participants also commented on the impact of the care home culture on their ability to communicate well. Many said that positive interaction needed to be encouraged and led from a managerial level. This involved making it a priority of the day-to-day activities of the work place and staff training sessions. Staffing levels were also thought to affect the quality of communication as interaction was seen as an activity that could easily be squeezed out due to the pressure of other tasks.

Finally, the interviewees noted the importance of adequate space and an ambient environment where auditory and visual stimulation were kept in balance. This ambient environment was thought to prevent withdrawal but also not overload a resident making it difficult to engage their attention.

#### **4.5.2 Attributes of healthcare professionals to facilitate communication**

The participants spoke of the attributes required by a healthcare professional in order to facilitate communication with people with dementia. Some of these attributes support existing models of communication and previous research in this field.

The skill of altering communication style in accordance with the characteristics of the individual was an underlying theme that permeated through the interviews and all of the subsequent themes in the analysis. The essential nature of this concept supports the way in which an individualised approach is seen to be crucial in the communication enhancement model. According to this model an individualised approach seeks to reverse the problems caused by a communication style based on the stereotypes of old age and the expectancy of certain abilities or disabilities simply because of appearance or diagnosis. Although the individuality of people with dementia is emphasised in the philosophy of person-centred care, and therefore the best-practice guidelines (National Institute for Health and Clinical Excellence, 2012),

interestingly, very little is said about individualised communication in the research literature. Most research studies are based on a design where the aim is to apply the same pure intervention to a homogenous sample. Only one study sought to administer an individualised communication 'prescription' to 10 people with dementia (Acton et al., 2007). When this prescription was used there were signs of increased communicative behaviour in the people with dementia. The average number of words used per topic increased and participants with a lower MMSE score also doubled the percentage of topics that they initiated. The individualised prescription in Acton et al.'s research was based on the experience of one conversation with a person with dementia yet the data from this study have elaborated on the factors that should be considered when individualising communication. These factors included background information about previous jobs, hobbies, interests and level of education. Participants also said that they considered the day to day responses of that person with dementia to elements such as humour or the use of their first name when attempting to individualise communication. This study supports the importance of individualised communication and elaborates on the practical ways in which communication should be personalised.

The topic of personhood, central to the philosophy of all participants in this study is also central to person-centred care (Tom Kitwood, 1993, 1997). However, the participants' definition of personhood seemed to differ from that of the person-centred care theory. In Kitwood's work personhood is defined as "a standing or status that is bestowed on one human being, by others, in the context of relationship and social being." (Tom Kitwood, 1997, p. 8). By this definition personhood is a social construct which relies on another for the impartation of the status. In contrast, participants in this study spoke of personhood as an intrinsic characteristic of the



individual with dementia that could either be recognised and reinforced or ignored through communication. Although personhood is a widely used concept in dementia care (Meyer & Owen, 2008; National Institute for Health and Clinical Excellence, 2012) the practicalities of endorsing personhood through day-to-day communication is rarely mentioned in previous research. Data presented in this study show ways in which healthcare professionals believe this is done. They mention attempting interaction despite communication difficulties thereby expressing a wish to have a relationship with the person with dementia. They spoke about not talking over the person with dementia to a colleague, the use of manners and respectful address, and offering choice thereby assisting the person with dementia to maintain a sense of agency. These interventions were thought to confirm, rather than be the basis of the person with dementia's personhood, and empower them to continue in their communication, as is explained in the communication enhancement model (Ryan et al., 1986).

The concept of engaging with the person with dementia's version of reality was talked about extensively by the participants in the interviews. In this theme the two seemingly irreconcilable approaches of validation therapy and reality orientation were discussed. Validation therapy is a therapeutic intervention where the therapist accepts the 'personal truth' of another's experience as opposed to dismissing it as unreal. Research into validation therapy for people with dementia has resulted in mixed results (Neal & Barton Wright, 2003). Some found improvements when group validation therapy was used but it was rarely statistically significant and often sample sizes were small, most studies consisting of a single case design. However, the approach spoken of in the interviews does not involve distinct sessions as in the research but an all-encompassing, constant environment of therapeutic communication employed by all care home staff. Reality orientation was another

approach discussed in the interviews which works on the basis of consistently orienting confused individuals to time and place, both through conversation and the use of orienting displays such as clocks and calendars. Research into the effect of reality orientation on people with dementia have shown favourable outcomes for the orientation of people with dementia to time and place (Orrell, Spector, Thorgrimsen, & Woods, 2005) yet research does not comment on the impact of reality orientation on interaction, the emotions of the person with dementia and relationships between people with dementia and healthcare professionals. The interesting finding from the present study is the way in which the healthcare professionals do not profess to holding to any one approach. Instead they suggest a 'tool-box' approach where healthcare professionals choose the intervention most appropriate and least distressing for the person with dementia at the time. In order to make this choice the participants reported considering the underlying emotional needs communicated through the words and expressions of the person with dementia. This enabled them to empathise with the state of mind of the resident and to decide on the least distressing course based on their knowledge of the individual and their past experiences of the effect of the different therapeutic styles in certain circumstances.

Of the personal characteristics that were thought to facilitate interaction with people with dementia, only the attribute of sensitivity to residents' responses has been investigated in the literature. A study by Magai et al. (2002) trialled a care worker training intervention that taught care workers to be sensitive to the non-verbal emotional signals of people with dementia. This approach has similarities to the concept of sensitivity to resident responses and mood, but there are two main differences. Firstly the concept of sensitivity was portrayed by the participants in this study is an innate characteristic of the healthcare professional that is developed

over time by experience in dementia care settings. The staff training intervention sought to teach this technique in a class room context, without the necessity of innate ability or years of experience. Secondly, the concept as described by the participants in the present study refers to sensitivity to all kinds of resident response, whether verbal, non-verbal, emotional or otherwise. The staff training refers only to non-verbal emotional sensitivity. The study by Magai et al. showed that care home residents with dementia cared for by staff who were sensitive to micro-reactions showed increased expressions of positive affect by care home residents. This supports the participant testimony in this study. However, the Magai et al. study also showed that, contrary to the views of the participants, this sensitivity can be taught using didactic methods and does not have to be an innate characteristic, or the result of years of experience in dementia care settings. The reason for this view in the participants may be due to the content of the training they had experienced, none of which seemed to teach or access the skills referred to by Magai et al. in their training intervention.

Another controversial characteristic mentioned by participants was honesty. Some participants advocated never telling a lie, whereas others would advocate 'playing along' with the delusions of a person with dementia. The literature on deception in dementia care also reports this phenomenon as controversial. Although there have been no experimental studies looking at the effect of deception in dementia care on people with dementia there have been interview studies, both with healthcare professionals (James, Wood-Mitchell, Waterworth, Mackenzie, & Cunningham, 2006; Tuckett, 2012) and with people with dementia (Day, James, Meyer, & Lee, 2011). These studies support the reported behaviour of healthcare professionals in this study; that most professionals use some form of deception when communicating with people with dementia (James et al., 2006) but that this is mostly for the purpose

of easing the distress of people with dementia and most often involves omitting elements of truth (Day et al., 2011). As the present study did not ask explicitly about the use of deception it is interesting that participants very rarely used the words 'deception' or 'lie' and preferred to use terms such as 'tact' and 'side-stepping' the truth. However, the literature would still define these as a category of deception (Blum, 1994). This supports research on the topic deception in dementia care saying that healthcare professionals are uncomfortable about the practice of deception and could benefit from the generation of best-practice guidelines on this issue.

The other personal characteristic spoken of by participants was tolerance, or patience. Although there has been research into the effect of care giver characteristics such as resilience, research often focuses on the effects of these characteristics on the caregivers themselves rather than on those they care for and have only been carried out on informal care givers (Fernandez-Lansac, Lopez, Caceres, & Rodriguez-Poyo, 2012; Gonzalez-Abraldea, Millan-Caloenti, Lorenzo-Lopez, & Maseda, 2013). Only one study has been found that compared the personal characteristics of formal care givers in elderly healthcare situations to the characteristics of matched individuals in the general population. Richter, Astrom, and Isaksson (2012) found that professional caregivers were generally slower-tempered and more stoic and reflective than members of the general population. Professional caregivers also scored lower on the harm avoidance scale suggesting that they would be more optimistic in potentially aggressive situations. The participant responses from the present study go some way to explaining the high incidences of such personality traits in formal caregivers of people with dementia. By prizing the ability to tolerate challenging behaviour a profession would attract those with personality traits such as a slow-temper, reflective attitude and willingness to endure the potentially harmful situations encountered in dementia

care. However, there is still no research that considers the impact of these personality traits on people with dementia. According to the participants of this study, the consequences of impatient or intolerant caregivers are a greater level of agitation and the possibility of humiliating the person with dementia and damaging what should be a therapeutic relationship.

#### **4.5.3 Strategies**

The strategies suggested by the participants in this study give practical detail to the more philosophical theories featured in the introduction. Interestingly, there was an initial hesitation by many of the care workers when asked if they altered their communication style when interacting with residents with dementia. For some of the care workers there seemed to be an initial 'learned response' stating that they did not alter their communication and that they aimed to speak to residents in the same way that they would speak to anyone. However, these care workers would often then go on to discuss some of the ways in which they would modify their communication. This shows that there may be an underlying belief that altering their communication is in some way wrong, maybe due to the idea that any change in communication style would result in 'over-accommodation' and lead to infantilisation as can be seen in the literature on elderspeak.

As described in the literature review, elderspeak is a collection of ways in which a person may alter their communication style in order to accommodate for the assumed disabilities of an older person based on the stereotype of old age. These alterations include linguistic features such as reduced sentence complexity, simplified vocabulary and the use of diminutives such as 'dear' and 'love'. Alterations also include paralinguistic features such as increasingly varied pitch and raised volume. Some of these modifications to communication style have been

found to be helpful, however, some have been found to be less beneficial and can be termed as 'over-accommodating' (Kemper & Harden, 1999). The effect of reducing the complexity of language is one of the strategies that has been most researched and was also the verbal strategy most mentioned by the participants in the interviews. Previous research has found that complexity of syntax affected comprehension in both healthy older adults and people with dementia. One study found that sentences which included dependent clauses, e.g. 'Touch the little blue square if there is a big black circle' were most difficult for people with Alzheimer's disease to comprehend. Interestingly Tomoeda et al. found no independent effect of the rate of speech, only an interactional effect with syntactic complexity (Tomoeda et al., 1990). This piece of research supports the interview participants' view that speech should be simpler but only partially supports the view that speech should be delivered at a slower rate. According to Tomoeda et al.'s study this is only helpful when the sentence is syntactically difficult. If the sentence being delivered has simple syntax then slowing the speech rate could be seen as patronising and disrespectful (Hummert et al., 1998). Another more recent paper which confirms these findings was carried out by Small, Kemper and Lyons (1997). They found that syntactic complexity made comprehension more difficult, especially when sentences contained embedded clauses, e.g. 'The woman who the girl followed shouted at the boy'. They found that interpretation of these sentences took place in a linear order which they concluded showed that loss of working memory was one of the causes of sentence comprehension deficits in AD (Small, Kemper, & Lyons, 1997). According to this study, care workers slowing their speech could be a problem as a person with short term memory deficits could not retain the relevant information for the amount of time taken to complete the sentence. So research in this area supports the

participants' strategy for the use of syntactically simple sentences but would not recommend the slowing of speech rate unless the sentence more complex.

Repetition was another strategy recommended by the interview participants. The participants showed a preference for paraphrasing rather than repetition verbatim as this allowed for the possibility that the person with dementia was not able to understand the original syntax or vocabulary in the first sentence. Although a study on healthy older adults found no difference in comprehension when comparing these two types of repetition (Kemper & Harden, 1999), participants in the present study refer to the word recognition difficulties and short term memory deficits of people with dementia as the reason for preferring paraphrasing. A paraphrase will often alter the vocabulary in a sentence, allowing alternative options for comprehension which would not necessarily be helpful for a healthy adult. In addition, rephrasing a sentence usually results in a shorter sentence which is easier to remember for a person with short term memory deficits.

Another element of elderspeak that was described by the participants in the interview study was vocal tone. This refers to paralinguistic features such as volume, pitch and prosody. In the literature it is referred to as emotional tone because it is through these paralinguistic features that implicit emotional messages are thought to be communicated. Participants from the interview study indicated that the vocal tone of a sentence could be of even greater importance than the words spoken. It was thought that even if a person with dementia had a diminished capacity to comprehend words, their ability to comprehend emotional expression is preserved. The research on emotional tone supports this view. Cunningham and Williams (2007) found that interactions where the care worker's emotional tone was rated highly for a respectful tone had fewer incidences of resistance to care and Small,

Gutman, Makela, and Hillhouse (2003) found that interactions containing more communication breakdowns between interlocutors were also rated less respectful in tone. The literature on vocal tone restrict the underlying messages to the dimensions of control, care and respect. However, the participants in the interviews indicated that much more could be communicated through vocal tone such as cheerfulness and calm, or more negative messages such as tiredness, panic or anger. It was thought that these different implicit messages could be communicated through a mixture of altered pitch, speed, volume and prosody, however, there is no research as yet to indicate the paralinguistic features of each message.

Questioning was a strategy discussed by participants of the interview study. Some spoke of using closed questions in order to better understand the communicative behaviour of a person with dementia. Other participants spoke of the damaging nature of 'test questions' that required the use of impaired memory and may be embarrassing for the person with dementia. The use of questions when interacting with a person with dementia is something that has not been covered in the research literature apart from one study that looked at compliance with certain command types. Christenson et al. (2011) examined the compliance rate of a group of care home residents with dementia to different types of instructions or 'commands' given by care workers. One command type consisted of interview questions. These demanded a verbal, factual answer from the participant and could refer to either of the types of questioning mentioned by participants in the interview study. Interview commands were the most common instruction type accounting for 26% of all instructions given in the care sessions. Although 69% of these questions were met with compliance it is not stated whether the responses were appropriate. The participants may have 'complied' by answering yet that answer may have been 'I don't know', or 'I can't remember'. In addition to this, the reasoning behind the



interview participants' advice to limit the use of questions was to shield the resident from incidences that exposed their memory deficits and may cause distress. This study does not document the emotional reaction of residents to these questions. The interview study has revealed other factors that should be considered when asking questions of people with dementia. Firstly, questions should only be asked with the purpose of understanding the needs and preferences of the person with dementia. Secondly, questions should not emphasise the memory deficits of the person with dementia as this could lead to embarrassment or distress.

Participants in the interview study also referred to non-verbal communication techniques and the importance of these when communicating with people with dementia, especially those with severe dementia. Participants spoke of eye contact as a way in which people with dementia can communicate their emotions and also a way in which care workers can overcome any power imbalance in the dyad.

Participants also indicated that eye contact was a way in which care workers could maintain the attention of the person with dementia and prevent withdrawal. The only reference to eye contact in the research literature was in the paper by Hammar et al. (2011) in their qualitative analysis of Music Therapeutic Caregiving (MTC). They noted that when the residents were responding inappropriately to the care worker's instructions there tended to be little eye contact between the participants.

However, when the resident was responding appropriately to the care worker there was a noticeable increase of eye contact. The authors also noted that the combination of eye contact and waiting for a response from the resident was received as an invitation to participate in the interaction whereas lack of eye contact amounted to an exclusion from interaction. This use of eye contact as an invitation to interaction is similar to the interviewees' view of eye contact as a strategy to prevent withdrawal. Yet this study also supports the views of the interview

participants in other ways. The participants in the interviews said that eye contact was a way in which people with dementia can communicate their emotions to the care worker. It would be natural for a care worker to avoid engagement with these emotions when having to complete a task which causes the resident distress. This avoidance of eye contact could be a coping mechanism for the care worker, a way of distancing themselves in a distressing situation. In addition, if eye contact was thought to restore the balance in power between the person with dementia and the care worker, it follows that a care worker seeking to complete a care task with an uncooperative resident would not wish to restore any power to the person with dementia. Not making eye contact with the person with dementia may be a method by which the care worker seeks to retain control of the situation and finish the care task.

The interview participants also spoke of communication aids, demonstration and gesture. In the literature these are often referred to as Augmentative and Alternative Communication (AAC). These are methods of communication that support or replace spoken communication. In general there are two types of AAC: aided communication and unaided communication. Unaided communication refers to communication techniques that do not require any other equipment and would include strategies such as gesture and pointing (Garrett & Lasker, 2005). When care workers spoke of techniques that they use to assist or replace their speech it was often these unaided methods that were preferred. Aided communication methods are methods of communication which require an additional piece of equipment. These were mostly mentioned by the interviewees who were not care workers; the occupational therapist, the speech and language therapist, the activities coordinator, the clinical psychologist and the mental health specialist. One study in the literature described a staff training intervention that taught the use of memory books, a form

of aided communication (Burgio et al., 2000; Dijkstra et al., 2002). These memory books consisted of laminated books containing biographical information, photographs of people they knew, their daily routine and instructions on activities of daily living. It was found that the use of these books by staff lead to increases in coherence, the use of unique words and decreases in the use of indefinite words by the care home residents with dementia. Although the use of memory books or boards were mentioned by the interviewed care workers, picture cards were the form of aided communication most spoken of and most widely used by those interviewed. This may be an issue of practicality as each individualised book is meant to be kept with the person with dementia at all times, traveling with them throughout the day, yet were often left in resident's rooms. But memory cards were portrayed as practical and easy to use as these could be kept on a key ring in a care worker's pocket or hanging from their belt and could be used for any resident. It may be that both of these methods of AAC have different purposes and could be used at different times; the memory books for extended periods of personalised interaction with the purpose of stimulating memory and conversation, and the picture cards for short bursts of interaction to assist care workers attempting to discern or explain care needs

Pacing was a strategy used by the participants which has only been addressed in the literature as part of a larger staff training intervention and also as part of a qualitative analysis of MTC. No study has looked at pacing as a strategy by itself. One of the few studies to refer to it is Dijkstra et al. (2002) who incorporated the idea of allowing sufficient time for the person with dementia to respond before moving on with the task. The time they allotted was 5 seconds. According to the participants, pacing combined the idea of slowing speech with the idea of slowing the whole interaction; the time allowed for response, both verbally and physically,

should be increased, and the rate at which a carer performs a task should be slowed to the speed of the resident. For some residents this may be very similar to that of a normally functioning healthy adult, for others this may be much slower. Although the training intervention by Dijkstra et al. (2002) was successful in increasing coherence, the use of unique words and decreasing indefinite words in the participants with dementia, it is not known whether pacing was one of the active ingredients that caused this success. It is also not known whether the care workers in the study employed pacing as intended by the authors of the study. The effect of pacing was also observed in the study by Hammar et al. (2011). The authors noted that the combination of eye contact and waiting for a response from the resident was received as an invitation to participate in the interaction. This supports the interview participants' opinion that pacing creates a more interactive and cooperative environment.

#### **4.5.4 Training and organisational factors**

The third overarching theme discussed by the participants related to the organisational factors that effected the employment of the communication strategies and attributes discussed in the previous themes. Participants spoke of the way in which a bio-medical culture in the care home would not prioritise communication and relationship building. This organisational level, although not dominant in the literature on the topic of communication between care home residents and staff, has been seen as relevant in the area of quality of care for people with dementia. One study (van Beek & Gerritsen, 2010) found that different types of organisational culture was related to the quality of care given by nurses, both self-reported by the nurses and observed by those outside the organisation. They compared the effects of a 'clan' culture and a 'market' culture. A clan culture was characterised by shared values and goals, cohesion and participation and leadership

took the form of a mentoring, parent-like relationship. They found that this clan culture produced better quality care than a unit with a market culture which was oriented around productivity, profits, achievement and competition and where the leader took the role of a task driver in order to achieve the best performance from their workers. These two cultures have obvious differences in their values and goals with the market culture resembling the task-oriented approach so criticised by the interviewees. It is poignant to note that nurses from units of different cultures still assigned themselves similar priorities and it was the culture of the unit that either facilitated or hindered them from performing to their priorities as they wished. This study supports the opinions of the care workers who expressed the importance of care home culture in their ability to communicate and build relationships with their residents. In addition, the study's findings on the way in which culture can prevent nursing staff from performing according to their own priorities present one explanation for the interviewees' apparent contradiction between their positive attitude towards communication but their reported inability to engage with the residents at the level that they wished.

The interview participants discussed the way in which the culture or ethos of the care home is often determined by the leadership within that home. The roles of the manager or senior carers were often mentioned as factors affecting their ability to interact with residents as they wished. These effects were manifested through the aspects of care that were encouraged by managers and also through the way in which the leaders were seen as role models for care worker behaviour. The effects of these factors are supported by the literature. One study by Helgesen, Larsson, and Athlin (2010) found that organisational conditions, especially leadership, greatly affected the way in which care workers interacted with residents with dementia and the extent to which they were 'present' in the interaction in body, mind and

'morality', a condition based on the humanistic values of respect and individualised care. They found that the ability of leaders to communicate positive values and direction to the staff influenced whether the care workers could be present with the resident in 'morality'. The participants in Helgesen et al.'s study commented on rarely receiving feedback from their managers about the way in which they interacted with residents but would relish this in their desire to improve their care. This supports the views of the interview participants who complimented their managers on the way in which they encouraged or advised their staff on how their interactions could be improved. Helgesen et al. also noted the way in which the managers' interactions with residents were seen as a 'frame of reference' for what was acceptable interactional behaviour. This supports the views expressed in the interviews as participants wanted to see their leaders on the 'frontline' as an example of good quality communication. In addition to this, the interview participants also expressed a wish to see their managers interacting with residents with the purpose of knowing that their managers were experienced in the day-to-day activities of their staff. This was thought to lend greater validity and relevance to their manager's decisions and instructions and would increase the care workers' respect for their authority.

The other factor that the participants said effected their communication was that of dementia training. It must be noted that many of the participants in the interviews had not experienced the same training, especially those from other professional backgrounds from the care workers. This will have influenced their views on the impact of the training that they had received and their beliefs about what constitutes effective training. There were mixed views on whether they had received enough training for communicating with people with dementia and some participants said that they found the training they had received patronising. Nolan et al. (2008)

conducted a review of training in residential care homes and came to the conclusion that education and training for staff of care homes is inherently good but has variable results. They suggested a number of factors that mediate any effect that training would have on the residents. They suggested that training tends to address three broad aspects of care; affective, management and physical. The review shows that training tends to focus on the physical aspects of care. This type of training prioritises the acquisition of skills and abilities, and very little training focuses on the affective, interpersonal dimensions of care. Nolen states that this is because resources available for training are often so scarce that the small amount of time and money available must be spent training in skills that fulfil the legislative needs of the home rather than looking at interpersonal and emotional issues of care. However the interview participants would agree with Brooker (2008) who says that training must capture 'the hearts and minds' of those who are being trained. The interview participants suggested role play and discussion that would help them to empathise with those they are caring for. It was thought that only this type of training can make a lasting impact on the attitudes and perceptions of staff.

In the literature there are four studies that present the results of educational interventions for care workers that aim to increase the quality and quantity of interactions with people with dementia (Burgio et al., 2000; Magai et al., 2002; McCallion et al., 1999; Wells et al., 2000). None of the participants in the interview study would have experienced the training described in these studies. Yet it is interesting to note the similarities and differences between programmes devised by researchers and the training characteristics recommended by healthcare professionals. As the interview participants recommended, all of the staff training interventions contained an element of educating care workers in the effects of dementia on communication, behaviour and abilities. However, none of these

interventions reported attempting to impart the attitudes and personality traits discussed in the first overarching theme or an element that causes them to see the world from the point of view of the person with dementia, an element thought to be central to the effectiveness of the training by participants. One of the points most emphasised by the interview participants was that communication skills are difficult, or even impossible, to learn didactically. Yet only one of the four training interventions presented a method of integrating what had been learned within the training sessions into daily practice. Burgio et al. (2000) had a supervisory structure which was designed to give feedback to the care workers on their progress and implementation of the strategies taught in the classroom sessions. This system was effective in increasing the amount of communication strategies used by care workers according to a communication skills checklist (Burgio et al., 2002). Although the other staff training interventions also showed positive outcomes for the residents, the participants in the interview study make it clear that, as their job is practical, training should be practical also and should assist in the application of techniques to daily practice.

#### **4.5.5 Evaluation**

Despite a growing body of literature relating to communicating with people with dementia, this study, to the best of the researcher's knowledge, is the first study that has asked those who communicate with people with dementia on a daily basis to describe the facilitators and barriers to communicating with people with dementia. By interviewing those experienced in dementia care this study has utilised the 'untapped well of knowledge' that was missing from the literature (Perkins et al., 1998). This study utilised the opinions of a number of people from different healthcare roles and professional backgrounds and consequently the results are rich, comprehensive and accessible to healthcare professionals from many different



contexts. By using semi-structured interviews it was possible to not only learn the strategies that healthcare professionals use when interacting with people with dementia, but also to learn the reasons behind the use of these strategies and the other factors which healthcare professionals believe affect their communication behaviour. The format of the semi-structured interview enabled the researcher to elucidate their understanding of the views expressed by the participants and also to expound on topics not yet mentioned either in the literature or by other participants in the study. The freedom of the interview method also allowed participants to speak about elements of the topic that they thought important rather than being restricted to factors assumed important by the researcher. In addition to this, the inductive, bottom-up approach to analysis meant that unexpected findings, such as the importance of the personal attributes of healthcare professionals, were not dismissed but were able to appear in the results with the importance assigned to them by the participants. A deductive approach where a coding scheme is devised by a researcher before data collection, may not attribute as much value to unexpected themes. Furthermore, the input of multiple researchers during the coding process to challenge the definitions and positions of codes within the coding scheme increased the reliability of the coding scheme as a summary of the interview data.

There are some limitations to this study. It is not known whether the strategies reported by the participants have a significant effect on communication with people with dementia, especially those strategies which seem to contradict what has been found in the literature. The opinions expressed by the participants in this study are evidence of the opinions of these individuals only. The purposive nature of the sampling meant that these participants were not a representative sample of all healthcare professionals who work with people with dementia. The snowballing

method of sampling used for recruiting the healthcare professionals who were not care workers made it likely that the potential participants suggested by recruited participants would share similar opinions to those who recommended them. Also, the care workers were chosen from care homes who had a reputation for excellence in dementia care and a willingness to be involved in research. It may be that care workers from other care homes would have different opinions on the facilitators and barriers to communication with people with dementia. However, the rationale behind purposive and snowball sampling was to obtain the opinions of those with a reputation for delivering high quality dementia care and therefore those at the cutting edge of effective care delivery. Another limitation of this study is that the behaviour reported in this study is only reported. It is not known whether the care workers actually use the strategies that are reported here. Social desirability is a form of bias that must always be addressed in research that relies on the reports of participants (Crowne & Marlowe, 1960). However, it was always the intention of this study to discover what healthcare professionals deem to be 'best practice', therefore social desirability would not alter the report of what participants think are the facilitators of communication with people with dementia. Despite this, it can be argued that there is evidence within the study that social desirability was not a factor in these interviews. Participants featured in these interviews were volunteers and were not offered any incentive for being interviewed other than being involved in research. In addition, participants sometimes commented on more controversial topics such as deception and the temptation to ignore or be irritated by people with dementia. Participants would not have spoken of topics that could be interpreted negatively by the researcher if they were concerned about appearing socially acceptable.

#### **4.5.6 Implications**

The facilitators and barriers to communication with people with dementia described in this study have implications for future research into dementia care and the training of formal care givers.

The participants believed that the personal attributes of a healthcare professional could be a significant facilitator or barrier to communication. The participants spoke of certain values such as the belief in personhood, philosophic approaches such as individualised communication, using each interaction as a therapeutic intervention and attempting to engage with the residents' reality and 'virtues' such as patience and honesty. Although there has been preliminary research into the impact of informal care giver personality traits, there has been little research into the personal characteristics of formal care givers and the impact of these attributes on their interaction with people with dementia. Future research could seek to establish the way in which certain care worker values, attitudes or personality traits affect the communicative behaviour of care workers and care home residents with dementia.

Another question raised from the implied importance of such attributes is whether it is possible for formal care givers to be trained in these communication facilitating qualities. Although staff training interventions show that practical communication strategies can be taught and executed in healthcare contexts the instilling of certain values and attitudes in a workforce is more difficult to demonstrate. One intervention in the literature was able to train care workers in sensitivity to non-verbal emotional cues, a skill thought to be innate by some participants in this study. Future research should aim to determine whether other values, attitudes and 'innate' skills are possible to train into a workforce.

There were some strategies discussed by the participants that have not yet been addressed in research. It is therefore not known whether these strategies are

effective as reported. Some of the strategies mentioned were distraction, disengagement, explanation of actions, pacing and the use of positive facial expression. Although some are referred to in staff training interventions these strategies are not yet known to be effective in their own right. Some, such as explaining actions, were slightly controversial as too much explanation was thought by some participants to overstimulate and confuse a person with dementia. Before these strategies are taught to care workers it is important to first establish an evidence base. The effects of such strategies on the interactive behaviour of people with dementia, in isolation from other facilitators and in experimental conditions would determine the effectiveness of these strategies.

An important finding from this study was the way in which healthcare professionals did not hold to a particular therapeutic approach when communicating with a person with dementia. Their use of both validation and reality orientation techniques in their interactions showed that instead they choose from a 'tool-kit' of techniques and strategies which are individualised to the person and the situation. This has implications for communication training. Participants reported feeling patronised by training sessions when they were instructed to use principles in ways which violated their previous experiences. Instead of advocating a 'pure' intervention to care workers, training session should seek to teach distinct evidence-based strategies that could be added to their 'tool-kit' and then teach the basis on which to determine the appropriateness of each strategy in each situation. The idea of the dementia communication tool-kit empowers the care worker to use their knowledge of the individual and their expertise to determine the best way in which to individualise each interaction.

The participants also spoke of other elements that should be involved in training such as the opportunity to apply training to practice. This would involve training programmes with feedback and refresher sessions. Participants also suggested that the training sessions that were effective were those that made them empathise with the person with dementia and had an emotional impact. In addition, the organisational factors mentioned by the participants emphasise the importance of incorporating elements for managers into training programmes to ensure that the content of any training is implemented rather than overwhelmed by existing practices. The concepts of the strategy tool-kit, a parallel management programme and the need for care worker training to be empowering, practical and emotionally impacting should be incorporated into care worker training programmes devised for future testing and implementation.

## **4.6 Conclusion**

The healthcare professionals interviewed in this study identified four main ways in which communication with people with dementia could be facilitated. The most important factor for the participants was the attributes of the healthcare professional; their skill in forming relationships with those they care for, their personal characteristics and their understanding of dementia. The participants then spoke of a number of strategies they would use in individualised circumstances. These communication strategies were both verbal and non-verbal. The participants then referred to factors which affected the employment of communication skills and strategies. These took the form of the ethos and management of the home, staffing levels and the form and content of dementia training. The physical characteristics of

the workplace were also believed to affect their ability to communicate effectively with people with dementia.

This study has shown the way in which communication research in dementia care has only begun to address the many factors which affect communication between healthcare professionals and people with dementia. Many of the concepts and strategies believed crucial to effective communication with members of this population have not been addressed in observational, let alone experimental research.

It is recommended that researchers seeking to improve communication for people with dementia in care homes use the opinions of those experienced in dementia care as a basis for their research topics and questions. These results also have implications for the content and form of care worker training and issues such as practicality, emotional impact and the importance of also involving management in training. All of these factors should be considered when devising training programmes for care workers.

## **4.7 Summary**

This chapter presented the method, analysis, results and conclusions of an interview study that sought to determine the facilitators and barriers to communication between healthcare professionals and people with dementia. According to the exploratory mixed-methods design the next chapter will build on the results of this study by selecting two of the strategies referred to by participants and proposing a method of experimental analysis.

## **5. Development of experimental method based on interview findings**

### **5.1 Chapter Overview**

This chapter aims to use the data from the previous qualitative study and literature review to formulate a proposal for a quantitative, experimental study.

Considerations of the independent and dependent variables, setting, method of data collection and the design of the study will be presented in preparation for the procedure, analysis and results presented in chapter six.

## **5.2 Aims**

According to the explanatory, mixed-methods design described by Creswell and Plano Clark (2011), this thesis should start with qualitative data which then builds to a quantitative phase. The purpose of the interview study in this project was to inform the researcher of strategies used to facilitate communication with people with dementia which could be manipulated using an experimental design.

The objectives of the experimental study were:

- To vary care worker communication style in two conditions, the content of which is based on the current research literature and the strategies described by participants in the interview study.
- To assess the effectiveness of these strategies according to measurements of the communicative behaviour of care home residents with dementia.

The aim of this chapter is to explain the process by which the researcher built upon the results of the interview study and how the strategies under study were selected and developed into an intervention that could be tested with quantitative methods.

## **5.3 Summary of interview data**

From the beginning of the research process it was the practical strategies employed by people who work with people with dementia that were the focus of investigation.

The interview study provided insight into what these strategies were but also produced unexpected factors that are worthy of investigation and should be considered in research into communication with people with dementia. The personal attributes, organisational factors and environmental factors identified by



the participants warrant more extensive investigation than is possible in this thesis.

The focus of the investigation will therefore be narrowed to the practical communication strategies identified in the interviews.

The participants noted many strategies that they frequently used to facilitate communication with people with dementia. Some of these were verbal; such as modifying language complexity, keeping speech quiet and calm, explaining activity as it takes place, repeating instructions and using simple questions to establish the meaning behind resident initiated interaction. Other strategies were non-verbal; such as the use of eye-contact, facial expression, touch or communication aids such as pictures and gesture to elaborate on language. Participants also stated the importance of pacing an activity at a speed suitable to the resident, knowing when to disengage from an interaction and the use of distraction or rewards when completing a disagreeable task.

Two of these strategies were selected for investigation in the following phase. As communication is a two-way process it was decided that one strategy should be chosen for its ability to enable understanding of the care worker and the other strategy should be selected as a strategy that facilitates resident response.

## **5.4 Development of communication strategies for testing**

When selecting appropriate strategies to investigate there were certain criteria that effected selection. It was thought that that strategy must be:

- Capable of use independent of resident behaviour

- This means that the strategy does not require the resident to be exhibiting signs of distress, challenging behaviour or confusion for the strategy to be employed.
- Not yet measured experimentally in a care setting
  - This was in order for the experiment to make a unique contribution to the literature.
- Capable of measurement through the use of video
  - Certain speech characteristics such as a vocal tone have not yet been studied sufficiently to allow manipulation and measurement apart from group observer rating
- Capable of being taught to care workers quickly as an experimental condition
  - Some strategies could be taught sufficiently over time, yet this is to be a simple and quick intervention due to the time pressures placed on care workers
- Not a strategy where over use would induce negative effects
  - Some strategies such as eye contact and touch required the care worker to establish a 'suitable dose' for each individual. It was reported that different individuals require certain amounts and too much would induce discomfort and a loss of rapport. This would be difficult to manipulate and measure.
- Established parameters of measurement

- Some strategies already lend themselves to measurement using established instruments or methods of categorisation that are already validated and used in the literature

#### **5.4.1 Facilitating resident understanding**

The strategy chosen to facilitate resident understanding was the manipulation of language by using short, simple and precise sentences. The use of short sentences and clear vocabulary was a feature of effectual communication endorsed by every participant in the interview study. The motivation for choosing this communication strategy was to demonstrate the effect of care worker language on the ability of residents to understand them.

The effect of reducing the complexity of language is one of the strategies that has been most researched. One study found that complexity of syntax affected comprehension in both healthy older adults and a group with AD. Sentences which included dependent clauses, e.g. 'Touch the little blue square if there is a big black circle' were most difficult for the AD group to comprehend (Tomoeda et al., 1990). Another more recent paper which confirms these findings was carried out by Small, Kemper and Lyons (1997). They found that syntactic complexity made comprehension more difficult, especially when sentences contained embedded clauses, e.g. 'The woman who the girl followed shouted at the boy'. They found that interpretation of these sentences took place in a linear order which they concluded showed that loss of working memory was one of the causes of sentence comprehension deficits in AD (Small et al., 1997). A further piece of research looked at care worker language in an observational study in a care home setting. Christenson et al. (2011) categorised care worker instructions, or commands, into command types and subtypes based on the way in which instructions were phrased.

Based on methods used in education research they devised and modified a coding system of commands used in nurse-resident interactions. In the coding system they included nine different command types, most of which can be divided into either alpha or beta subtypes. Alpha commands are precise instructions where an action or verbal response is appropriate or feasible such as “roll over to the right”. Beta commands are instructions where compliance may be difficult due to vagueness, indirectness or forced compliance, where the care giver completes the request for the person with dementia such as “there’s your glasses”. They calculated the frequencies and percentages of each command that resulted in each response type and found that alpha commands resulted in greater compliance when compared to beta commands.

Using simple, precise instructions has been shown to have effects in observational data in care settings (Christenson et al., 2011) and in experimental data in laboratory settings (Tomoeda et al., 1990) but has not yet been shown to be effective under experimental conditions in a care setting. The coding scheme developed by Christenson et al. (2011) also provides an instrument that could be used to assess the implementation of this intervention.

#### **5.4.2 Facilitating resident response**

The strategy chosen to facilitate resident response is pacing. This involves the care worker interacting at the same speed as that of the resident by allowing time within the interaction for the resident to respond.

Pacing was a strategy referred to by the interview participants which has only been addressed in the literature as part of a larger staff training intervention. No study has looked at it as a strategy by itself. One of the few studies to mention it is Dijkstra et al. (2002) who incorporated the idea of allowing sufficient time for the person

with dementia to respond before moving on with the task. The time they allotted was five seconds. Although pacing is similar to slowing speech participants said that this was not always so. Pacing may involve speech occurring at the same speed as normal, however, the time allowed for response, both verbally and physically, should be increased. For some residents this may be very similar to that of a normally functioning healthy adult, for others this may be much slower. Although the training intervention by Dijkstra et al. (2002) was successful, it is not known whether pacing was one of the active ingredients that caused this success. It is also not known whether or how easily the care workers in the study employed pacing as intended by the authors of the study.

The experimental study is an opportunity to see the effects of this communication strategy in isolation from other strategies and also to document the ease with which care workers adopt and employ this intervention.

## **5.5 Dependent variables**

The goal of this experiment is to determine whether the communication strategies used in the different conditions increase communication between the care workers and the residents. In order to do this the quality of communication between the interlocutors must be measured. Communication is a complex phenomenon and is defined as the conveying of information from one person to another.

Communication is also two-way. It depends on a message being conveyed by one person and another person receiving and interpreting that message. In this study it is therefore important to measure, not only the residents' ability to receive the messages of the care worker, but also the inclination of the resident to convey messages of their own. According to the need-driven dementia-compromised

behaviour model, all behaviour is a form of communication (Algase, 1996), therefore the method of measuring the resident's conveyance of information will have to be defined widely.

Over the course of the interviews many participants expounded on a theory of communication that is made up of three crucial components. In order for communication to take place the resident would have to be engaged with the care worker, they would then have to understand the information being conveyed and then have to have the opportunity and be willing to offer a response. There are therefore three different elements of communication to measure:

- Engagement/attention: This could be assessed by measuring commitment to a task or eye gaze
- Comprehension and appropriate response: This could be assessed by recording the frequency of task completion or appropriate verbal and physical responses
- Willingness to communicate: This could be assessed by measuring resident verbosity, the frequency of resident contributions, initiation of interaction or eye contact

The measure of communication used in this study should attempt to measure all three of these elements.

Another consideration is that not all communication, as defined by Algase' model, is positive. There are elements of communication that care workers and residents would wish to experience less. During the interviews many participants agreed with Algase' model that challenging behaviour, such as physical aggression and vocalisation are methods of communication that express needs that could not be

communicated in other ways, due to their dementia. It is therefore important to also measure this 'negative' communication to see if these communication strategies decrease the need for residents to communicate in these more challenging ways.

## **5.6 Setting and task**

In order to make a contribution to the literature it was important for this experiment to take place in a naturalistic but controlled setting. As one of the ways to measure understanding is task completion the setting had to be one in which the participants have to cooperate in order to complete a task.

Activities of daily living (ADLs) are tasks that are performed every day by residents and often require assistance from care workers. They include tasks such as washing, dressing, bathing, eating and toileting. These are also the activities that are often accompanied by challenging behaviour and occupy the majority of staff time. In the interviews the care workers spoke of these ADLs as opportunities for one-to-one interaction without distractions or interruptions. In addition to this, they are similar for all residents and filming these interactions would not mean that valuable participant time would be taken from their normal activities meaning they may be more willing to take part.

## **5.7 Design**

Although a randomised controlled trial is the 'gold standard' of experimental design (Higgins & Green, 2011), as this is a preliminary study the design must be on a smaller scale to first demonstrate the possible effectiveness of such strategies before

progressing to the considerable investment required for an RCT. A multiple case-study design is therefore proposed.

In order to demonstrate the effectiveness of these communication strategies both verbal and non-verbal behaviour would have to be recorded and analysed.

This would require either the physical presence of the researcher or video-recordings. Either way the data collected and the analysis would be labour intensive meaning that the participant numbers would have to be small. In addition, the individual differences between each person with dementia would mean that a process such as finding matched controls would be extremely difficult, therefore a multiple case study design where each participant serves as their own control would be the most effective in determining change. Replication of the experimental process in a number of other dyads would strengthen results. Therefore, a multiple case study design, using three care worker-resident dyads, was utilised for this study.

## **5.8 Research proposal for experimental phase**

It is therefore proposed that an experimental study of a multiple case study design where care workers are asked to manipulate their communication style during an ADL on a number of different days should be implemented to analyse the efficacy of two communication strategies. In one condition care workers will change their language making instructions simpler, shorter and more precise. In the other condition care workers will pace their interaction, allowing more time for residents to respond.

The effectiveness of these communication strategies will be measured using instruments that assess the residents' engagement, their appropriate responses and



their attempts at interaction. Negative communication such as verbal and physical aggression will also be measured.

## **5.9 Summary**

This chapter has built on the findings of the interview study in chapter four. The two communication strategies to be analysed in the experimental study were discussed and selected. The dependent variables, setting, task and design were also considered and an experimental study proposed. The following chapter presents the procedure, analysis, results, discussion and conclusion of that study.

## **6. The effect of care worker communication style on the communicative behaviour of care home residents with dementia: an experimental study**

### **6.1 Chapter overview**

This chapter describes the methodology, implementation, analysis, results and discussion of an experimental study aiming to manipulate care worker communication style and analysing the effect of this on the communicative behaviour of care home residents with dementia.

## **6.2 Rationale and aims**

The aim of this experimental study was to determine whether communication with people with dementia can be facilitated by varying the communication style of the care worker.

This study seeks to answer the following research questions:

1. Can care workers be trained to modify their communication style?
2. Is there an effect of care worker communication style on the communicative behaviour of care home residents with dementia?
3. Can the effects within dyads be confirmed across dyads?
4. Are there differences in resident behaviour across different command subtypes?
5. Are care workers aware of their communication style and the effect it has on residents?

## **6.3 Method**

### **6.3.1 Setting**

All data collection occurred in a privately owned, 41 bed, residential care home located in the East Midlands. Of the four care homes invited to participate in the research this was the only care home to accept. Two homes refused participation because of time pressures due to building work and imminent inspections. One home was prevented from involvement by the higher management tier of the company. This home was selected due to the manager's willingness to be involved in research. The facility was not a dementia specialist home and catered for elderly residents with a variety of physical and cognitive impairments. It was thought that

working with staff who do not work exclusively with people with dementia would show a typical care worker's ability to adapt the strategies needed in this study. Staffing ratio was approximately 1:5. Although this study was experimental in nature it was important that the setting was kept as naturalistic as possible for the participants and therefore all data collection took place in the setting in which the task performed would normally take place. Although this meant that there were some uncontrolled variables, e.g. the size of the space being used, lighting, temperature, external noise; collecting the data in a setting that the participants were familiar with and resembled normality added to the authenticity to the results.

### **6.3.2 Participants**

Participants consisted of three care workers paired with care home residents with dementia. From literature on conversation and interaction (Ripich et al., 1991) and also from the interviews conducted with experts it was evident that interaction is unique for each dyad. Interaction style can differ according to factors such as each participant's personality, conversational preferences or ability, or their social role. For example an introvert conversing with an extrovert may say very little but the same individual conversing with another introvert may dominate the conversation. Another example would be a person interacting with a stranger in contrast to their interaction with their spouse. The person with whom an individual interacts can determine their use of body language, eye contact, complexity of language and many other linguistic features. Therefore, in order to control for the factor of individual differences in communication between different dyads, the same dyads were maintained throughout the conditions.

There were two sets of participants in this study, each with their own set of inclusion criteria. Below is stated the inclusion criteria and the rationale for these criteria.

### 6.3.3 Care workers

#### 6.3.3.1 *Inclusion criteria for care workers:*

- English speaking.
- Have at least 6 months experience of care work with people with dementia in a professional capacity. In the interview study participants commented on the steep learning curve experienced by people new to care work. This time period of work experience meant that participants would be able to focus on manipulating their communication style in addition to completing care tasks. Other research studies in this field have also used this criteria e.g. (Wang et al., 2013).
- Willing to change their communication styles during ADLs with their residents. This criteria was simply to highlight that some care workers may not find the idea of changing their communication style possible or appropriate.
- Have worked with the resident in their dyad for at least 1 month prior to the start of the study. One of the main factors effecting communication mentioned by care workers in the interview study was the extent to which they knew the individual they were caring for. It was therefore important that the care worker had been working with the resident for a certain amount of time so that they could grow accustomed to their preferences and cognitive and physical abilities before the commencement of data collection.

### **6.3.3.2 Care worker recruitment process:**

On the approval of the owner, the manager and a senior care worker at the facility, care workers who met the inclusion criteria were identified by the senior care worker and asked if they would be willing to be contacted by the researcher. Contact was made by the researcher and a meeting was arranged between the researcher, the care worker and the senior care worker. In this meeting the care worker was given the introductory information in appendix 9 and asked if they would be willing to be involved. The different conditions were not explained to the care workers at the first meeting to prevent their knowledge of the strategies from interfering with the baseline measures and other condition. At this meeting the care workers were also given a consent form and the opportunity to ask any questions they had about the study. Care workers were given a period of at least 24 hours to decide if they wished to be involved and then asked to return the signed consent forms to their care home manager to be retrieved by the researcher.

Two staff members who were approached declined participation due to not wishing to be filmed. A total of three care workers participated. Their demographics are displayed in Table 5.

**Table 5. Demographics of care workers**

<b>Participant no.</b>	<b>Gender</b>	<b>Age (years)</b>	<b>Ethnicity</b>	<b>Experience with dementia</b>	<b>Experience with resident</b>
1	Male	28	White British	7 years	3 months
2	Female	53	White British	4 years	4 years
3	Male	19	White British	8 months	3 months

### **6.3.4 Residents**

#### **6.3.4.1 Inclusion criteria for residents:**

- English speaking.

- Have a diagnosis of dementia, probable dementia or confusion. Many care home residents have a diagnosis of 'confusion' or 'probable dementia' due to the ongoing debate on the benefits/costs of a diagnosis. As this is standard throughout the UK it was decided not to exclude those with a 'probable' diagnosis of dementia. This information was obtained from the care plans of the participants.
- Full-time resident in the residential care home i.e. not day-care/respice care. This was to ensure constant access to the resident. In addition, this meant the need for assistance and familiarity with being assisted by care workers was more probable.
- Sufficient auditory and visual acuity to take part in an interaction. This was to ensure that any lack of or mistaken response by a resident to a care worker's communication was not due to the inability to hear or see the care worker. This information was obtained from residents' care plans and also confirmed by care workers and relatives of the resident.
- Require some form of assistance/supervision while completing ADLs. One of the most fundamental, and difficult roles for care workers when caring for people with dementia is assisting with ADLs. In order to observe these situations and the interactions that take place within them it was crucial for the resident to require such assistance.
- Medically stable. It is common in dementia research for participants to be frail and at risk of medical decline during the course of research. The resident being medically stable at the commencement of the research is the

best way to protect against losing participants to hospital admission or mortality.

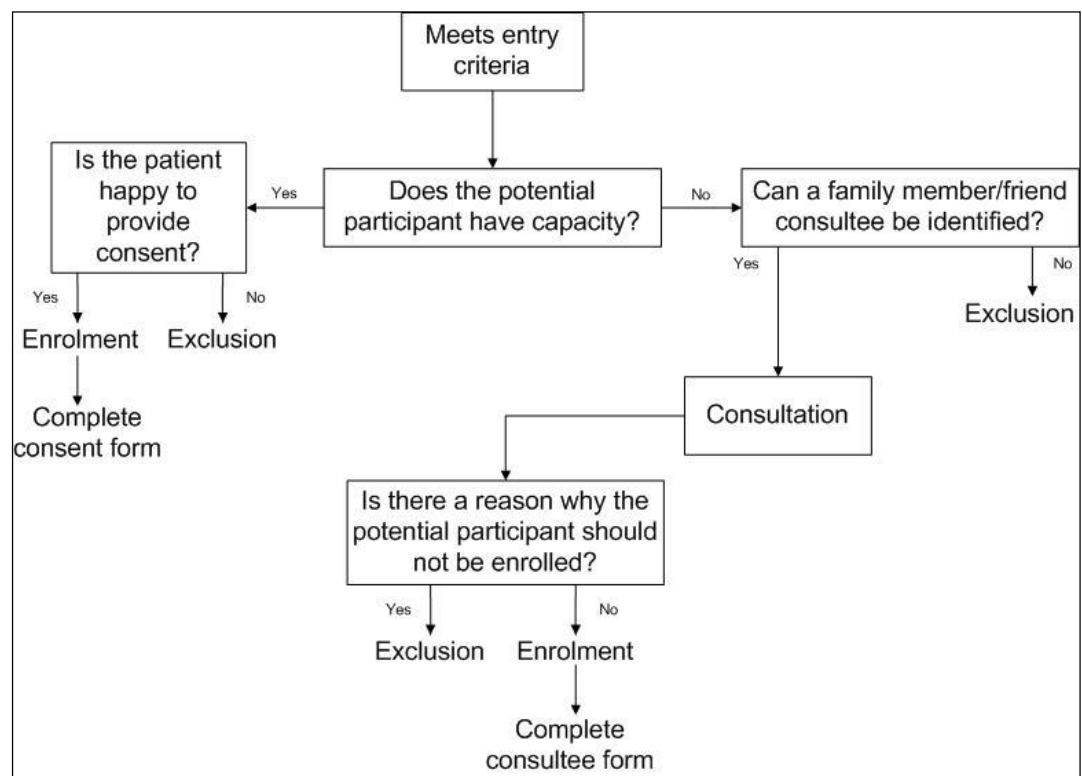
- The availability of an appropriate consultee if the resident does not have the mental capacity to give informed consent under the Mental Capacity Act 2005. If the resident did not have the mental capacity to give informed consent for participation and an appropriate consultee was not available then proceeding with recruitment would not be ethical according to the Mental Capacity Act 2005.

#### ***6.3.4.2 Recruitment process for residents:***

The recruitment process used for this study had been designed to follow well established, published processes in research with people who may lack the mental capacity to consent (Gladman, 2010; Gordon et al., 2014). Following consent, the care workers were asked to identify residents in their care who fulfilled the resident inclusion criteria and who in their opinion might be willing, with their consent or that of their consultee, to be involved in research. The initial approach for inclusion in the study was carried out by the senior care worker who asked the resident whether they were willing to speak to the researcher. On first contact with the resident the researcher determined whether the resident had the mental capacity to give informed consent for participation in the research according to the Mental Capacity Act 2005. This was decided according to the two-stage capacity test form used by the Nottingham University Health trust and under the direct mentorship of a consultant geriatrician. See appendix 10 for the mental capacity assessment form. The opinions of care workers, the care home manager and relatives were also taken into consideration as they had a greater knowledge of the residents' abilities over time.



Due to the selection criteria of having a diagnosis of confusion or (probable) dementia none of the residents asked to participate were determined to have the mental capacity to give fully informed consent. This diagnosis was essential to meet the aims of the study and so fulfilled the requirements of the Mental Capacity Act guidelines for research. An appropriate consultee was sought for all of the prospective participants with dementia. This was the next-of-kin for all residents involved. If an appropriate consultee could not be found, the residents would have been excluded from the study, however, this was not the case for any of the residents involved. See Figure 6 for a diagram of the recruitment process for residents with dementia.



**Figure 6. Enrolment process for care home residents**

Although unable to consent to research involvement themselves, the residents were still approached and informed as much as possible, in the presence of their

consultee, about the purpose and content of the study. An adapted, simplified information sheet was provided for prospective participants with dementia which can be found in appendices 11 and 12. Consultees were asked to consider what would be in the best interests of the resident according to previously expressed views of the resident, advance directives, the likely views and wishes of the resident and currently expressed views. Consultees were given 24 hours to consider whether to give consent. Those who agreed to be involved were asked to sign a consent form, both the consultees and the residents if possible. The consent form is found in appendix 13.

A total of five residents consented to take part in the study. One resident, during the first session of morning care, was found to be too independent to require much assistance from the care worker, and so did not meet the inclusion criteria. One resident passed away suddenly before data collection had commenced. Table 6 presents the demographics of care home residents who were filmed in the study.

**Table 6. Demographics of residents**

<b>Participant no.</b>	<b>Gender</b>	<b>Age (years)</b>	<b>Ethnicity</b>	<b>Diagnosis</b>	<b>MMSE score</b>	<b>Time in present residential care home</b>
1	Female	84	White British	AD	6/30	3 months
2	Female	92	White British	VaD	1/30	6 years
3	Female	85	White British	AD	13/30	6 months

*AD=Alzheimer's Disease, VaD=Vascular Dementia*

As the design of the study utilized the individuality of a case study design it was important to collect personal information describing the individual participants. In addition to the usual demographic information such as gender, age and diagnosis, the researcher also collected information about the residents' lives prior to their diagnosis and were asked general questions about their childhood, working lives, significant life events, family, general character and how they came to be in the care

home. See appendix 14 for resident and care worker profiles. This information was collected by the researcher by direct interview with the residents and their consultee and from care workers. Information on the subtype of dementia was obtained from resident care plans by a senior care worker at the request of the researcher. In previous studies the diagnosis of subtype was found to be an important factor affecting the way in which symptoms were manifested. For example a person with AD would be expected to have more difficulty with word finding than a person with DLB. In addition to this, information about the residents' medication was collected from the senior care worker with the purpose of ensuring that no changes were made to pharmacological treatments over the course of the research. The residents' cognitive function was also assessed by the researcher using the Mini-Mental State Exam (MMSE) (Folstein et al., 1975). This has been used in many other studies as an indication of the severity of the participants' cognitive deficits and is a measure which many clinicians recognise.

#### **6.3.5 Withdrawal**

All participants were made aware that they were allowed to withdraw from the research at any point. This was documented on the information sheet. No participants withdrew their consent once they were enrolled onto the study.

The withdrawal of a resident without the mental capacity to give informed consent followed the process stipulated in the Mental Capacity Act guidelines for researchers. Residents were informed of being filmed at the beginning of each data collection period. If they showed any distress related to the presence of the researcher or the presence of the study equipment data collection would discontinue at that time. No distress was shown by any of the residents as a result of the presence of the researcher or the research equipment during any filmed session.

### 6.3.6 Ethical Considerations

When devising a research project it is important to limit any factors that may leave participants or researchers vulnerable to harm or exploitation. In some circumstances, for research to be of benefit for the populations the research is seeking to help, it is necessary to involve people who are classed as vulnerable, such as people with dementia, or to collect data which is classed as sensitive, such as video data where the participants are identifiable. In these cases the research protocol must be justified and parameters developed to minimise risk to those involved. There are a number of ethical issues that had to be considered when devising the research protocol for this study. These were:

- a) The necessary involvement of participants who may not have the mental capacity to give informed consent
  - According to the Mental Capacity Act 2005 guidelines for researchers, research involving participants without the mental capacity to give informed consent can only be approved if:
    - the research is directly connected with the impairing condition or its treatment,
    - a study of comparable benefit cannot be carried out with people with the mental capacity to give informed consent
    - the research has the potential to benefit the participants without imposing a burden that is disproportionate to the potential benefit to the participant
  - It was necessary to involve people with dementia in this study. If the participants involved did not have dementia, and had the mental

capacity to give informed consent, it would not fulfil the purpose of the research. In addition, past research indicates that the proposed interventions were likely to improve communication between the participants and reduce confusion and frustration. This potential benefit outweighed any possible burden caused by the presence of a video camera or change from their normal routine. To minimise risk to the participants the research protocol followed the stipulated procedure of appointing a consultee who decided on the potential participant's involvement based on the person with dementia's best interests.

b) The use of video data where participants would be identifiable

- Due to the occurrence of non-verbal communication, and its apparent importance in interactions with people with dementia, it was necessary to collect visual as well as auditory data. Other methods of collecting visual data, such as the presence of the researcher in the room, was thought to be more invasive for the participants and less effective in gathering the complex data required for this study.
- In order to minimise the risk to participants only the researchers named on the research protocol were permitted to view the videos unless given permission by the participants or their consultee for use in other contexts.

c) The necessity of filming participants when unclothed

- Due to the necessity of filming the activity of washing and dressing, as stated earlier, and the wish for the activity not to be disturbed by the researcher entering and switching on the video camera, it was necessary to film the whole washing and dressing procedure. This included sections where the participant with dementia was unclothed.
  - In order to minimise the sensitivity of the data, although these sections were filmed, on first watching of the videos the sections where the participants with dementia were unclothed were edited out by the primary researcher and the original videos then deleted so that only the edited videos remained. Participants were informed of this procedure during the recruitment process.
- d) The procedure for identifying when participants with dementia wished to withdraw from the research
- The Mental Capacity Act 2005 states that a person without the mental capacity to give informed consent must be allowed to withdraw from the project if they show any signs of objecting to the research process or if they state they wish to withdraw their participation.
  - In order to identify when the participant without the mental capacity to give informed consent wished to withdraw from the project it was necessary to delineate objection to 'usual care' from objection to the research procedure. This was because it was expected for a person with dementia to sometimes show objection to their care as this was

one element of behaviour that was measured as a clinically significant outcome. A participant's wish for withdrawal from the project was therefore defined as signs of distress or verbal objection when informed of filming at the beginning of each session or signs of distress at, or objection to, the presence of the researcher or video camera at any point in the filming.

Ethical approval for this study was granted by the Institute of Work, Health and Organisations Ethics Committee at the University of Nottingham.

### **6.3.7 Procedure**

The study was a multiple case study design. Interactions between dyads were filmed while completing the morning care routine. The care workers were asked to manipulate their communication according to three conditions: baseline/communication as usual (A), alpha commands (B) and pacing (C). Each dyad served as its own control. The conditions were run in an A<sup>1</sup>BA<sup>2</sup>C design.

### **6.3.8 Justification of experimental design**

A multiple systematic case study design was chosen for this study. This research design is often used in clinical research. Most multiple systematic case studies focus on demonstrating change as the effect of an intervention but they also allow the evaluation of alternative explanations for change. As this experiment is exploratory in nature it was pertinent to have the opportunity to examine other explanations for change, or lack of it, and build these into the design of the experiment. Systematic case studies are described by Barker, Pistrang, and Elliott (2002) as having the following attributes;

- They systematically use quantitative data with multiple assessments of change over time,

- They analyse multiple cases,
- They analyse change in previously chronic or stable problems and,
- They look for immediate or marked effects following the intervention.

These features were believed to improve a researcher's ability to show that an intervention was the cause of any change, increasing the internal validity of the study from that of a single case study. In addition to this, the fact that the study was still in essence a set of case studies helped to preserve the unique variations found in each case and prevented them from being "submerged by the act of averaging across a larger group" (Barker et al., 2002, p. 136). This design was chosen over other research methods for the following reasons:

1. The nature of dementia means that there is large variability in the manifestation of symptoms and severity as well as the presence of other age related disorders. A design where the participants provided their own controls would provide greater reliability than finding a separate control group and attempting to match participants.
2. In line with the mixed-methods approach and the fact that this is an exploratory study it was thought that the inclusion of qualitative process information as well as quantitative measures would shed greater light on the underlying mechanisms of the video data, rather than simply the quantitative measures alone.
3. This methodology also maintains the importance of more than one case and the ability of the researcher to suggest that an intervention could have an effect outside of a single case.



An A<sup>1</sup>BA<sup>2</sup>C design was chosen to ensure that the care workers were able to return to their usual method of communication between the two conditions and to measure any residual effects from the conditions on the care workers or the residents.

### **6.3.9 Filming**

The dyads were filmed using a digital video recorder during the morning care routine. The videoing of these care interactions was crucial in order to capture non-verbal behaviour important in interactions between care workers and people with dementia (Kovach, Noonan, Schlidt, Reynolds, & Wells, 2006). It was also thought that researcher observation, with the researcher present in the room, would be more intrusive for the resident and may cause the care worker to alter their normal care behaviour due to observer bias. The presence of a video-camera was thought to be less intrusive and, as shown in other research studies, was soon forgotten by the participants (Gotell et al., 2009). In addition to this, two of the measures used in analysis involved watching the behaviour of the participants and filling in a tick list of behaviours that were present. In other studies where the researcher was present in the room the recording of behaviour on the tick list took place within the observation time meaning that ten seconds out of every 30 seconds was spent recording rather than observing. Filming the data allowed the researcher to watch, re-watch, pause and slow down the data so that no observation time was lost to the recording of data. The existence of recordings also allowed the researcher to assess inter-observer reliability as another researcher was able to analyse the same footage as the primary researcher.

### **6.3.10 Morning care**

The morning care routine was chosen as the task to observe in these interactions. Before deciding on the situation to film a number of care workers from the interview

study were asked which interactions or tasks were most challenging for care workers. Most care workers stated that the times when most miscommunications took place were in activities of daily living such as bathing, toileting, dressing and transferring. The nursing literature also confirms this (Barrick, Rader, Hoeffler, Sloane, & Biddle, 2008; Beck et al., 1998; Beck, Rossby, & Baldwin, 1991). For reasons of ethics and the sensitive nature of filming, it was thought that bathing and toileting would not be appropriate for this study. The activity of transferring residents from one chair to another often did not take sufficient time to involve the specific behaviours coded in analysis and in addition, some of the residents with more severe dementia were hoisted from chair to wheelchair or toilet which often did not require cooperation from the resident. The morning care routine was thought to be a task which:

1. Included similar elements for most residents,
2. Is repeated every day in a similar way so can be repeated for different conditions,
3. Required interaction, cooperation and the following of instructions by residents so there would be opportunity to observe and measure communicative behaviour,
4. Was often challenging for care workers and residents and therefore had the propensity to be clinically relevant to care workers,
5. Had large proportions of the task that could be filmed without using film that shows the residents unclothed,
6. Often took between 10 and 30 minutes to complete allowing for multiple data collection points.

#### **6.3.11 Data collection procedure**

Before morning care commenced the researcher entered the room with the care worker and reminded the resident of the research and the filming to be taking place that morning. The video camera was then placed in an appropriate position to film both the resident and the care worker during the activity. For dyad one the camera was placed in the washroom, for the other two dyads the camera was placed on a shelf overlooking the bed. The camera was set filming before the researcher left the room. The whole of the care routine was filmed and the camera retrieved at the end of the care routine. Although the washing and dressing sequence was filmed in full the parts of the film where the resident was undressed were edited out before analysis as stipulated in the ethics protocol.

Data collection took place over the course of three months during which a total of 19 morning care routines were filmed; six recordings of each dyad comprising of two recorded pilot sessions, one usual communication (A<sup>1</sup>), one alpha commands (B), another usual communication (A<sup>2</sup>) and one pacing (C). One recording was taken of the participant who was found to be too independent and therefore did not meet the inclusion criteria and was excluded from the experiment. The date and time of data collection were determined by the care workers' shift patterns. Once signed consent forms and demographic information had been gathered the primary researcher conducted two pilot recordings where the care worker was asked to communicate as usual. This allowed the researcher to make decisions about the appropriate positioning of the camera, use of microphones and the frequency of the behaviours that were to be measured and manipulated in the following conditions. In addition to this, these pilot recordings served as an opportunity for the care worker to acclimatise to the presence of the video-camera. Other studies that involve the filming of participants often discard the first ten minutes of filming to overcome observer bias, however, because of the short duration of the task, this was

not possible. Instead, it was proposed that the first baseline condition be repeated on three separate days. This allowed the care worker to become accustomed to the presence of the recording equipment and to give feedback to the researcher.

### **6.3.12 Conditions**

#### ***6.3.12.1 Communication as usual (A)***

In this first condition the care worker was instructed to communicate as usual. The first two were discarded to reduce the probability of including data biased by acclimatisation and observer effect.

#### ***6.3.12.2 Alpha commands (B)***

The motivation for choosing the use of alpha commands as a communication strategy was to demonstrate the effect of care worker language on the comprehension ability of the person with dementia. This adjustment in communication style had been shown to have effects in observational data but had not yet been shown to be effective under experimental conditions. In addition to this, the use of short sentences and clear vocabulary was a feature of effectual communication endorsed by every participant in the interview study.

In this condition the care workers were asked to adjust the way in which they requested cooperation from the resident. In the literature these are called 'commands'. In an observational study Christenson and colleagues (Christenson et al., 2011) found that alpha commands where the request was delivered directly, precisely and simply had the highest rate of compliance and the lowest rates of noncompliance and forced compliance. In contrast, beta commands where the appropriate response for the resident was vague or impossible were found to result in lower rates of compliance and higher levels of noncompliance and forced compliance. In this condition the care workers were trained to increase the number

of alpha commands and decrease beta commands that were found to be less effectual by Christenson et al. (2011) and are commonly used by care workers during care activities.

Following the filming of condition B care workers were asked to return to communication as usual for one session (A<sup>2</sup>).

#### ***6.3.12.3 Pacing (C)***

The motivation for using pacing was to contrast from the first condition in using a strategy that encouraged resident expression. This variable had not been extensively studied in the literature but was a theme in the interview study that many participants advocated. For this condition the care workers were asked to communicate and respond at the same pace as the resident. To achieve this, when an interaction was initiated by the care worker, the care worker was asked to wait either for a response from the resident or for at least five seconds before repeating the sentence or moving on to a new sentence or task. This five second gap has been used in research by Christenson et al. to determine the difference between non-compliance and forced-compliance and was thought to be an appropriate interval within which a person with dementia can devise and begin to respond.

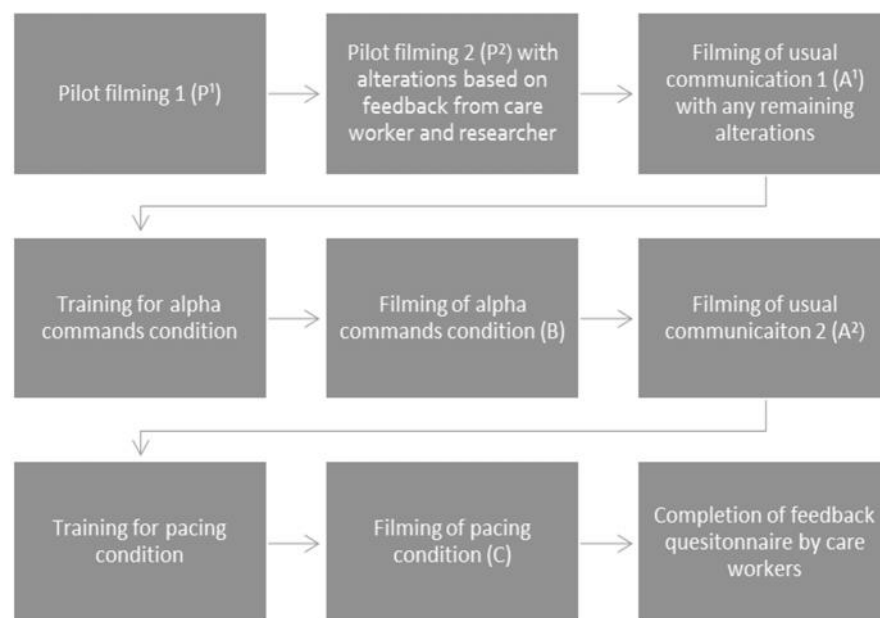
#### ***6.3.12.4 Staff training***

The training materials were designed to be administered to one trainee at a time as the different dyads were often at different points in the process. The care workers were asked not to discuss the content of the conditions with each other in order to maintain care worker blindness and to reduce bias. Training consisted of a short presentation by the researcher informing the care worker of the strategy to be employed, though not revealing results found in previous research. The care worker was given the opportunity to practice this strategy through a series of exercises

involving role play and a question and answer session. The materials used in the care worker training can be found in appendix 15. The care workers were given feedback on their performance in the exercises and the opportunity to ask questions. Each training session lasted approximately 20 minutes. The training for conditions B and C took place on separate occasions as can be seen in Figure 7.

#### **6.3.12.5 Care worker feedback**

On completion of the filming the care workers were given a short questionnaire asking care workers for demographic information such as age, gender and number of years' experience. They were also asked whether they thought they communicated as instructed in the training sessions and whether they thought the resident behaved differently in the different conditions. The post-intervention feedback form for care workers can be found in appendix 16. This contributed to the discussion and evaluation of the experiment.



**Figure 7. Filming process for each dyad**

#### **6.3.13 Analysis**

Four videos from each dyad were analysed. The first two videos from each dyad were discarded to allow for acclimatisation and to avoid analysing data that could contain observer bias. The videos were first edited to remove any content in which the residents were not clothed or any times at which the care worker was not in the room. The edited videos were then analysed quantitatively using the ELAN 4.6.1 software programme. This computer programme allows the researcher to make complex annotations on video or audio data. Using this programme the researcher was able to accurately analyse the frequency and duration of certain behaviours by slowing and speeding up video and audio as well as rewinding and replaying selected sections of the data. See appendix 17 for researcher's guidelines for the analysis process and see appendix 18 for a screen shot of the ELAN video analysis tool. Each video was analysed individually with all measures administered to each video before analysing the next. As the analysis progressed through the videos some operational definitions were adjusted and sections were revisited and recoded as operational definitions were tightened and understanding of the data increased.

It was not possible to blind the researcher to the condition being analysed as the principal investigator collected and edited the data and so was able to identify which video was from which condition even if the order of the videos were randomised. However, analysis of one dyad's data only began after all of the videos from that dyad had been collected. This was to prevent the investigator from giving feedback to the care worker that may affect the way in which they administered the next intervention.

When videos were transferred onto the ELAN programme all dialogue between the care worker and the resident was first transcribed. This script and the video data were then coded using the following measures and operational definitions.

### **6.3.14 Measures and operational definitions**

The independent variables were:

- Command subtype
- Pacing

The dependent variables were:

- Positive resident behaviour
- Negative resident behaviour
- Compliance to instructions

I will now describe the rationale and the measurement for each.

#### ***6.3.14.1 Measuring Independent Variables***

The frequency of alpha and beta commands and the extent to which care workers interacted at the same pace as the residents were measured to determine the extent to which care workers administered the conditions according to their training.

##### **6.3.14.1.1 Command Type**

Command type and subtype was coded according to the coding scheme and operational definitions devised by Christenson et al. (2011), see Figure 8. Firstly a command was defined as:

A verbal request stated by the care worker in the hearing of the resident which requires, or could be interpreted as requiring, a response by the resident.

All commands issued by the care workers in the videos were then coded according to nine types; interview, question, regular, indirect, exclusionary, collaborative, compound, sequence and contextual. During the first two videos it was noted by the researcher that there was another type of command not accounted for in Christenson et al.'s coding scheme. Another command type, conditional commands, was added to refer to instructions where the care worker uses terms such as 'if' or



'when' to instruct the resident. For example "If you sit down I can take your shoes off for you" or "When you've finished I'll carry on". This type of command was given a number of times by different care workers and was not accommodated in the original coding scheme. As well as the different command types, care workers' commands were also coded into command subtype, either alpha or beta.

Alpha commands were defined as: A command in which a motoric or verbal response is appropriate and feasible.

Beta commands were defined as: A command in which compliance may be difficult due to vagueness, indirectness, interruption, or carried out by the care worker within five seconds of issuing the command.

Each command type could have alpha or beta subtypes, with the exception of indirect commands which by definition are beta commands as they required the recipient of the command to infer what response was expected.

During the coding process some of the operational definitions were tightened so that some of the more borderline commands could be systematically allocated to one of the command types. See the Figure 8 for definitions and examples of each command type. Alterations that have been made to the original coding scheme as set out by Christenson et al. (2011) have been written in italics.

1. **Conditional commands:** Commands phrased so that the care worker will do an action or task if the resident does a certain action or task:
  - A example: "If you sit down I can take your shoes off for you." "If you lift your arm up I'll wash underneath."
  - B example: "If you could just move." "When you stop I'll carry on."
2. **Interview Commands:** Questions that require the resident to answer verbally. Also commands that end in a question e.g. "Okay?" or "Isn't it?" Whether these are alpha or beta depends on the specificity of the preceding instruction.
  - A example: "What is your name?" "How are you feeling?"
  - B example: "What's going on?" "What?" "Okay?" When terms such as "Alright?" occur in isolation these are coded as interview beta.
3. **Question Commands:** Questions that require a non-verbal response even though a verbal response is possible but not appropriate.
  - A example: "Would you step out of the shower?" "Can you lift your feet up?"
  - B example: "Can you please move?" "Could you help me?" "Why don't you sit down?"
4. **Regular Commands:** Instructions that are stated directly (not in question form).
  - A example: "Sit down." "Stand up." "Move your body forward." "Put your hands up."
  - B example: "Get back." "Move." "Stay there." "Come here." "Wait."
5. **Indirect B Commands:** Suggestions that leave the resident to guess what response might be needed. Not in question form.
  - Example: "Here." "There's your glasses." "Calm down." "Let me rinse you." "Take your time."
6. **Exclusionary Commands:** Instructions to stop some form of behaviour.
  - A example: "Don't sit down." "Stop hitting." "No biting."
  - B example: "Don't do that." "Just stop." "Knock it off." "No."
7. **Collaborative Commands:** Instructions that require cooperation and begin with or include words in the third person referring to the carer and the resident. Collaborative A commands are instructions where the carer and the resident could both do the activity. B commands are instructions that the resident and care worker cannot do the activity together.
  - A example: "We're going to the bathroom." "Let's go for a walk."
  - B example: "We're going to sit in this chair." "How about we have a bath?" "Let's go and take a nap."
8. **Compound Commands:** Two or more different commands given in one statement (within 5 seconds of each other with no response from the resident). Compound A end with an A command and compound B end with a B command.
  - A example: "I need you to sit back and I need you to lift your leg up so I can wash your legs and your feet." "Put your elbows in, hold on here and lift your feet up."
  - B example: "We're going to sit down and take your shoes off, ok?"
9. **Sequence Commands:** Rapid repetition of the same command in one statement.
  - A example: "Wash your face, you've got to wash your face." "Lift your feet up, lift your feet up."
  - B example: "Give me that, give me that." "Wait, wait, wait."
10. **Contextual Command:** A command that clarifies or restates the previous command of the care worker or the resident's response. Alone this command would be a B command but in the context of the previous command it can be either A or B.
  - A example: "Here, under your arm" "Over there, in the blue chair." Or an exact repetition of the resident's response e.g. Care worker: "Where would you like to sit?" Resident: "Lounge chair." Care worker: "Lounge chair."
  - B example: "Here." "Over there." (Not specifying where)

If a B command is accompanied by a gesture such as a point or wave which makes the command more specific then it is considered an A command rather than a B command.

Commands that are interrupted by the resident are not coded as commands.

Figure 8. Coding scheme for command types, adapted from Christenson et al. (2011)

#### **6.3.14.1.2 Pacing**

In order to measure the extent to which the interaction moved at the same pace as the resident the time between the end of a care worker command and either the resident's response or the initiation of a new action was measured. This was possible using the ELAN software programme. To the knowledge of the researcher this has not been done in previous research. The aim was to measure the amount of time that the care workers allowed for a response from the resident before continuing with the task.

By measuring command subtypes and the extent of pacing in all of the conditions it was possible to determine whether conditions B and C were significantly different from communication as usual and therefore whether any change in the dependent variables was due to the independent variables.

#### ***6.3.14.2 Measuring dependent variables***

When selecting instruments to measure the dependent variables a number of factors were considered. The characteristics of the measures required were as follows:

- Disease specific, as dementia hinders many of the aspects usually considered in such measures. For a scale to be sensitive enough to change it must be devised for people with dementia
- Measure communicative behaviour, not only verbal but nonverbal
- Measure minute actions rather than composite actions
- Able to capture immediate change
- Used in previous research
- Not reliant on retrospective care worker reports

When choosing measures the definition of measuring communicative behaviour was extended to include measures of quality of life and wellbeing. The reason for this

was that quality of life and well-being measures often include components that measure interaction as an indication of quality of life or wellbeing. However, it was also appreciated that not all communication indicates a positive experience by the person with dementia. The decision was made to use two measures, one that would measure positive interaction and another that would measure negative interaction. This was so that communication scores would not be artificially inflated by aggressive or distressed interaction.

#### **6.3.14.2.1 Positive Response Schedule**

The positive Response Schedule (PRS) was devised by Perrin (Perrin, 1997). It built on the work of Dementia Care Mapping (DCM) (Bradford Dementia Group, 1997; T. Kitwood & Bredin, 1994) and Gaebler and Hemsley (1991) who assessed the affect of people with severe dementia. Both sought to ascertain the wellbeing of people with dementia through the intense observation and coding of their behaviour. However, Perrin wished to devise an instrument that could measure the effect of interventions delivered over a short period of time, such as 20 minutes, and for a population with severe dementia who were not able to perform the composite behaviours measured in DCM. Composite behaviours are behaviours that are a combination of smaller components (Perrin, 1997). Perrin instead chose to measure those component micro-behaviours e.g. a gesture, a smile or a nod, which still remain when the ability to perform composite abilities is reduced. Based on Gaebler and Hemsley's instrument she modified and added some behaviours, such as 'vocalisation' and 'looks at carer', and expanded the descriptive criteria of all categories. The PRS measures the frequency of the following ten behaviours: deliberate body movement, deliberate head movement, vocalisation, looks at environment, looks at carer, initiates interaction, engagement, happy, sad and fear. The presence or absence of these behaviours would be indicated in each 20 second time frame. A summary of

the data for each session could be achieved by summing the total number of points in the session and dividing by the total number of possible points. This number could then be multiplied by 100 to give a percentage of positive response out of possible response score. This summary score could be used in a chi-squared test of significance.

The purpose of using this instrument was to measure the positive interactional behaviour of the residents and to have another measure for negative interactional behaviour. It was therefore not necessary to include all the behaviours here proposed by Perrin as some, such as an intentional leg movement could actually involve negative interactional behaviour such as a kick. Furthermore, this measure was first devised for use with individuals with very severe dementia and therefore micro-behaviours such as the deliberate movement of the head or body were viewed as important components indicating quality of life. The participants in this study were not at the very severe stage of dementia but were in the mid-range where deliberate movement and vocalisation were frequent occurrences and the presence of these did not necessarily indicate positive interaction. Therefore, the instrument was amended for the purpose of this study so that only behaviours that pertained to positive, intentional interaction were used. These were: looks at carer, initiates interaction and engagement. The operational definitions were as follows, again, instructions in italics have been added by the author to clarify the criteria:

Looks at carer: Any deliberate turning and/or following of the carer. Only record in this category for carers engaged in personal intervention with the client. Example: a carer calls the client's name and the client's eyes move to meet the carer's. (Looking at carer's not involved in a personal interaction should not be recorded). *When the care worker is close to the resident only attempts for the resident to look at the care*

*worker's face should be coded. The resident watching the care worker's hands should not be coded.*

Initiates Interaction: Any attempt to initiate interaction or obtain attention by either vocal or non-vocal means; that is, by facial, bodily or vocal gestures to another. Example: a client reaches a hand towards a nurse, stammering out a repeated syllable; a client goes to pat the hand of another who appears upset.

Engagement: Any absorbed commitment (passive or active) to *the same activity as the care worker*. Example: singing; following the movements of a hand massage; participating in exercise; having an extended conversation. *Only applies to times when the resident is following the same activity as the care worker e.g. the resident may be engaged in the activity of taking her quilt cover off of the quilt, however, this is not engagement with the care worker who is wishing to help the resident to get dressed. Therefore it should not be coded.*

#### ***6.3.14.2.1.1 Rationale for employing the PRS***

The only instruments found in the literature that measured communicative or interactive behaviour in people with dementia were subscales of quality of life or wellbeing instruments. An amended version of the PRS was chosen as a measure of interactive behaviour as, unlike other instruments, this instrument measured the occurrence of the micro-behaviours still present in severe dementia after the ability to perform the composite behaviours observed in Dementia Care Mapping have been lost. The PRS was also able to capture data in a short space of time (a few minutes) and did not depend on an intervention lasting over an extended period (a few hours, days or months). The PRS was also one of the few measures that did not rely on caregiver report, a method often questioned in the literature (Ettema, Droes, de Lange, Mellenbergh, & Ribbe, 2005). This measure was the only observational

instrument suitable for people with severe dementia and employable to determine the immediate effects of a short intervention.

The inter-observer reliability of the PRS was demonstrated, both by Perrin herself where she obtained inter-observer agreement average of 80%, which is acceptable according Kazdin (2003), and then later by Hadley, Brown, and Smith (1999) who achieved agreement of 99%, however they calculated these percentages in different ways with Perrin using the more conservative test. Criterion validity is impossible to establish as there are no similar instruments found in the literature. However, it can be argued that the face validity of this instrument is high as it is so closely linked with the phenomena it is concerned with (Perrin, 1997).

#### **6.3.14.2.2 RTC-DAT scale**

The Resistiveness to Care Scale (RTC-DAT) was first developed by Mahoney et al. (1999) with an article that described the development, reliability testing and refinement of the instrument. The aim was to develop an observational instrument that would measure resistiveness as a stand-alone concept and not under the general category of “disruptive behaviours” as is often the case in behavioural inventories. They devised an observational instrument that recorded 13 items of resistive behaviour. These were: gegenhalten (which refers to body movements which are of equal force but in the opposite direction from those of the caregiver), grab object, say no, adduct (which refers to clenching the limbs next to the body), grab person, pull away, clench, cry, scream, turn away, push away, hit/kick and threaten. Each occurrence of resistive behaviour was also rated by duration and intensity. Duration was measured on a five-point scale: 0 (absent), 1(<16 seconds), 2 (16-59 seconds), 3 (1-2 minutes), or 4 (>2 minutes). Intensity was measured on a three-point scale: 1 (mild), 2 (moderate), or 3 (extreme). The writers claim that the

interaction of duration and intensity showed the severity of resistiveness, therefore the duration and intensity scores were multiplied. All scores could then be summed to give a total score for the interaction. As the interactions were all of different lengths the RTC-DAT scores were also submitted to the same formula used for the amended PRS scores resulting in a percentage of RTC-DAT behaviour of the highest possible score.

#### *6.3.14.2.2.1 Rationale for employing the RTC-DAT*

The RTC-DAT was used to measure the negative communicative behaviour of the resident. On a search of the literature it was clear that most other instruments, such as the Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield, 1986), rely on the caregiver to remember and record instances of agitated behaviour whereas it was found that care givers often forgot instances of aggressive behaviour that they can rationalise (Mahoney et al., 1999). It was therefore important to use an instrument that could be used by an impartial observer. In addition to this, the window in which the aggressive behaviour is observed by these inventories is often over the course of hours, days and weeks whereas the instrument required for this study had to be sensitive enough to credit behaviours that take place within a few minutes. Also, to the author's knowledge, the RTC-DAT was the only measure that would measure resistance to care in isolation from agitation, a phenomenon which could take place without the presence of the care worker and therefore could not necessarily be described as communicative behaviour. The RTC-DAT was also the instrument used most regularly in similar research studies (Cunningham & Williams, 2007; Herman & Williams, 2009; Williams & Herman, 2011) and had the most information on validity and reliability.



In the original instrument development article Mahoney et al. assessed the reliability and validity of the RTC-DAT. Studies who have used the instrument have since added to this evidence. They established inter-observer reliability at 95% and demonstrated internal consistency in two dementia populations (Cronbach's alphas .82-.87) (Mahoney et al., 1999; Williams & Herman, 2011). Construct validity was established using principle components factor analysis, resulting in a 3-factor solution that explained 52.3% of the variance. Content validity is reported at 1.0 ( $p < 0.5$ ) and a significant positive correlation with the Discomfort Scale for Dementia (Hurley, Volicier, Hanrahan, Houde, & Volicier, 1992) provided evidence for the criterion-related validity of the RTC-DAT (Williams and Herman 2011).

#### **6.3.14.2.3 Compliance**

It was also decided to measure resident compliance to care worker instructions. Although compliance is a separate construct from communication, compliance entails a level of understanding only achieved through communication. Compliance was measured in Christenson et al.'s study. It was thought that measuring compliance, non-compliance and forced compliance would yield results which could be compared to past research. The definitions were taken from Christenson et al's study and were based on those used before them by McMahon and Forehand (2003):

Compliance: An appropriate behaviour initiated within five seconds following a command that terminated with the completion of the assigned task.

Noncompliance: The failure to initiate an appropriate response within five seconds following a command issued by the care worker.

Forced compliance: When the requested response is completed by the care worker, instead of the resident, within five seconds of the command.

Every command issued by the care workers were coded with a response of compliance, noncompliance or forced compliance.

#### **6.3.15 Validation**

In the words of Cone (1988) behavioural research rests on a foundation of accurate measurement. As data collection and analysis were completed by the same researcher it was important to demonstrate the reliability of the coding and analysis process. In order to show this a representative sample of the videos were coded by another researcher to enable the calculation of inter-observer agreement.

The primary researcher compiled an edited video consisting of a representative sample of 25% of the overall video data. As the videos were of varying length this was achieved by calculating the minutes and seconds required from each video then randomly selecting the start time of the selection in each video. This prevented the same part of the activity from featuring in each segment. These segments were then edited together and entered into the ELAN video analysis programme for the second observer. The second observer was blind to the aims of the research and the conditions and was only told that the research was concerned with interactions between care workers and people with dementia.

Training for the coding was carried out by the primary researcher and involved the joint analysis of a segment from the initial pilot videos discarded from the main analysis. The coding of command types and subtypes, the amended PRS, compliance and the RTC-DAT were discussed and coded by the second researcher in the presence of the primary researcher. When disagreements arose these were discussed so that the decision process of the first researcher was understood by the second researcher. The second researcher was then left to code the sample video

alone with the set of instructions used in the training session for reference. See appendix 17 for these instructions.

When choosing the way in which to assess inter-observer agreement there were a number of different calculations that could have been used. The Kappa coefficient was chosen for use in this study as, in contrast to calculating the percent of agreement, it takes into account the number of agreements that could occur by chance. Watkins and Pacheco (2000) note the way in which percentage agreement statistics artificially inflate the degree of perceived observer agreement. The more conservative of the tests was chosen for use in this study.

#### **6.3.16 Considerations for method of analysis**

There are many methods for analysing the data of small case number experimental studies. It is important when selecting analysis methods to first consider the questions that are being answered by the data. The research questions were:

1. Can care workers be trained to modify their communication style?
  - a. Did care workers increase the number of alpha commands after the alpha commands training?
  - b. Did care workers slow the pace of their instructions after the pacing training?
2. Is there an effect of care worker communication style on the communicative behaviour of care home residents with dementia?
  - a. Are there significant differences in amended PRS scores after care worker training?
  - b. Are there significant differences in RTC-DAT scores after care worker training?

- c. Are there significant differences in levels of compliance to alpha commands and beta commands?
- 3. Can the effects observed within dyads be observed across dyads?
  - a. Is there any correlation between proportion of alpha commands and amended PRS score?
  - b. Is there any correlation between proportion of alpha commands and RTC-DAT score?
  - c. Is there any correlation between proportion of alpha commands and compliance?
  - d. Is there any correlation between pacing and amended PRS scores?
  - e. Is there any correlation between pacing and RTC-DAT scores?
  - f. Is there any correlation between pacing and compliance?
- 4. Are there differences in resident behaviour across different command types?
- 5. Are care workers aware of their communication style and the effect it has on residents?
  - a. Did the care workers perceive any changes in their communication?
  - b. Did the care worker perceive any changes in the behaviour of the residents?

Questions 1 and 2 will be addressed by analysing each dyad independent of the other dyads. Questions 3 and 4 these will be addressed by analysing data from all dyads. Question 5 will be addressed by comparing the responses on the care worker feedback forms to the results of the statistical analysis.

**1. Can care workers be trained to modify their communication style?**

- a) **Did care workers increase the number of alpha commands after the alpha commands training?**

Question 1a was best answered by comparing differences in alpha command percentages in condition A<sup>1</sup> to those in condition B, A<sup>2</sup> and C which took place after alpha command training. In order to answer the question it was important to know whether any differences in alpha command usage between the conditions could be accounted for by chance. The percentage of alpha commands, rather than frequency counts, was used in this statistic because the conditions were of different lengths and therefore the frequency counts did not portray the proportion of alpha to beta commands used in each condition. As the variable of condition was categorical a one-variable  $\chi^2$  test was used to analyse any differences between the percentages of alpha commands in different conditions. The hypothesis was that there would be a significant difference between the percentage of alpha commands used in the baseline conditions and those following the training.

**b) Did care workers slow the pace of their instructions after the pacing training?**

The extent to which the care workers employed the pacing techniques taught in the pacing training were ascertained in two ways. If the technique of allowing more time for the resident to respond to a command had been employed, two outcomes could be expected. Firstly, that the proportion of commands where the resident responded first would increase. Secondly, the time allowed by the care worker for a response from the resident before they themselves continued with the task would increase. Therefore, question 1b was answered firstly by comparing the proportion of commands responded to by the resident before and after the pacing training. Secondly, by comparing the mean amount of time, or the mean time lapse, left by care workers between a command and the care worker continuing with the task. The hypothesis was that a significantly higher proportion of commands would be responded to by the resident in condition C when compared to conditions A<sup>1</sup>, B and

A<sup>2</sup>. The other hypothesis was that the time lapse between the end of a command and the care worker continuing with a task would be significantly longer in condition C when compared to conditions A<sup>1</sup>, B and A<sup>2</sup>. To test the first of these hypotheses one-variable  $\chi^2$  tests were performed to assess any differences in the percentages of commands responded to first by the residents or by the care workers. To test the second of these hypotheses the time lapses of the commands where the care worker responded first were subjected to an ANOVA to assess differences in time lapse between conditions. As there were different numbers of commands of this type in each condition the non-parametric Friedman's ANOVA was used.

## **2. Is there an effect of care worker communication style on the communicative behaviour of care home residents with dementia?**

### **a) Are there significant differences in amended PRS scores after care worker training?**

Question two was addressed by comparing the amended PRS summary scores across the four conditions. The amended PRS summary scores of the four conditions were entered into a one-variable  $\chi^2$  test to see if differences in scores were significantly different to those expected by chance. The hypothesis was that there would be a significant increase in amended PRS scores in the conditions after the two training sessions in conditions B and C.

### **b) Are there significant differences in RTC-DAT scores after care worker training?**

A one-variable  $\chi^2$  test was performed using the RTC-DAT summary scores. The hypothesis was that there would be a significant decrease in RTC-DAT scores in the conditions after the two training sessions. Bar charts were constructed to show the

changes in percentages of alpha commands, amended PRS scores and RTC-DAT scores across the different conditions.

**c) Are there significant differences in levels of compliance to alpha commands and beta commands?**

As there was an assessment of compliance for each command the question of whether compliance significantly differed across the command subtypes of alpha and beta was answered using a  $2 \times 3 \chi^2$  test. The hypothesis was that there would be significantly greater levels of compliance to alpha commands compared to beta commands.

**3. Can the effects observed within dyads be observed across dyads?**

Question three was addressed by using the summary data from each condition to answer questions of correlation between variables. For these questions each condition formed one data point to provide a total of 12 data points for analysis. A scatter plot for each sub-question was constructed and then Spearman's rho calculations were conducted to determine the direction and strength of any associations. The hypothesis was that there would be:

- a) a positive correlation between percentage of alpha commands and amended PRS summary scores,
- b) a negative correlation between percentage of alpha commands and RTC-DAT summary scores,
- c) a positive correlation between percentage of alpha commands and levels of compliance
- d) a positive correlation between mean time lapse and amended PRS summary scores

- e) a negative correlation between mean time lapse and RTC-DAT summary scores
- f) a positive correlation between mean time lapse and levels of compliance.

#### **4. Are there differences in resident behaviour across different command types?**

Question four was addressed by examining the frequencies of different command types and comparing the levels of compliance, non-compliance and forced-compliance resulting from each command type over the course of the whole study. Summary statistics were presented in the form of a bar chart. Due to the small frequencies of some of the command types more complex statistical analysis was not appropriate.

#### **5. Are care workers aware of their communication style and the effect it has on residents?**

- a) Did the care workers perceive any changes in their communication?
- b) Did the care workers perceive any changes in the behaviour of the residents?

Question five will be addressed by summarising the answers to the care worker feedback questionnaire and comparing these answers to the statistical results.

#### ***6.3.16.1 Reasons for not using visual analysis***

When deciding the methods by which to analyse the quantitative section of this project it was important to consider methods of analysis other than those used. Visual analysis methods are often used in single case design research. This often consists of the construction of graphs showing the distribution of data over time with the aim that any differences in responses due to conditions should be immediately obvious to the person viewing the graphs. However, there has been some dispute over the objectivity of such methods (Cohen, Feinstein, Masuda, & Vowles, 2013).



Visual analysis is most suited to studies which possess certain characteristics which include; studies which seek to determine a trend in the dependent variable over time, studies that employ a dependent variable that shows stability across data collection points, and studies where data collection occurs at consistent points across conditions. This experiment was ill suited to visual analysis as the change in the dependent variable of resident behaviour was expected to take place instantly on employment of the communication strategies. Therefore the analysis methods needed to show a meaningful instant change rather than a trend. In addition to this, the dependent variable measured micro-behaviours that depict responses to the smallest of events and therefore an average over a length of time was a better depiction of response than depicting the score of each 20 second interval on a line graph as in visual analysis. Finally, data collection for the different conditions took place on different days. Although data collection on different days is often the case in time-series research this would require the data collection points themselves to be days apart rather than seconds apart. Depicting results on a line graph for the comparison of the four conditions would be deceptive for the reader as the time axis would not be continuous as is usually the case in time-series research. As the data did not fulfil the assumptions of time-series analysis, statistical analysis was better suited for analysing and describing the data according to the research questions.

#### ***6.3.16.2 Reasons for using non-parametric tests***

Non-parametric tests were used throughout data analysis as they make no assumptions about the data. There were many ways in which the data from this experiment violated the assumptions of parametric tests. Firstly, most of the measures operated on the nominal level, such as command type and compliance, or the ordinal level, such as the RTC-DAT or the amended PRS and therefore the assumption of a normally distributed sample could not be met. In addition, there

were often unequal amounts of data in each condition due to each video lasting different lengths of time. Analysis across dyads employed non-parametric tests due to the small sample size being analysed.

## 6.4 Results

### 6.4.1 Dyad 1

#### 6.4.1.1 Question 1: *Has care worker communication style been modified?*

##### 6.4.1.1.1 Question 1a

Table 7 presents the frequencies and percentages of the different command subtypes in each of the four conditions. The frequencies indicate a greater proportion of alpha commands used following the alpha command training between conditions A<sup>1</sup> and B. It can be seen that the alpha commands condition has more alpha commands than the usual conditions but the pacing condition is even richer in alpha commands than the other conditions.

**Table 7. The frequencies and percentages of command subtypes for dyad 1**

Condition	No. of alpha commands	No. of beta commands	Percentage of alpha commands
Usual 1	22	17	56.41
Alpha commands	23	7	76.67
Usual 2	10	5	66.67
Pacing	39	7	84.78

A  $\chi^2$  test of difference was performed to examine the relation between condition and percentages of alpha commands in dyad 1. The relation between these variables was approaching significance,  $\chi^2 (3, N = 285) = 6.64, p = 0.084$ . With the probability score approaching significance it can be concluded that there are differences

between the percentages but any conclusions must be drawn with the caveat that the differences may be due to chance.

#### 6.4.1.1.2 Question 1b

Table 8 shows the percentage of commands responded to by the resident, those responded to by the care worker and the mean time lapse between the end of the commands and care worker responses. From the frequencies the percentage of commands where the resident responds first appear to be greater in the pacing condition than the other conditions and the mean time lapse before the care worker continues with the task appears to be longer in the pacing condition than the other conditions.

**Table 8. The respondents and time lapse following each command in dyad 1**

<b>Condition</b>	<b>No. Resident responses</b>	<b>No. Carer responses</b>	<b>% resident responses</b>	<b>Mean TL for all (secs)</b>	<b>Mean TL for carer responses (secs)</b>
Usual 1	31	8	79.49	0.65	1.15
Alpha commands	25	5	83.33	0.64	0.97
Usual 2	11	4	73.33	1.26	2.12
Pacing	42	46	91.30	0.75	3.63

A  $\chi^2$  test of difference was performed to examine the relation between condition and percentages of commands to which the resident responded first in dyad 1. The relation between these variables was non significant,  $\chi^2 (3, N = 326) = 2.1, p > 0.05$ . There is a high possibility that any differences between the conditions are due to chance.

A Friedman's ANOVA was performed to determine whether there were significant differences between the observed time lapses before the care worker responded and those expected by chance. The relation between these variables was found to be

insignificant  $\chi^2 (3, N = 15) = 0.91, p > 0.05$ . There is a high probability that any differences between the conditions are due to chance.

#### **6.4.1.2 Question 2: Is there an effect of care worker communication style on resident behaviour?**

##### **6.4.1.2.1 Question 2a**

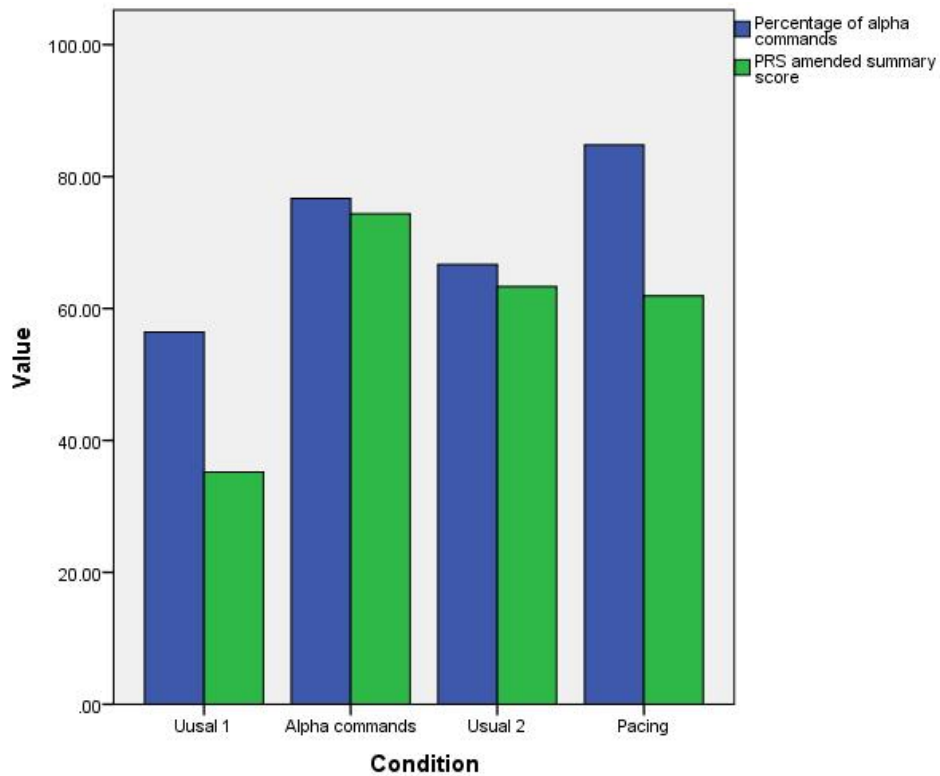
Table 9 shows the amended PRS summary scores in each condition. From the frequencies it can be seen that amended PRS scores are greater in the conditions after the alpha command training.

**Table 9. Amended PRS summary scores for each condition in dyad 1**

Condition	Amended PRS summary score
Usual 1	35.19
Alpha commands	74.36
Usual 2	63.33
Pacing	61.90

A  $\chi^2$  test of difference was performed to examine the relation between condition and amended PRS summary scores in dyad 1. The relation between these variables was significant,  $\chi^2 (3, N = 234) = 14.1, p < 0.01$ . The resident was more likely to show positive communicative behaviour in the conditions following alpha commands training.

Figure 9 shows the amended PRS summary scores and the percentage of alpha commands given in each condition in dyad 1. The amended PRS summary scores are seen to increase with the increase of alpha commands after the first usual condition.



**Figure 9.** Bar chart representing the percentage of alpha commands and amended PRS summary scores for dyad 1

#### 6.4.1.2.2 Question 2b

Resistive behaviour was rarely exhibited in this dyad. The resident only displayed two mild instances of resistive behaviour, once in the first usual condition and once in the pacing condition. There was too little resistive behaviour displayed by the resident in this dyad to make statistical analysis viable.

#### 6.4.1.2.3 Question 2c

Table 10 shows the rates of compliance, non-compliance and forced compliance across alpha and beta command subtypes. As can be seen from the frequencies in the table, the majority of beta commands resulted in non-compliance or forced-compliance and the majority of commands resulting in compliance were of the alpha type.

**Table 10. Resident's levels of compliance to alpha and beta command types in dyad 1**

		Compliance			Total
		Compliance	Non-compliance	Forced-compliance	
Command subtype	Alpha	56	76	0	132
	Beta	13	24	33	70
Total		69	100	33	202

A 2x3  $\chi^2$  test of difference was performed to examine the relation between command subtype and compliance in dyad 1. The relation between these variables was significant,  $\chi^2 (2, N = 202) = 74.86, p < 0.001$ . Cramer's V was found to be 0.61. Therefore over 37% of the variation in compliance can be explained by the command subtype used. It can be concluded that the resident was significantly more likely to comply with alpha commands and that beta commands were significantly more likely to lead to non-compliance or forced-compliance.

#### **6.4.1.2.4 Questions 2d and e**

As the measures for pacing were not found to be significantly different between the conditions, either in the proportion of commands responded to first by the resident or the time lapse left by the care worker before proceeding with the task, statistical analyses of this data was not thought to be appropriate.

### **6.4.2 Dyad 2**

#### **6.4.2.1 Question 1: Has care worker communication style been modified?**

##### **6.4.2.1.1 Question 1a**

Table 11 presents the number and percentages of the different command subtypes in each of the four conditions in dyad 2. The frequencies indicate a greater proportion of alpha commands used following the alpha command training after the first usual condition. It can be seen that the alpha commands condition has more

alpha commands than the usual conditions but the pacing condition is even richer in alpha commands than the other conditions.

**Table 11. The frequencies and percentages of command subtypes for dyad 2**

Condition	No. of alpha commands	No. of beta commands	Percentage of alpha commands
Usual 1	23	27	46.00
Alpha commands	12	5	70.59
Usual 2	10	21	32.26
Pacing	20	5	80.00

A  $\chi^2$  test of difference was performed to examine the relation between condition and percentages of alpha commands in dyad 1. The relation between these variables was significant,  $\chi^2 (3, N = 229) = 25.7, p < 0.01$ . The care worker used a significantly greater proportion of alpha commands in the alpha commands condition and the pacing condition.

#### 6.4.2.1.2 Question 1b

Table 12 shows the percentage of commands responded to by the resident, those responded to by the care worker and the mean time lapse between the end of the commands and the care worker responses in dyad 2. From the frequencies the percentage of commands where the resident responds first appear to be greater in the pacing condition than the other conditions but the mean time lapse before the care worker continues with the task appears to be shorter in the pacing condition than the other conditions.

**Table 12. The respondents and time lapse following each command in dyad 2**

Condition	No. resident responses	No. Carer responses	% resident responses	Mean TL for all	Mean TL for carer responses
Usual 1	35	15	70.00	0.11	0.06
Alpha commands	12	5	70.59	0.43	0.6
Usual 2	19	12	61.29	0.34	-0.01
Pacing	22	3	88.00	-0.03	-0.67

A  $\chi^2$  test of difference was performed to examine the relation between condition and percentages of commands to which the resident responded first in dyad 2. The relation between these variables was insignificant,  $\chi^2 (3, N = 290) = 5.26, p > 0.05$ . There is a high possibility that any differences between the conditions are due to chance.

A Friedman's ANOVA was performed to determine whether there were significant differences between the observed time lapses before the care worker responded and those expected by chance. The relation between these variables was found to be insignificant  $\chi^2 (3, N = 3) = 1, p > 0.05$ . There is a high probability that any differences in time lapse between the conditions are due to chance.

#### **6.4.2.2 Question 2: Is there an effect of care worker communication style on resident behaviour?**

##### **6.4.2.2.1 Question 2a**

Table 13 shows the amended PRS summary scores in each condition for dyad 2. From the frequencies it can be seen that amended PRS scores are greater in the conditions after the alpha command training.

**Table 13. Amended PRS summary scores for each condition in dyad 2**

Condition	Amended PRS summary score
Usual 1	56.25
Alpha commands	70.83
Usual 2	47.22
Pacing	93.33

A  $\chi^2$  test of difference was performed to examine the relation between condition and amended PRS summary scores in dyad 2. The relation between these variables was significant,  $\chi^2 (3, N = 267) = 18.2, p < 0.001$ . The resident was more likely to show



positive communicative behaviour in the conditions following alpha command training.

Figure 10 shows the amended PRS summary scores and the percentage of alpha commands from each condition in dyad 2. The amended PRS summary scores are seen to increase with the increase of alpha commands after the first usual condition.

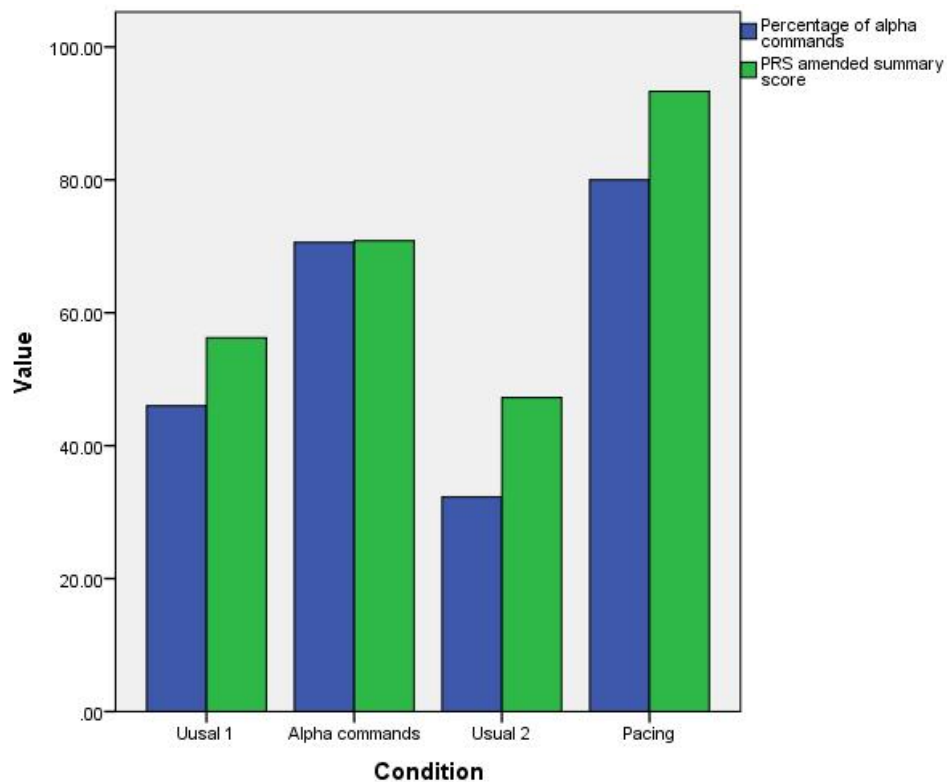


Figure 10. Bar chart representing the percentage of alpha commands and amended PRS summary scores for dyad 2

#### 6.4.2.2.2 Question 2b

The association between alpha commands and RTC-DAT summary scores was completed in the same way as that for the amended PRS scores. The resident in dyad two exhibited a greater amount of resistive behaviour than the residents from the other dyads making this analysis possible. Table 14 shows the RTC-DAT summary

scores in each condition for dyad 2. As can be seen from the frequencies the most resistive behaviour was exhibited in the usual communication conditions.

**Table 14. RTC-DAT summary scores for each condition in dyad 2**

Condition	RTC-DAT summary score
Usual 1	17.5
Alpha commands	1
Usual 2	8.3
Pacing	4.7

A  $\chi^2$  test of difference was performed to examine the relation between condition and RTC-DAT summary scores in dyad 2. The relation between these variables was significant,  $\chi^2 (3, N = 32) = 19.75, p < 0.001$ . The resident was more likely to show negative communicative behaviour in the conditions where the care worker was using their usual communication style.

Figure 11 shows the RTC-DAT summary scores and the percentage of beta commands from each condition in dyad 2. The RTC-DAT summary scores are seen to decrease with the decrease of beta commands in the alpha commands and pacing conditions.

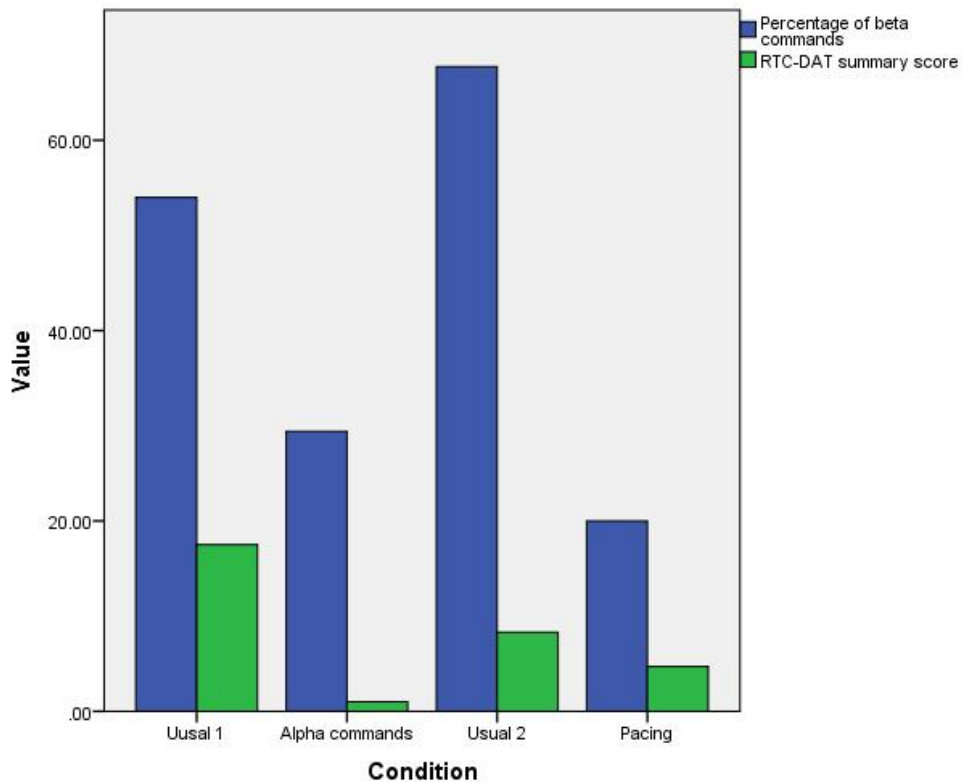


Figure 11. Bar chart representing the percentage of beta commands and RTC-DAT summary scores for dyad 2

#### 6.3.2.2.3 Question 2c

Table 15 shows the rates of compliance, non-compliance and forced compliance across alpha and beta command subtypes in dyad 2. As can be seen from the frequencies in the table, the majority of beta commands resulted in non-compliance or forced-compliance, the majority of alpha commands resulted in compliance and the majority of commands resulting in compliance were of the alpha type.

Table 15. Resident's levels of compliance to alpha and beta command types in dyad 2

		Compliance			Total
		Compliance	Non-compliance	Forced-compliance	
Command subtype	A	50	16	0	66
	B	22	25	45	92
Total		72	41	45	158

A 2x3  $\chi^2$  test of difference was performed to examine the relation between command subtype and compliance in dyad 2. The relation between these variables

was significant,  $\chi^2 (2, N = 158) = 55.08, p < 0.001$ . Cramer's V was found to be 0.59.

Therefore nearly 35% of the variation in compliance can be explained by the command subtype used. It can be concluded that the resident was significantly more likely to comply with alpha commands and that beta commands were significantly more likely to lead to non-compliance or forced-compliance.

#### 6.4.2.2.4 Questions 2d and e

As the measures for pacing were not found to be significantly different between the conditions, either in the proportion of commands responded to first by the resident or the mean time lapse left by the care worker before proceeding with the task, statistical analyses of this data was not thought to be appropriate.

### 6.4.3 Dyad 3

#### 6.4.3.1 Question 1: *Has care worker communication style been modified?*

##### 6.4.3.1.1 Question 1a

Table 16 presents the number and percentages of the different command subtypes in each of the four conditions in dyad 3. The frequencies indicate a greater proportion of alpha commands used following the alpha command training after the first usual condition. It can be seen that the alpha commands condition has more alpha commands than the usual 1 condition but the usual 2 condition is even richer in alpha commands than the other conditions.

**Table 16. The frequencies and percentages of command subtypes for dyad 3**

Condition	No. of alpha commands	No. of beta commands	Percentage of alpha commands
Usual 1	17	16	51.52
Alpha commands	10	7	58.82
Usual 2	13	12	86.67
Pacing	19	10	65.52

A  $\chi^2$  test of difference was performed to examine the relation between condition and percentages of alpha commands in dyad 3. The relation between these variables was significant,  $\chi^2 (3, N = 264) = 10.39, p < 0.05$ . The care worker used a significantly greater proportion of alpha commands in the usual 2 condition.

#### 6.4.3.1.2 Question 1b

Table 17 shows the percentage of commands responded to by the resident, those responded to by the care worker and the mean time lapse between the end of the command and the care worker responses in dyad 3. From the frequencies the percentage of commands where the resident responds first appear to be greater in the pacing condition than the other conditions and the mean time lapse before the care worker continues with the task appears to be longer in the pacing condition than the other conditions.

**Table 17. The respondents and time lapse following each command in dyad 3**

Condition	No. Resident responses	No. Carer responses	% resident responses	Mean TL for all (secs)	Mean TL for carer responses (secs)
Usual 1	15	18	45.45	0.98	1.38
Alpha commands	10	7	58.82	1.04	1.74
Usual 2	15	10	60.00	0.69	0.81
Pacing	19	10	65.52	1.62	2.26

A  $\chi^2$  test of difference was performed to examine the relation between condition and percentages of commands to which the resident responded first in dyad 3. The relation between these variables was insignificant,  $\chi^2 (3, N = 230) = 4.12, p > 0.05$ . There is a high possibility that any differences between the conditions are due to chance.

A Friedman's ANOVA was performed to determine whether there were significant differences between the observed time lapses before the care worker responded

and those expected by chance. The relation between these variables was found to be insignificant  $\chi^2 (3, N = 7) = 0.43, p > 0.05$ . There is a high probability that any differences in time lapse between the conditions are due to chance.

### **6.4.3.2 Question 2: Is there an effect of care worker communication style on resident behaviour?**

#### **6.4.3.2.1 Question 2a**

Table 18 shows the amended PRS summary scores in each condition for dyad 3.

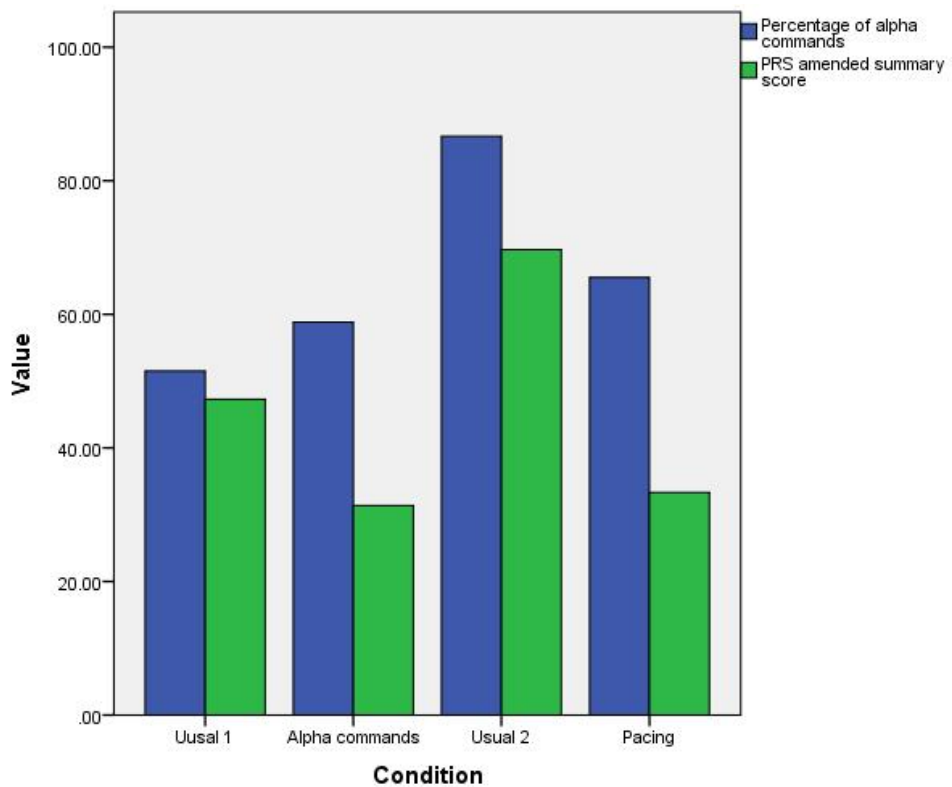
From the frequencies it can be seen that amended PRS scores are greatest in the second usual condition.

**Table 18. Amended PRS summary scores for each condition in dyad 3**

<b>Condition</b>	<b>Amended PRS summary score</b>
Usual 1	47.29
Alpha commands	31.37
Usual 2	69.7
Pacing	33.33

A  $\chi^2$  test of difference was performed to examine the relation between condition and amended PRS summary scores in dyad 3. The relation between these variables was significant,  $\chi^2 (3, N = 181) = 21.41, p < 0.001$ . The resident was more likely to show positive interactional behaviour in the second usual condition.

Figure 12 shows the amended PRS summary scores and the percentage of alpha commands from each condition in dyad 3. The amended PRS summary scores are seen to increase in the second usual condition with the proportion of alpha commands used by the care worker.



**Figure 12.** Bar chart representing the percentage of alpha commands and amended PRS summary scores for dyad 3

#### 6.4.3.2.2 Question 2b

As with dyad 1, resistive behaviour was rarely exhibited in this dyad. The resident only displayed instances of resistive behaviour in the pacing condition where she scored 41, the highest RTC-DAT score of the study. As there was no other resistive behaviour displayed in any other condition statistical analysis was not viable.

#### 6.4.3.2.3 Question 2c

Table 19 shows the rates of compliance, non-compliance and forced compliance across alpha and beta command subtypes in dyad 3. As can be seen from the frequencies in the table, the majority of beta commands resulted in non-compliance or forced-compliance, and the majority of commands resulting in compliance were of the alpha type.

**Table 19. Resident's levels of compliance to alpha and beta command subtypes in dyad 3**

		<b>Compliance</b>			<b>Total</b>
		Compliance	Non-compliance	Forced-compliance	
<b>Command subtype</b>	Alpha	29	30	0	59
	Beta	11	12	22	45
<b>Total</b>		40	42	22	104

A 2x3  $\chi^2$  test of difference was performed to examine the relation between command subtype and compliance in dyad 3. The relation between these variables was significant,  $\chi^2 (2, N = 104) = 36.59, p < 0.001$ . Cramer's V was found to be 0.59. Therefore nearly 35% of the variation in compliance can be explained by the command type used. It can be concluded that the resident was significantly more likely to comply with alpha commands and that beta commands were significantly more likely to lead to non-compliance or forced-compliance.

#### **6.4.3.2.4 Question 2d and e**

As the measures for pacing were not found to be significantly different between the conditions, either in the proportion of commands responded to first by the resident or the time lapse left by the care worker before proceeding with the task, statistical analyses of this data were not thought to be appropriate.

#### **6.4.4 Question 3: Are there any correlations between the measures across dyads?**

In order to answer this question, correlation analyses were performed on the summary scores of all of the conditions of all three dyads. The total number of data points for each correlation is 12 as this is the total number of conditions. Due to the small sample size the non-parametric correlational statistic of Spearman's rho was used to address all questions.



#### 6.4.4.1 Is there any correlation between command subtype and PRS?

Figure 13 shows the relationship between the percentage of alpha commands and the mean amended PRS scores in each condition across the three dyads.

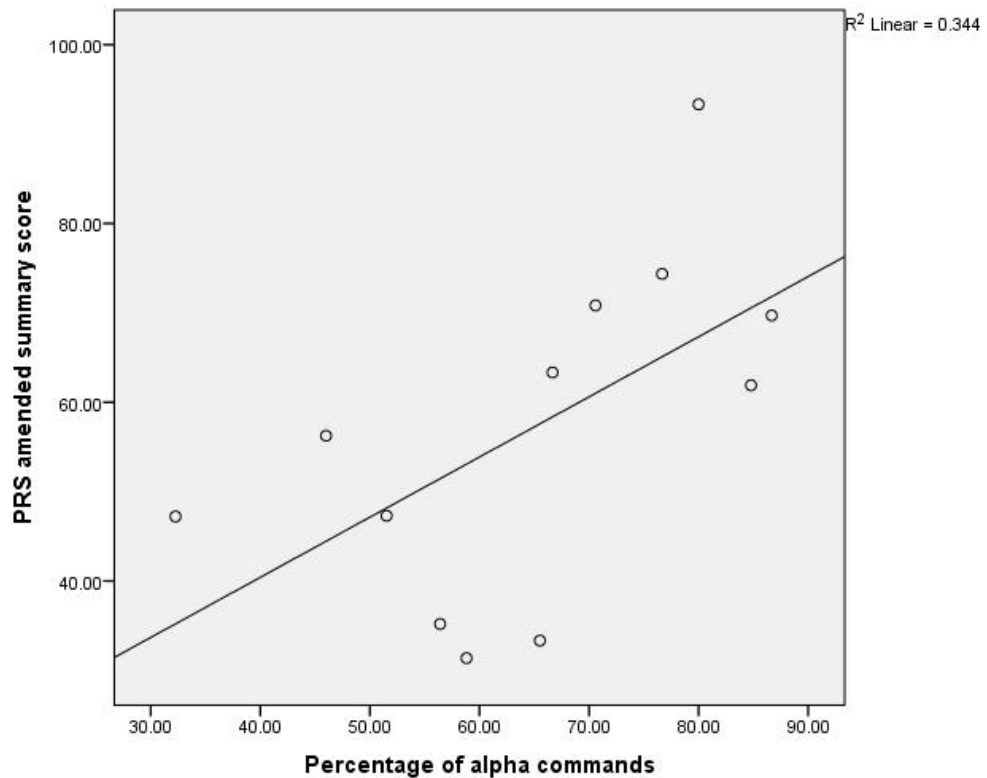
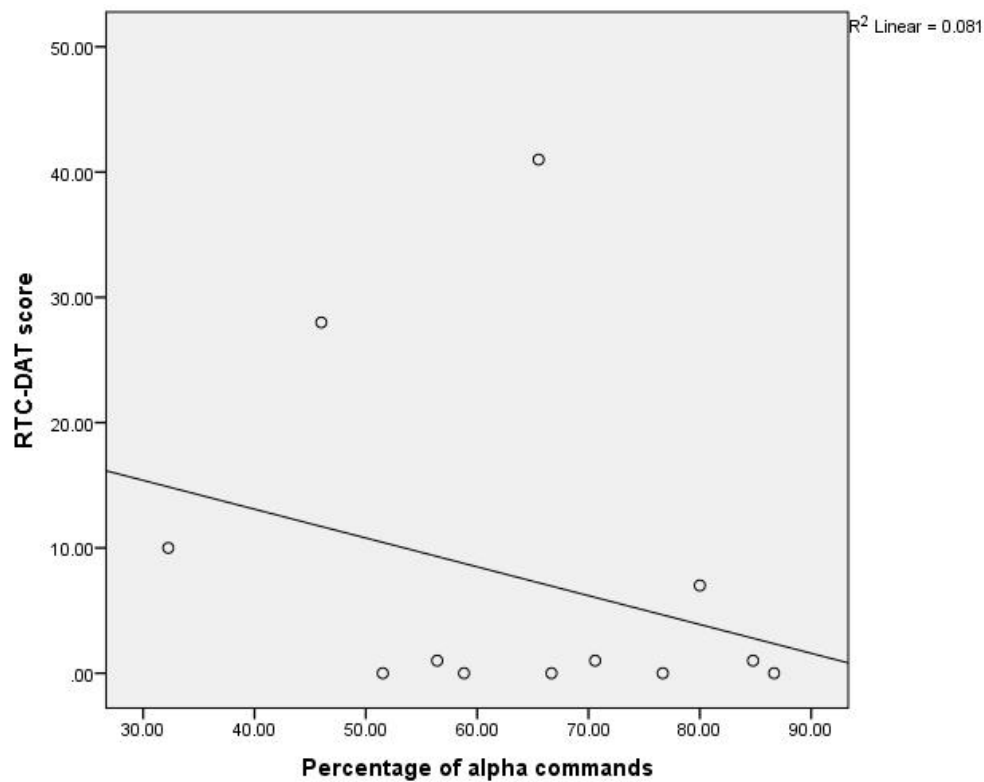


Figure 13. Scatter graph showing distribution of amended PRS summary scores and percentage of alpha commands for all dyads

From the scatter graph it can be seen that there may be a positive relationship between command subtype and amended PRS scores. A Spearman's rho was then conducted. The relationship between amended PRS summary score and the percentage of alpha commands was found to be positively and moderately related ( $r = +0.65$ ,  $p < 0.05$ ). As percentage of alpha commands increases, so does amended PRS score.

#### 6.4.4.2 Is there any correlation between command subtype and RTC-DAT?

Figure 14 shows the relationship between percentage of alpha commands and RTC-DAT scores in each condition across the three dyads.



**Figure 14. Scatter graph showing distribution of RTC-DAT scores and percentage of alpha commands for all dyads**

A Spearman's rho was conducted. A relationship between RTC-DAT score and the percentage of alpha commands was found to be negatively and weakly related though this was found to be statistically insignificant ( $r = -.32, p = .31$ ). Thus, as the percentage of alpha commands increases RTC-DAT score decreases, though there is a high probability that this could be due to sampling error.

#### ***6.4.4.3 Is there any correlation between command type and compliance?***

Figure 15 shows the relationship between percentage of alpha commands and the percentage of compliance in each condition.

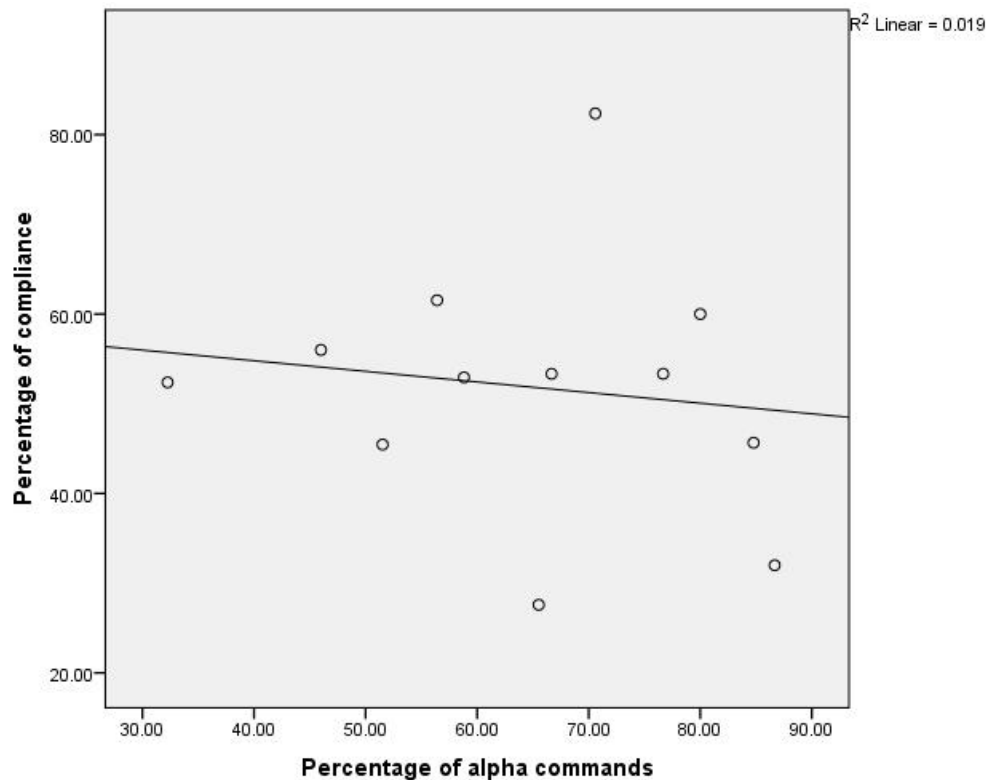


Figure 15. Scatter graph showing distribution of percentage of compliance and percentage of alpha commands for all dyads

A Spearman's rho was conducted. There was found to be no relationship between compliance and the percentage of alpha commands, though this finding was insignificant ( $r = -.07$ ,  $p = .81$ ).

#### **6.4.4.4 Is there any correlation between pacing and amended PRS, RTC-DAT and compliance?**

As none of the conditions showed statistically significant differences in either the proportion of commands responded to by the residents as opposed to the care workers, or in the mean time lapses between the command and the care worker responses, it was not appropriate to conduct this analysis using this data set.

#### **6.4.5 Question 4. Are there differences in the levels of compliance across the different command types?**

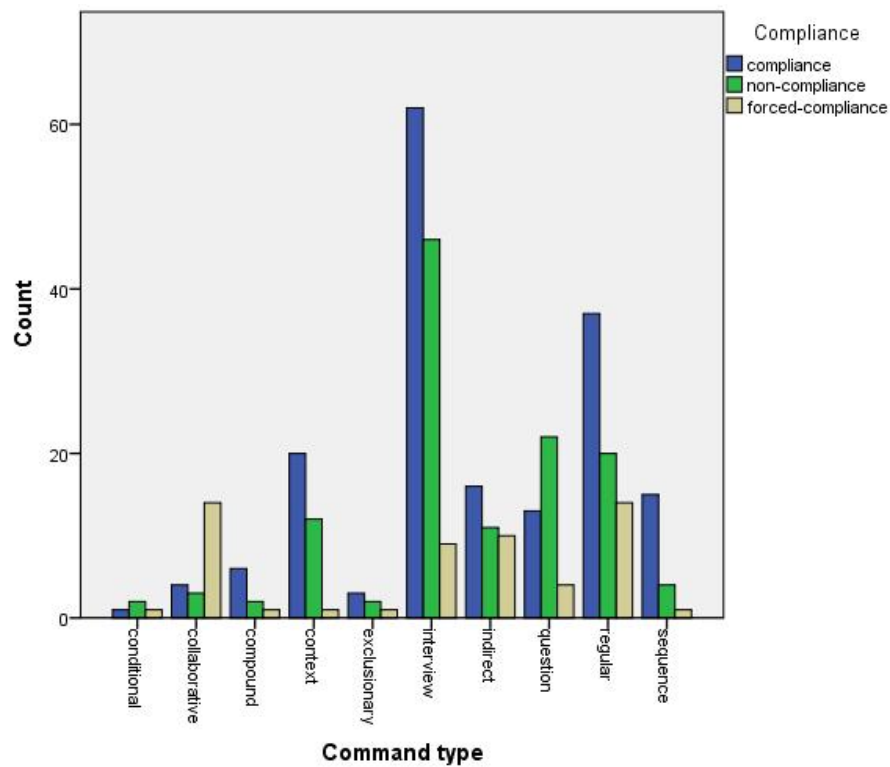
Due to the categorical nature of this data and the low frequencies of some of the command types, it was best to restrict analysis of these command types to visual

analysis. Table 20 shows the frequencies of the different command types used across all conditions in all dyads and the levels of compliance, non-compliance and compliance for each.

**Table 20. Frequencies of command types and compliance rates across all conditions**

		Compliance			Total
		Compliance	Non-compliance	Forced compliance	
<b>Command Type</b>	Conditional	1	2	1	4
	Collaborative	4	3	14	21
	Compound	6	2	1	9
	Context	20	12	1	33
	Exclusionary	3	2	1	6
	Interview	62	46	9	117
	Indirect	16	11	10	37
	Question	13	22	4	39
	Regular	37	20	14	71
	Sequence	15	4	1	20
<b>Total</b>		<b>177</b>	<b>124</b>	<b>56</b>	<b>357</b>

Figure 16 shows the frequency of compliance to each command type.



**Figure 16. Bar chart showing frequencies of commands and compliance for all dyads**

From this data it is possible to see which commands occur most often and which commands most often resulted in compliance, non-compliance or forced compliance. From this graph it can be seen that interview commands were most used, followed by regular commands. Command types used least often were conditional, exclusionary and compound. The command types that showed the highest levels of compliance were regular, context and interview commands. Commands that resulted in higher levels of non-compliance than compliance were question and conditional commands. Forced compliance was most often preceded by collaborative commands.

#### **6.4.6 Question 5. Are care workers aware of their communication style and the effect it has on residents?**

##### ***6.4.6.1 Care worker 1***

Care worker one reported that he was very interested in the alpha commands condition and thought that he executed it as instructed though he found it 'surreal' as he felt he was being impolite by speaking so abruptly. However, he felt that the resident responded well and that it took fewer attempts to perform the requested tasks.

After the training and before filming of the pacing condition, care worker one said that he felt dismissive of the pacing condition and that it was a waste of time, yet he still tried to execute the condition as instructed. He did not comment on whether he thought he had achieved this or not. He said that he did not notice any obvious change in resident behaviour or understanding.

In comparison to the statistical analysis, the care worker's feedback on the alpha commands condition showed that he was conscious of his change in communication style and also the change in resident communicative behaviour. However, his

feedback from the pacing condition shows that he was not conscious of his use of alpha commands in this condition, or the positive change in resident communicative behaviour.

#### **6.4.6.2 Care worker 2**

Care worker two commented that she thought she was able to successfully change her communication style in the alpha commands condition but that she found she was very conscious of her speech throughout the filming. She said she did not observe any real differences in resident behaviour.

In the pacing condition she stated that she found leaving five seconds before continuing very difficult as the resident was very talkative that day so answered or filled silences very quickly and often not 'correctly'. She said that the resident's behaviour was no different than other days.

When comparing this feedback to the results of the statistical analysis it can be seen that the care worker was conscious of changing her communication style in the alpha commands condition but she was not conscious of using more alpha commands in the pacing condition. Care worker two was conscious of the way in which she had difficulty executing the pacing condition as instructed. Care worker two said that she noticed no real difference in the behaviour of the resident in the different conditions despite increases in amended PRS scores in the alpha command and pacing conditions. Yet the care worker did say that the resident was especially 'talkative' in the pacing condition. It is not known whether the resident behaviour was caused by the care worker's communicative behaviour or whether the resident was in a communicative mood that day.

#### **6.4.6.3 Care worker 3**

Care worker three said that he found it quite difficult to remember to change his communication style in the alpha commands condition and that he kept forgetting half way through the filming and then remembering again. However he felt that overall he was able to use more alpha commands.

He said that he found the pacing condition extremely difficult as the resident was being particularly uncooperative and aggressive on this occasion and so he was not able to put the training into effect.

On comparing the care worker feedback to the statistical results the care worker's difficulty in using alpha commands in the alpha commands condition is reflected in only a slight increase in the proportion of alpha commands used. However the care worker seems unaware of the vast increase in alpha commands used in the second usual condition, despite being asked to revert to communication as usual. Care worker three expressed difficulty with the pacing condition though the reason was the resident's uncooperative and aggressive behaviour. This care worker did not mention whether he thought the resident's behaviour changed over the conditions despite there being a large increase in the amended PRS score in the second usual condition.

#### **6.4.7 Inter-observer reliability**

Inter-observer reliability tests were conducted on command category, the amended PRS, the RTC-DAT and measures of compliance on a representative sample of the video data. The ratings of the primary researcher and the second researcher were subjected to kappa coefficient tests. Classification of command type and compliance were both found to have very high levels of agreement ( $k=0.81$ ,  $p<0.001$ ) and ( $k=0.8$ ,  $p<0.001$ ) respectively. Agreement between observers for the amended PRS was

found to be acceptable ( $k=0.61$ ,  $p<0.001$ ) and the RTC-DAT scale again was found to have high levels of agreement ( $k=0.81$ ,  $p<0.001$ ).

## **6.5 Discussion**

### **6.5.1 Summary of results**

In dyad one the care worker used significantly more alpha commands in the alpha commands conditions and the pacing condition. The alpha commands condition showed the highest levels of resident communicative behaviour. It was found that 37% of variance in resident compliance could be explained by the command subtype used. Resident one did not exhibit enough resistive behaviour to warrant analysis and there were no significant differences in care worker pacing behaviour between the conditions.

In dyad two the care worker used significantly more alpha commands in the alpha commands condition and the pacing condition. The resident showed significantly higher levels of communicative behaviour in the alpha commands and pacing conditions. It was calculated that 35% of variance in resident compliance could be explained by command subtype used by the care worker. The two conditions where the care worker used communication as usual showed significantly higher levels of resistance to care behaviour from the resident. There were no significant differences in care worker pacing between the conditions.

In dyad three, the second communication as usual condition was found to be richest in alpha commands. This condition also produced the highest level of resident communicative behaviour. It was found that 35% of variance in resident compliance could be explained by command subtype. Resident three only exhibited resistive



behaviour in the pacing condition and there were no significant differences in care worker pacing behaviour between conditions.

Across the dyads there was found to be a moderate positive correlation between amended PRS summary scores and the percentage of alpha commands used in each condition. No significant correlations were found between the other measures although a negative trend was observed between alpha commands and RTC-DAT summary scores.

The most common command types used were interview and regular commands. Conditional, exclusionary and compound commands were rarely used. The command types that resulted in the highest levels of compliance were regular, context and interview commands. Commands that resulted in higher levels of non-compliance than compliance were question and conditional commands. Forced compliance was most often preceded by collaborative commands.

The care worker feedback showed that the care workers were generally aware of their ability to execute the alpha commands intervention within the alpha commands condition. However, they showed lack of awareness when they used an increased proportion of alpha commands in the proceeding conditions. Care workers two and three were aware of not employing the pacing strategy as instructed and in both cases this was attributed to the residents' mood on that particular day. With the exception of care worker one seeing an increase in positive behaviour in the alpha commands condition, the care workers seemed unaware of varying levels of resident positive response behaviour across the conditions.

Inter-observer reliability testing resulted in high levels of agreement for command type, compliance and the RTC-DAT scale. An acceptable level of agreement was

observed in the amended PRS showing that the coding used in the statistical analysis is reliable.

### **6.5.2 Alpha commands and amended PRS**

Alpha commands were defined as instructions that were precise and possible for the resident to fulfil and where the resident was given the opportunity to respond appropriately. Data from all three dyads suggested a relationship between the use of alpha commands and greater levels of positive communicative behaviour from the resident according to the amended PRS. When data from across all three dyads were analysed a moderate positive correlation was found.

There are some possible explanations for this correlation. Firstly, the precision of alpha commands reduce confusion in people with dementia leading to increased confidence and interactional behaviour. Apart from Christenson et al.'s study there is no research that looks at the effect of alpha commands on people with dementia (Christenson et al., 2011). Yet there are similarities between alpha commands and some of the linguistic strategies examined in previous research. The main feature of alpha commands is that they are precise. Unlike beta commands, they do not require any form of assumption or interpretation from the person with dementia. Previous research has shown that people with dementia are not as aware of situational factors when compared to healthy controls (Kemper et al., 1994). This may impact their ability to interpret instructions on the basis of context. For example, if a care worker handed a resident their shirt and gave them a beta command, "Here's your shirt" within the context of a dressing situation, a healthy adult would be able to infer from the situational cues that they are meant to put the shirt on. However, a person with dementia, who is not as able to make inferences

from the situational context and social scripts (Grafman et al, 1991; Kemper & Lyons, 1994) would react with confusion.

The correlation was found between the proportion of care worker alpha commands and resident positive response. Positive response consisted of eye contact with the care worker, initiating interaction with the care worker and any committed engagement to the same activity as the care worker. It has been found in previous literature that people with dementia have a different conversational style than healthy controls. These differences include more non-verbal responses, fewer assertive statements, fewer words per turn and a greater number of unintelligible responses (Ripich et al., 1991). Ripich and colleagues suggested that these conversational differences may be the result of the person with dementia attempting to 'mask' their confusion from their conversational partner. It may be that the precision of alpha commands reduces confusion about what is required of the person with dementia and enables them to comprehend and react confidently to the care worker throughout the interaction. This confidence can be seen through increased eye contact, a strategy spoken of by participants in the interview study that rectifies power imbalance and was also referred to by Hammar et al. (2011) as a subconscious reward issued by care workers for the appropriate behaviour of residents with dementia. This confidence may also lead to greater engagement with the care task and a higher frequency of self-initiated communication, responses that were referred to by participants in the interview study when a person with dementia felt they were safe and were not going to have their deficits exposed during an interaction.

Another reason for the correlation between alpha commands and resident positive response is that the alpha commands issued were shorter and syntactically simpler

than the beta commands, leaving the resident with greater attentional resources. The participants in the interview study referred to shortening and simplifying sentences as strategies to facilitate communication with people with dementia. It is these features that led to the choice of alpha commands as a communication strategy for testing. Previous research has found that syntactic complexity and sentence length were the main factors affecting auditory comprehension in people with dementia (Kemper & Harden, 1999; Small et al., 1997; Tomoeda et al., 1990). The reason for this was thought to be due to the compromised working memory of people with dementia. This makes longer sentences and embedded clauses more difficult to hold in memory. It may be that the use of shorter, simpler instructions meant that the memory and reasoning abilities often compromised by dementia were not as strained in alpha rich interactions. This meant that greater attentional resources could be devoted to the task in hand, or even to initiating interaction with the care worker themselves.

Simple syntax and short sentence length are two of the features common to both alpha commands and elderspeak (Caporael, 1981). Previous research has found that interactions with high levels of elderspeak also contained high levels of resident resistance to care (Cunningham & Williams, 2007; Herman & Williams, 2009; Williams & Herman, 2011). Participants in the interview study also expressed their concern about oversimplifying their language and infantilising their residents. The communication predicament of ageing model also refers to infantilisation as a consequence of elderspeak, what they call over-accommodation (Ryan et al., 1995). In the present study alpha commands did not seem to trigger the same effects as elderspeak. There was even a negative trend in data across the dyads indicating that a higher proportion of alpha commands may reduce resistance to care. One reason for this may be that alpha commands contain speech accommodations that are

effective in accommodating to communication deficits without infantilisation. Kemper and Harden (1999) attempted to disentangle the helpful ingredients of elderspeak from those that infantilised participants. They found that decreasing syntactic complexity increased comprehension without causing negative self-evaluations in the participants. They also found that exaggerated prosody, another feature of elderspeak decreased comprehension and triggered negative self-assessments. Although Kemper and Harden's study was conducted on healthy older adults rather than those with dementia, it can be concluded that it is possible to accommodate communication to older adults without infantilisation. The lack of resistance to care and increased positive responses witnessed in the conditions with higher proportions of alpha commands show that syntactic simplicity and shorter sentence length may be elements of elderspeak that do not produce negative responses in people with dementia.

Another way in which alpha commands seem to contradict previous literature is the way in which they were seen to benefit all three participants with dementia to a similar extent. According to the communication predicament of ageing model and the communication enhancement model (Ryan et al., 1995), modification of communication techniques should be done on an individualised basis to prevent the reinforcement of old age stereotypes and the loss of self-esteem for the older person. Yet the communication enhancement model does not stipulate the basis on which communication should be individualised. The way in which alpha commands were seen to be effective across all three dyads show that there is a possibility that alpha commands could be beneficial to a large proportion of people with dementia. Research into the benefits of simplified syntax and shortened sentence length show that there may be some communication strategies that can be generalised to the rest of the population of people with dementia (Kemper & Harden, 1999; Small et al.,

1997; Tomoeda et al., 1990). It may be that, based on information such as a diagnosis of dementia, certain speech modifications can be assumed to be effective. These assumptions are based, not on stereotypes, but on knowledge of the effects of dementia and empirical evidence of the effectiveness of certain speech modifications. It can be argued that this form of generalised speech modification would be more likely to empower a person with dementia in an initial interaction rather than constrain opportunities for communication. Individualised communication is an important philosophical approach both for the healthcare professionals in the interview study and in models of communication. Yet, if a person is known to have dementia, individualised communication should involve the use of communication strategies known to facilitate communication in a generalised sample of people with dementia. Effective individualisation may require the application of concepts established through generalisation from a sample to a population.

### **6.5.3 Alpha commands and compliance**

The lack of correlation between alpha commands and percentage of compliance in data taken across the dyads was unexpected. Previous research by Christenson et al. (2011) had found an increased rate of compliance when alpha commands were used. He found that 71% of alpha commands resulted in compliance. In contrast the present study found that only 45% of alpha commands resulted in compliance. Yet when looking at only those commands that resulted in compliance the present study found that 76% of commands resulting in compliance were of the alpha type. This is comparable to Christenson's 68% of compliant responses that were preceded by alpha commands. There are some possible explanations for the differences in findings between the present study and that of Christenson et al. Firstly, Christenson et al. analysed 822 commands from 11 nursing assistants and 11 people with

dementia. The present study analysed 593 commands from 3 care workers and 3 people with dementia. The smaller sample in the present study means that the effect of individual differences is greater on the overall result. The most marked differences between Christenson et al.'s study and the present study is the difference in overall rates of compliance. In their study 55% of all commands were responded to with compliance, 35% with non-compliance and 10% with forced compliance. The present study had much higher instances of non-compliance and forced-compliance with only 30% compliance, 41% non-compliance and 28% forced-compliance. So although the alpha commands resulted in greater non-compliance than compliance, this could be a consequence of the higher levels of non-compliance in the present sample.

When looking closer at the rates of compliance across the dyads it is clear that there is wide variability between the participants. Resident one's compliance rates range from 45-61% over the four conditions. Resident two's percentage of compliance ranges from 52-82% across conditions, a range nearly twice that of resident one. And resident three's compliance rates range from 27-52% showing that the compliance rate of resident three at her most compliant was equal to that of resident two at her least compliant. This explains why a correlational analysis across all data sets is unlikely to have found any relationship between alpha command use and compliance and portrays the propriety of case by case analysis. One explanation for the difference in rates of compliance is the length of time that the residents had been living in residential care. Residents one and three had both moved into care relatively recently compared to the six years' experience of residential care for resident two. It may be that the longer period of time spent in residential care meant that resident two was more accustomed to the routine of the activity and the expectations of the care worker.

Another reason for this variability in levels of compliance may be the nature of the communication deficits in each participant with dementia. The two residents with AD showed lower levels of compliance than the participant with VaD, yet did not show lower levels of positive response or higher levels of resistance to care.

This could indicate that, for the participants with AD, lack of compliance may be due to lack of comprehension rather than unwillingness to comply with an instruction that has been understood. From previous literature it is known that an early feature of AD is difficulty in the comprehension and expression of specific words (Bayles et al., 1990; Bayles et al., 1992; Chertkow et al., 1989; Ripich et al., 1991). Closer inspection of the way in which the participants with AD reacted to alpha commands that resulted in non-compliance showed the use of inappropriate responses due to misunderstanding. An example would be a care worker asking the person with dementia to take off their pyjama trousers and they take off their pyjama top instead. This is similar to the mistakes documented in the literature where people with dementia have lost the ability to distinguish between distinct items within the same category (Chertkow et al., 1989), such as items of clothing. This mistake would be documented as non-compliance in the study; though often, on repetition of the same command, sometimes rephrased or with added demonstration or gesture, the participant complied. Despite this, alpha commands still resulted in a greater level of compliance than beta commands overall and, although there appeared to be no correlation between the use of alpha commands and compliance across dyads, there was a consistent finding that command category accounted for 35-37% of the variance in compliance scores in each of the dyads. Therefore, alpha commands were still seen to be more effective than beta commands with participants with AD, even if they had lower overall levels of compliance.



This discussion may also explain why there was no positive correlation found between the amended PRS scores and compliance. These results suggest that even though a person with dementia may show positive responses in an interaction it does not necessarily follow that they will comply with an instruction. There are two possible explanations for these differences, firstly that a resident can be engaged in an interaction but not necessarily comprehend an instruction as could be seen in the participants with AD. Another explanation is that the person with dementia is engaged, does comprehend but then chooses not to comply. Many of the commands resulting in non-compliance for the participant with VaD showed situations where the resident comprehended what was required of her but did not comprehend the reason for it. For example, the resident was asked to turn over in the bed so that the care worker could remove her night dress. The resident refused because she could not understand the reason for taking it off. When the care worker explained that she had worn the night dress for the past 24 hours and she had a fresh one to replace it, the resident complied. These situations often seemed to be the cause of the higher levels of resistant behaviour observed in dyad two that then abated when the care worker explained the situation. Reasons for non-compliance have not yet featured in the dementia literature but could impact the way in which communication is individualised according to dementia subtype. Yet, as with the residents with AD, alpha commands were still seen to be the most effective form of instruction to attain a compliant response.

#### **6.5.4 Command Types**

Although it was not possible to conduct any form of statistical analysis on the command types used, in the most part the frequencies and analysis of compliance rates support the findings of Christenson et al. (2011). They too found that the most common command types were interview and regular commands. They also found

that exclusionary commands were one of the types least used. My results support their findings that regular, contextual and interview commands result in the highest levels of compliance, that question commands result in a high level of non-compliance and that collaborative commands often precede forced compliance.

One possible explanation for the effectiveness of context commands is that they often take the form of a repetition or paraphrase of an instruction already given.

The definition for a contextual command is “A command that clarifies or restates the previous command issued by the care worker or a resident’s response” (Christenson et al., 2011, p. 51). Repetition and paraphrasing are both communication strategies believed to be effective by the participants in the interview study and have been found to aid comprehension in previous literature (Kemper & Harden, 1999).

Therefore it is not surprising that a command type which is, by definition, a clarification of a previous command or response should result in greater comprehension and compliance.

A possible reason for the high levels of non-compliance to commands that are phrased as questions e.g. “Can you step out of the shower?” is that a person with dementia may attend more closely to the prosody of the instruction rather than to the content of the instruction. The definition of question commands are “Questions that require a non-verbal response even though a verbal response is possible but not appropriate” (Christenson et al., 2011, p. 51). In the example given above the appropriate non-verbal response is for them to step out of the shower. The possible but inappropriate verbal response is to answer “yes” or “no”. The participants in the interview study stated their belief that people with dementia often pay greater attention to the paralinguistic features of speech such as vocal prosody rather than the words. Although this was spoken of in the context of the emotional messages

communicated through the paralinguistic features of speech, it shows that a person with dementia may rely on these features when attempting to comprehend and respond to an instruction. The prosody of a question is different to that of a regular instruction in that the pitch is raised after the focus of the sentence e.g. the word shower in the previous example. In a statement vocal pitch is lowered after the focus word (Liu & Xu, 2007). If a person with dementia attends to vocal prosody to a greater extent than the content of the command then instructions phrased in question form are more likely to elicit an inappropriate verbal response which would be recorded as non-compliance. In addition, the masking behaviours referred to by Ripich et al. (1991) would predict that people with dementia would respond quickly to a question, without spending time processing the meaning of that question.

Conditional commands were a type of command that were added to Christenson et al.'s coding scheme for the purpose of this study. These commands are "Commands phrased so that the care worker will carry out an action or task *if* the resident carries out a certain action or task". Although this type of command occurred rarely they resulted in high levels of non-compliance and forced-compliance. One possible reason for the high levels of non- and forced-compliance is that the 'if/then' nature of these commands introduces a dependent clause into the instruction. Dependent clauses are a complex form of syntax where the applicability of one clause of the sentence is dependent on an element stated in another part of the sentence. Tomoeda et al. (1990) found that instructions including dependent clauses e.g. 'Touch the little blue square if there is a big black circle' were the most difficult types of instructions for people with AD to follow. The low levels of compliance with these commands supports the previous research in this area.

Collaborative commands were the type of command resulting in the most forced-compliance. These were defined as, “Instructions that require cooperation and begin with or include words in the third person referring to the carer and the resident”. Examples would be, “We’re going to sit in this chair” or “Let’s do these buttons up”. On looking at the incidences of collaborative commands and forced-compliance, one explanation is that, in many of the instances of collaborative commands, they appear to have been used as a form of explanation of the care worker’s intended actions rather than commands that the care worker expected the resident to fulfil; they could be described as ‘rhetorical’ commands. Dyad two, especially, showed many instances of this and, as a result, the time lapse between the commands and the care worker moving on with the task has a negative value in the pacing condition, the condition in which the care worker was meant to leave five seconds after an instruction before continuing with the task. These results have implications for the care worker training as they show that care worker two did not grasp the definition of a command. Yet, this finding also conveys the individual differences between the care workers in the types of commands they chose to use in the care routines.

The agreement between the present findings and those of past work shows promising evidence of possible relationships between command types and compliance. This study has shown that it is possible to create conditions that are rich in a certain command type. In future work other command types such could be varied in experimental conditions with people with dementia to examine their effect on compliance.

### **6.5.5 Pacing**

The pacing condition, where the care workers were instructed to leave a five second gap for the resident to respond before continuing with the interaction, was not

found to be adequately employed in any of the dyads. Although there was a trend in all three dyads for the resident to be the first to respond to a greater number of instructions in the pacing condition, these percentages were not found to be significantly different from the other conditions. In dyads one and three the time lapse between the command and the care worker moving on with the task was greatest in the pacing condition. However, the differences in time lapse were not found to be statistically significant.

This was the first study which has attempted to measure the pacing of an interaction between care workers and people with dementia. It may be that the definition of pacing and the method of measurement used in this study did not capture this communication strategy adequately. The definition of pacing was taken from the definitions expressed by the participants of the interview study who said that pacing referred to the concept of carrying out a task or interaction at the same pace as that of the resident. The interview participants expressed that people with dementia often take longer to comprehend, construct and then express a response to an instruction. Therefore, the element of pacing most described by the interview participants was that of waiting for a response from the resident before continuing with a task. The period of five seconds was chosen on the basis of a staff training study by Dijkstra et al. (2002) who advised a care worker to wait five seconds for a response from a person with dementia and also because the period of five seconds was used by Christenson et al. (2011) to determine whether a non-response was coded as non-compliance or forced-compliance. Five seconds was therefore thought an appropriate period in which a person with dementia could comprehend, construct and begin to express a response to an instruction.

From the care worker feedback it can be seen that care worker two expressed difficulty in executing the condition due to the way in which the resident responded quickly to instructions. On closer inspection of the videos it can be seen that care workers one and two were rarely given the opportunity to employ this strategy as the residents mostly responded quickly to instructions, often inappropriately. Much of the non-compliance recorded in the videos for dyads one and two shows the employment of immediate 'knee-jerk' reactions by the residents. These often took the form of an utterance such as "Thank you" or "Yes" which, although verbally appropriate, did not lead to the physical response required by the instruction.

One explanation for these quick but inappropriate responses is the preserved ability of turn taking. Research has shown that although some conversational abilities are compromised in dementia, turn taking, where a person with dementia will still take alternate turns in a conversation, is preserved (Ripich et al., 1991). This turn taking follows the normal pattern of interaction, even if the utterances of the person with dementia are nonsensical. These automatic responses may be due to this preserved knowledge that, according to the verbal and non-verbal cues of the care worker, such as the prosody of the instruction or eye contact, a response is required, even if they have not had time to process the instruction and formulate an appropriate response. Informal analysis of these quick but inappropriate responses suggest that the person with dementia does make an appropriate response on the first or second repetition of an instruction, once the full attention of the person with dementia had been gained. It may be that pacing does not only refer to what a care worker does at the end of an instruction but the way in which the attention of a person with dementia is gained before the instruction and maintained throughout. Pacing may also incorporate elements of slowed speech and sensitivity to the point at which understanding is lost. This more holistic definition of pacing is supported by the

healthcare professional interviews. It may be that a technique such as conversational analysis would be an appropriate tool to analyse pacing, what it involves and how it effects interaction with people with dementia.

Another possibility is that this pacing technique would be more appropriate for people with DLB. In this subtype of dementia the individual displays symptoms described as Parkinsonism (Weiner & Lipton, 2012) a combination of symptoms comprising of extreme slow movement and reactions known as bradykinesia, facial masking where the face appears devoid of expression, and rigidity. People with dementia with DLB also display a relative preservation of memory in the first phases of the disease compared to those with AD. Although memory deficits increase as the disease progresses, memory problems are mainly deficits in retrieval rather than the encoding difficulties found in AD so the strain put on working memory by a slow, lengthened sentence would not be as problematic for people with DLB (Small et al., 1997). This combination of extreme slowness of reaction, largely preserved memory, or deficits that affect retrieval rather than encoding would mean that the pacing strategy would lend itself more to those with this subtype of dementia rather than those with AD or VaD as in the present sample.

#### **6.5.6 Use of amended PRS for less severe dementia**

The present study amended the PRS as devised by Perrin (1997) using only three of the original ten micro-behaviours measured by the instrument. The decision to amend the PRS was supported by the associations between the amended PRS and compliance seen within each dyad and the ability of the amended PRS to demonstrate a correlation between positive interactional behaviour and care worker use of alpha commands. In addition to this, on observation of the videos, using the complete PRS would have artificially inflated the positive engagement scores of some

segments of video where the resident interacted in a negative way. For example, physical aggression toward the care worker would have been counted as a deliberate body movement or a sentence uttered in a threatening manner would have been given a positive vocalisation score. During the segments that included resistive behaviour the three micro-behaviours the comprised the amended PRS were rarely counted. At these times vocalisation often indicated the resident's wish to end interaction, eye-contact with the care worker was rare and the resident was never engaged with the same task as the care worker. It is therefore recommended that the amended PRS could be used in future studies to determine the positive communicative responses of people dementia to interventions. It is recommended that the amended PRS be used with people with dementia at all stages of severity rather than just those with mild or moderate dementia. Out of the three participants with dementia in this study, two would be described as having severe dementia ( $MMSE < 10/30$ ). Furthermore it was with resident two, the participant with the most cognitive impairment with an MMSE score of 1/30, where the distinction between positive and negative communicative behaviour was most required. It would be recommend that the full PRS only be used when residents are in the very latest stages of dementia where response of any kind is minimal, withdrawal severe and negative communicative behaviour rare. This would avoid artificially inflating positive communication scores.

The amended PRS still achieved acceptable levels of inter-observer reliability as it attained a kappa coefficient of 0.61 which is over the generally acceptable level of agreement. However the validity of both the full PRS and the amended PRS is still to be established. Future work should establish the PRS's construct validity by comparing it with measures such as DCM (T. Kitwood & Bredin, 1994) or mean length of utterances. Discriminant validity could be determined by comparing the PRS with



measures such as the RCT-DAT or the frequency of communication breakdowns.

Factor analysis of the full PRS would also show whether the amended PRS represents an unobserved factor within the PRS such as engagement.

#### **6.5.7 Awareness of care workers to communication change**

The care worker feedback showed that the care workers were generally aware of their communication changes after the alpha command training. Care workers one and two were especially successful in implementing the use of alpha commands and then reverting back to their 'usual' method of communication in the second usual condition as instructed. Care workers two and three were also aware of not being able to employ the pacing condition as intended. However, it appears that both care workers one and two inadvertently employed the alpha command strategy in the pacing condition. The fact that the care workers were not aware of implementing alpha commands in later conditions may indicate that the care workers had already adopted alpha commands as a new strategy in their repertoire and were not conscious of when this strategy was utilised. Another explanation is that the use of simple and precise instructions is a by-product of the care workers' consciousness of their communication technique as they were used in both the alpha commands and pacing conditions. By making commands simpler the care workers would have been better able to monitor their own 'instruction, wait, continue' process.

Care worker three reported forgetting to change his communication style in condition two and only occasionally remembered at certain points during the filming. This is reflected in the slight increase in alpha commands in the alpha commands condition and the large increase in alpha commands in the second usual condition, despite being told to revert back to usual communication. The use of an increased proportion of alpha commands in conditions where care workers were meant to

have reverted to a usual level of alpha and beta commands indicates that the care workers did not have the amount of training and practice time required to be able to manipulate the communication strategies at will. This has implications for the training package. Twenty minutes was adequate for all three care workers to learn the alpha commands strategy, as all three employed this strategy post training without the need for follow-up or refresher sessions. However, it was not sufficient for care workers to be in control of the implementation of this strategy. Future training should contain more extensive use of practice and feedback sessions, maybe distributed over a number of days with the opportunity for care workers to use the strategy in between training sessions to grow accustomed to consciously using the strategy. In addition, to prevent contamination of conditions in future research, each condition could be employed for a longer period of time, for example a week of alpha rich communication followed by a week of no intervention and then a week of pacing. This would enable care workers to become accustomed to employing the strategy and it would be possible to observe the effects of an alpha rich environment or a paced environment on resident interactional behaviour over a longer period of time. Another way in which contamination between conditions could be accounted for is to divide the sample in half so that half of the dyads employ the alpha command strategy first and the other half employ the pacing strategy first. By doing this it would be possible to determine whether alpha commands are the product of the training or the product of care workers' consciousness of their communication style.

One interesting finding from the care worker feedback is that, in the most part, care workers were not aware of any changes in resident behaviour. It is not uncommon for the positive effects of an intervention on care home residents to have little impact on the care home staff (Wells et al., 2000). Another staff training study also

showed that real time observational measures were more sensitive to resident behaviour change than retrospective care giver reports of resident behaviour (Magai et al., 2002). One explanation for the discrepancy in care worker reported change and the changes noted from the video analysis is that the care workers may have been more concerned with resident compliance and the amount of time it takes to complete a task rather than the communicative behaviour measured by the amended PRS. As the questions in the feedback form did not ask about particular changes in resident behaviour the factors by which the care workers assessed resident behaviour change is unknown.

#### **6.5.8 Evaluation**

When assessing the conclusions of this study and the possibility of generalisation to the wider population of care home residents with dementia and staff there are a number of caveats that must be taken into consideration.

Firstly, participants consisted of only three care worker-person with dementia dyads.

Any conclusions drawn from such a small sample must be drawn with caution.

However, the purposes of using a multiple case study design were that each participant could function as its own control and also that the study could explore the possibility of underlying mechanisms of any change. Using case studies allowed for the consideration and discussion of variables such as dementia subtype and the content of resident responses that were not considered as factors in the original design (Barker et al., 2002). Had this study been any larger this may not have been possible. The factors identified in this exploratory study can now be carried forward to a larger, more controlled trial of these communication strategies.

Another consideration is that these results were only found in a one-to-one morning care setting. It is possible that the communication strategies studied in this

particular setting would work differently in another task or setting such as assisted transfers from one room to another or assisting a resident to the toilet. Also, all of the communication in the films occurred on a one-to-one basis. There are many other forms of communication such as the triad as in family visiting or a group setting such as meal times. From previous research and from the participants in the interview study it is evident that the number of participants in a conversation change the social rules and dynamics of interaction (Silliman & Lamanna, 1986). However, it was important to standardise the situation in which the communication strategies were administered. Future research could see the effects of these communication strategies in different contexts and with varying numbers of conversational partners.

Another limitation of this study is the lack of resistive behaviour exhibited by the residents. Only one of the three residents displayed enough resistive behaviour to compare frequencies between the four conditions. The low frequency of resistiveness to care or aggressive behaviour has been experienced by other studies (Burgio et al., 2000; Herman & Williams, 2009) and may be a product of sampling as the care workers were allowed to choose the resident with whom they interacted. It would be understandable for a care worker to choose a resident that was more cooperative in care tasks if they were going to be observed. However, the measurement of resistance to care was still thought to be appropriate in this study to balance and better inform the measurement of positive communicative behaviour. Analysis of dyad two showed the possibility of a negative correlation between alpha commands and resistiveness to care. In future researchers could purposefully recruit people with a history of resistive behaviour in order to avoid floor effects and examine this relationship further.

Despite the limitations addressed above this study offers a unique contribution to the research literature on the effect of care worker communication style on the communicative behaviour of care home residents with dementia. This study was the first to experimentally manipulate the communication style of a conversation partner of a person with dementia in a naturalistic setting. There have been many studies that analysed the impact of communication styles on people with dementia in a laboratory setting (Bayles et al., 1992; Ripich et al., 1991; Tomoeda et al., 1990) and many studies that have observed the impact of certain features of communication on people with dementia in a care home setting (Christenson et al., 2011; Cunningham & Williams, 2007; Herman & Williams, 2009; Williams & Herman, 2011) yet this study has been the first to analyse the responses of people with dementia to different communication interventions issued by care workers within a normal care situation.

This study also used real-time observation methods to establish the effect of the communication strategies on the participants with dementia, rather than relying on retrospective reports from care workers. Care worker reports have been shown to not be as sensitive to change as real-time observations in a previous staff training intervention study (Magai et al., 2002) and this is supported in the care worker feedback administered in the present study. Real-time observational measures, especially when administered based on video data that can be slowed down, paused and replayed is the closest a researcher can get to directly observing care without being in the room.

The instruments used to measure care worker and resident communicative behaviour were all found to have good inter-observer reliability. These instruments are promising measures to use in future communication research.

This was also the first study to utilise communication strategies that were based upon the suggestions of people experienced in dementia care. The examination of strategies recommended by healthcare professionals capitalised on the collective experience of people involved in the day to day care of people with dementia so that this expertise was incorporated, rather than disregarded (Perkins et al., 1998). As a result the communication training and strategies were not only evidence-based but were also intellectually accessible for care workers and feasible for execution in day-to-day care.

This study is also one of the first pieces of research that attempted to show the benefits of certain communication strategies in isolation from other strategies. One of the criticisms of the staff training intervention studies in the literature review was that, although they all showed signs of benefitting residents' and staff members' communicative behaviour, it was not known which elements of the training interventions were beneficial (Burgio et al., 2000; Dijkstra et al., 2002; Magai et al., 2002; McCallion et al., 1999; Wells et al., 2000). This study attempted to show the benefits of alpha commands and pacing as strategies in their own right. Despite the contamination of the pacing strategy with alpha commands, the alpha commands intervention was pure and their effect on the communicative behaviour of the three residents with dementia reliable.

#### **6.5.9 Implications**

The findings of this study have implications for future research and the communication of care workers with people with dementia.

Firstly, it was found that the use of alpha commands by the care workers produced a greater level of communicative behaviour from the people with dementia in this study. It has also been found that care workers can be trained to use alpha

commands in very little time or with little effort. Future studies should research the best process for training the alpha commands strategy, such as the optimal size of training group and the need for practical feedback sessions or refresher sessions (Magai et al., 2002). Future studies should also look at the role of self-reflection in staff training. Although the care workers were able to learn the strategy over a short period of time they were not able to control their use of it. Future studies should work on the care workers' consciousness of their own communication style. In addition, not all of the care workers were able to learn and control their communication style to an equal extent. There will be individual differences between care workers in the amount of teaching, application, practice and feedback required and future research should examine how these differences can be built into a training package.

The study also has implications for the design of future research on this topic. This study found differences in resident communicative behaviour after only very short periods of being exposed to alpha commands. The next step would be to examine resident's responses to this strategy over a longer period of time. It has been suggested in other research that exposure to communication enhancing strategies over time may have a cumulative effect for people with dementia (Dijkstra et al., 2002). Employing the strategies in conditions that last for longer periods of time, such as a week, and are all encompassing for the resident rather than just in morning care would show the effects of alpha commands in other care situations and also the effects of such an environment over time. In addition, the variability in mood in people with dementia, for example the high levels of resistiveness to care in resident three when filming the pacing condition, mean that filming multiple episodes for baseline and each condition will give a better indication of the effect of communication strategies despite variations in resident health or mood.

One of the variables thought to impact resident responses to the communication strategies was the subtype of dementia with which they were diagnosed. There were differences in response patterns between the two residents with AD and the resident with VaD. Although, due to the small sample, it cannot be concluded that these differences were due to their dementia subtype, such possible factors should be examined or factored into future research. In addition, there was an indication that there could be a negative correlation between alpha commands and resistance to care behaviour. In a future study it may be possible to sample care home residents with dementia who have a history of resistive behaviour to further establish this link.

Another element of this study that can be taken forward into future research was the use of video. Video was found to be crucial in the analysis of communication with people with dementia, especially when analysing eye contact and engagement between participants where instances were often fleeting but still indicative of resident engagement. The effectiveness of video to provide fine-grained analysis has been found in other studies (Milne, 2011). The video-recording of these interactions allowed for the reliable documentation of these small but meaningful actions. Filming also enabled the documentation of the care workers' behaviour to determine the extent to which the communication strategies were being implemented as instructed. Without the ability to measure the time lapse between a care worker's instruction and, an often non-verbal, response from either the care worker or the person with dementia it would not have been possible to see that the increases in positive responses in the pacing condition were most probably not due to the pacing strategy. Therefore, the use of video for future research in this field is recommended.



There are also implications for the future research of pacing and the methods used to research this strategy's impact on communication in this population. In the pacing condition the patterns of communication and response were found to be complex. There were important details of interaction between the dyads that could not be analysed with the instruments employed in this study. Future research into this communication strategy should employ other methods of analysis, such as conversational analysis, to examine the interactional details involved in areas of communication breakdown or success.

There are also implications for other strategies that could be examined using care worker training and the implementation of filmed conditions. Eye-contact has been a factor mentioned many times in this thesis, both as a factor in the results in the literature review, a strategy spoken of by participants in the interview study and as a part of the measurement of positive communicative behaviour in the present study. Although eye-contact was only used as a measure of resident communicative behaviour in the present study, it is evident from the literature review and from the interview study that eye-contact is two-way communication strategy that requires the commitment of both members of the dyad. Future research could look at eye-contact as a communication strategy in that it has to be enabled by the care worker in order to take place. Eye-contact also seems to be related to elements of control, cooperation, emotional communication, the initiation of interaction, attention and engagement as highlighted in the literature review, by participants in the interview study and supported in the findings of the present study. Eye-contact as determined by the care worker warrants further research in future.

## **6.6 Conclusion**

The findings from this experimental study indicate that care worker communication style appears to effect the communicative behaviour of care home residents with dementia. In interactions where the care worker varied their communication style from usual the communicative behaviour of the resident with dementia was seen to vary also.

The results of this study also seem to indicate that care workers should use short, precise and syntactically simple instructions, otherwise known as alpha commands, when communicating with people with dementia in order to increase the level of resident positive communicational behaviour. Although it must be cautioned that this study was only conducted on three care worker-person with dementia dyads the pattern of increased positive response behaviour in accordance with the use of alpha commands was observed in all three dyads. This study also indicates that training care workers in the use of alpha commands is a simple, efficient process.

This study also appears to imply that care workers should use alpha commands in order to increase the possibility of compliance. Again, with the caution that the effects of this communication strategy were only studied in three dyads, the use of alpha or beta commands by care workers accounted for 35-37% of the variance in compliance to instructions in each dyad. Therefore, the use of alpha commands could increase the compliance rate of residents with dementia by approximately a third in interactions with people with dementia.

## 7. Conclusion

To conclude this thesis the original research questions will be considered. The overall question that this research sought to address was:

**How does care worker communication style effect the communicative behaviour of care home residents?**

This question was answered by addressing the following sub-questions:

1. According to health and social care professionals, in what way does care worker communication style effect the communicative behaviour of people with dementia?
2. What are the factors that facilitate or hinder communication with people with dementia?
3. Can the effectiveness of communication strategies be demonstrated in an experimental context?

The first two questions were addressed in the analysis of 16 expert-interviews with healthcare professionals experienced in dementia care. While considering the limitations of sampling and the desire of the participants to appear socially acceptable to the researcher, the findings of this study were as follows:

- It was suggested that the personal attributes of the healthcare professional determine their ability to facilitate communication with a person with dementia. These attributes included whether the healthcare professional had the values and skills to develop relationships with the residents, whether they had character traits that induced trust and rapport, and whether they possessed knowledge of how dementia effected the behaviour of people with dementia. It was thought that these care giver attributes encouraged

communication between healthcare professionals and care home residents with dementia.

- There are practical strategies that facilitate communication between healthcare professionals and people with dementia. These included verbal strategies such as simplification and repetition, non-verbal strategies such as touch and eye-contact and other more general strategies such as pacing an interaction and distracting the resident from potentially distressing situations.
- There seem to be factors that affect the implementation of these strategies in a healthcare context. These include the management of the workplace and whether there is a communication friendly ethos. Another factor was whether healthcare professionals are given opportunities to receive training and to put training into practice by management. In addition, staffing appears to impact a healthcare professional's ability to engage with residents on a daily basis, as well as the physical conditions of the workplace and whether there are the ambient conditions for interaction with residents.

From these interviews it can be concluded that professionals who work with people with dementia believe that their personal values, characteristics and implementation of strategies determine the way in which they interact with residents and the way in which residents respond to them. However, the way in which the professionals implemented these factors were affected by the culture and physical characteristics of the workplace.

The interview study indicated that there are many factors that influence communication between healthcare professionals and people with dementia in healthcare contexts. From the literature review it was evident that very few of these

factors have been studied in previous research and it is therefore not possible to determine the impact of the factors and strategies referred to by the interview participants. Building on this knowledge, an experimental study was constructed to determine the effectiveness of two of the communication strategies referred to by the interview participants. In this way the third research question was addressed.

Three care workers were trained in the use of one of the strategies seeking to improve resident comprehension, that of using simple and precise instructions, otherwise known as alpha commands. The second strategy was chosen for the purpose of enabling resident expression, that of pacing the interaction to the same speed as the resident. Each care worker-resident dyad was then filmed carrying out their morning care routine on four separate occasions. Each filming session related to a condition. These conditions consisted of usual communication, a condition where the care workers were asked to use more alpha commands, a second communication as usual condition and a condition where the care worker was asked to pace the interaction by leaving greater opportunity for the responses of the resident.

The positive communicative behaviour of the resident was measured using an adapted version of Perrin's Positive Response Schedule which measured the frequency of instances when the resident sought eye-contact, initiated interaction or were engaged with the same task as the care worker. The level of negative communicative behaviour was measured using the Resistiveness to Care Scale (Mahoney et al., 1999) as these behaviours were thought to show an unwillingness to engage with the care worker. The residents' compliance to care worker instructions was also analysed.

Although this study was only carried out on three care worker-person with dementia dyads, the following tentative conclusions can be drawn from this experiment:

- There is a moderate positive correlation between the use of simple and precise instructions and the positive communicative behaviour of residents with dementia. This finding supports work carried out on communication styles and compliance (Christenson et al., 2011) and task completion (Kemper & Harden, 1999; Small et al., 1997; Tomoeda et al., 1990) but adds the new dimension of encouraging interaction rather than simply compliance.
- The technique of using simple and precise instructions can be taught quickly and easily to care workers with immediate effects on resident behaviour. However, the optimal approach for the training of this strategy, such as the length and frequency of teaching, practice and feedback sessions, has not yet been established and is a task for future research in this field.
- The best approach for teaching, implementing and measuring the strategy of pacing has not been established in this study. This strategy as defined by the healthcare professionals in the interview study has greater complexities which could be examined more effectively through the use of other research methods such as conversational analysis.
- There may be some form of positive relationship between the use of precise and simple instructions by care workers and compliance to those instructions by a person with dementia. Although this relationship was observed across conditions within dyads, no significant correlation was found across dyads. A larger sample size would assist in establishing the nature of this relationship.

This thesis has contributed to the research literature on the communication between care workers and people with dementia. It has addressed the following gaps that were identified in the literature:

- This thesis has introduced the voice of those who work with dementia on a regular basis into the dialogue on communication in dementia care. In consequence, new factors were identified which have not yet been addressed in previous research and could be crucial to the care of people with dementia.
- This thesis adopted an experimental design with the purpose of establishing the direction of causality between care worker communication style and resident communicative behaviour.
- This thesis identified individual communication techniques and sought to establish their effectiveness in isolation from other communication strategies with the use of real-time observational measures.

Following the findings of this exploratory study, the next step in this area of research is to further establish the relationship between care workers' use of simple, precise instructions and increased positive communicative behaviour in care home residents with dementia. This can be achieved through devising and implementing a more substantial training package in alpha command communication techniques for care workers followed by the implementation of a larger more controlled experimental study with a greater number of participants controlled for variables such as dementia subtype and severity. Conditions should be employed and filmed over longer periods to establish the longer term effects of alpha commands on care home residents with dementia.

In this way, the finding of this study, that training care workers to adjust their communication style does effect the communicative behaviour of care home residents, can be further strengthened.



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## Appendix 1. Participant information sheet



### Institute of Work, Health & Organisations

The effect of caregiver communication styles on care home residents with dementia: Stage I

As a care worker, you work with people with dementia on a daily basis and will have a lot of experience of communicating with this group of people. This is why I am asking you to participate in this research.

These interviews are part of a research project being undertaken by the Institute of Work, Health and Organisations at the University of Nottingham. Its aims are:

- To explore the challenges you face when communicating with people with dementia.
- To find out your opinion on what helps.

The ideas gained from these interviews will be used to design the next stage of the research and will provide information that may help to improve communication between people with dementia and those who care for them.

Over the next 30mins I would like to interview you to hear your opinions on this issue and gain your perspective. Please answer as openly as possible. Everything you say will be taken in complete confidence.

With your permission, the interview will be tape recorded to prevent me taking too many notes and missing anything important. Everything you say will be kept confidential and at no time will you be asked to identify yourself on the recording. The transcript of the interview, without your name, will be kept until the end of the research and will only be accessible to us as researchers.

This research is being conducted by Miriam Gray and supervised by Professor Amanda Griffiths, Dr Shirley Thomas and Dr Adam Gordon. At the end of the research results will be circulated to care home staff through your manager. If you would like to know more about the research, please contact Miriam (email: [lwmg@nottingham.ac.uk](mailto:lwmg@nottingham.ac.uk) tel: 0115 8467543) . If, after the interview, you have any concerns you wish to raise please approach your supervisor.



## Appendix 2. Interview guide for interviews with care workers

Main questions	Prompts and probes
<ol style="list-style-type: none"> <li>Just to start off with: In a couple of sentences, what does your job involve on a daily basis?</li> <li>For how long have you been working with people with dementia?</li> <li>Can you explain to me some of the challenges of communicating with people with dementia?</li> <li>From your experience, could you tell me about some of the tricks or strategies that you've found that help them understand what you're saying or what you want them to do?</li> <li>What about things that help you to understand them?</li> <li>People with dementia sometimes become worried or agitated, are there things that you do (or don't do) to help prevent that.</li> <li>Can you think of a situation where someone was acting in a way that actually hindered communication? Are there things which you think definitely don't work?</li> <li>In what kinds of situations does most of your communication with residents take place?</li> <li>This may be quite a difficult question but in what ways do you think you speak differently to residents than you would to say a friend or colleague? For example how loudly you speak, the words you use or the kinds of things you talk about?</li> <li>Have you ever had any training in communication?</li> <li>Do you think there's anything important that we haven't talked about?</li> </ol>	<p>Has your job always been the same or has it changed over the years?</p> <p>Probe 1: Strategies to encourage participation in communication.          Probe 2: Different for different residents?          Prompt: Maybe an approach or attitude?</p> <p>Probe 1: Do you do these things consciously?</p> <p>Prompt 1: Is it during care activities or can you stop and have a chat?</p> <p>Probe 1: Do you think these things help with communication?          Probe 2: Do you feel you have much chance for a proper chat with the residents?          Probe 3: Do you ever share your own thoughts and feelings with the residents? Do you/they enjoy this?          Probe 1: Was this helpful? In what way?</p>

### Appendix 3. Interview guide for interviews with other healthcare professionals

Main questions	Prompts and probes
<ol style="list-style-type: none"> <li>Just to start off with: In a couple of sentences, what does your job involve on a daily basis?</li> <li>For how long have you been working with people with dementia?</li> <li>Can you explain to me some of the challenges of communicating with people with dementia?</li> <li>Are there any strategies that you've found that help them understand what you're saying or what you want them to do?</li> <li>Is there anything that can help you to understand them?</li> <li>People with dementia sometimes become worried or agitated, is there anything, in your view, that can help prevent that?</li> <li>Is there anything that hinders communication? What doesn't work?</li> <li>Do you think there is anything that especially characterises conversation with people with dementia? Do you think in general you speak differently to dementia patients than to a friend or colleague?</li> <li>Have you ever had any training in communication?</li> <li>Do you think there's anything important that we haven't talked about?</li> </ol>	<p>Prompt: Has your job always been the same or has it changed over the years?</p> <p>Probe 1: Strategies to encourage participation in communication. Probe 2: Different for different residents?</p> <p>Prompt: Maybe an approach or attitude?</p> <p>Probe 1: Do you do these things consciously?</p> <p>Probe 1: Do you think these things help with communication? Probe 2: Do you feel you have much chance for a proper chat with the residents? Probe 3: Do you ever share your own thoughts and feelings with the residents? Do you/they enjoy this? Probe 1: Was this helpful? In what way? What did it involve?</p>

## Appendix 4. Example transcript

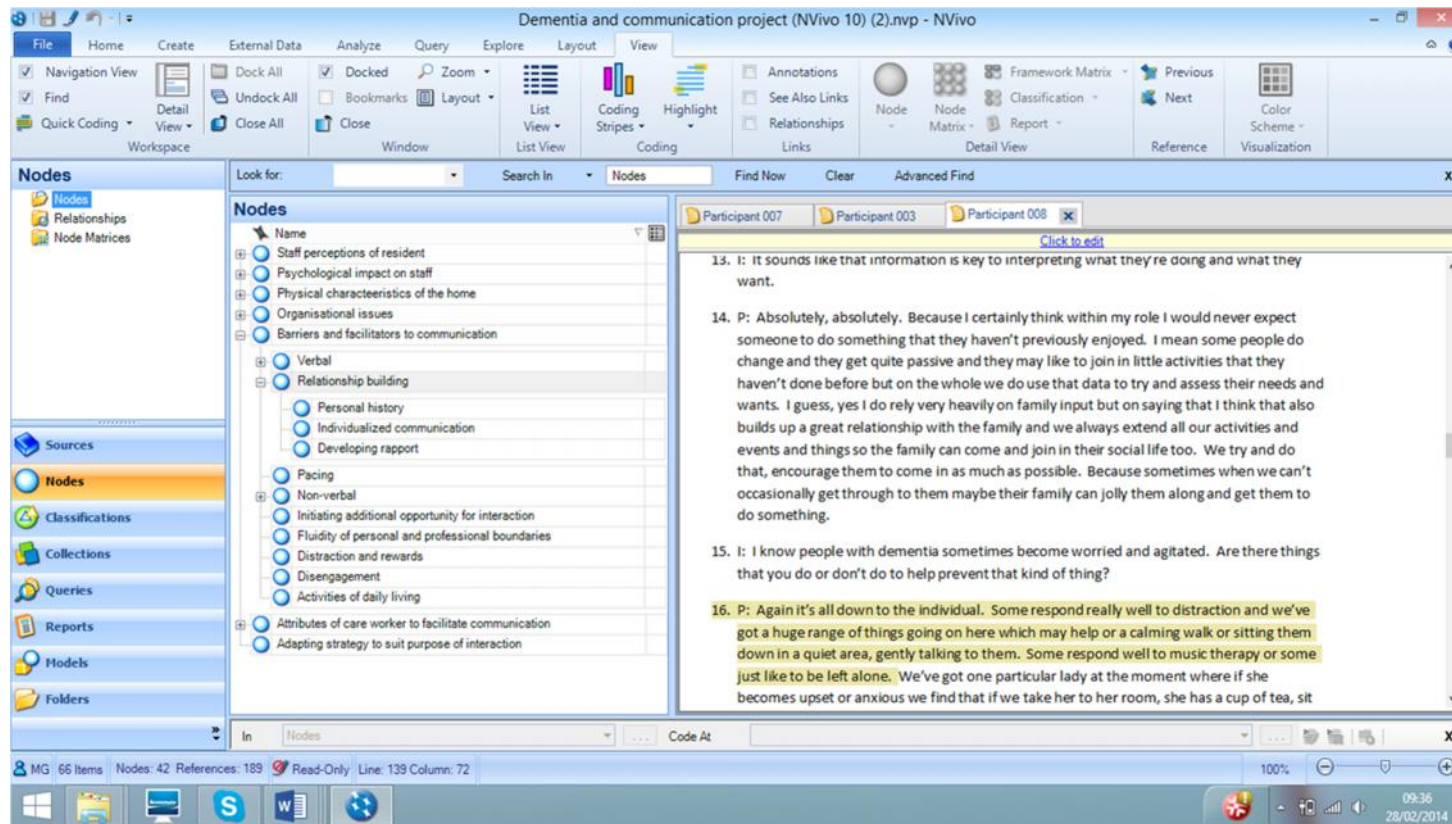
### Partial transcript of participant 7

13. I: It sounds like that information is key to interpreting what they're doing and what they want.
14. P: Absolutely, absolutely. Because I certainly think within my role I would never expect someone to do something that they haven't previously enjoyed. I mean some people do change and they get quite passive and they may like to join in little activities that they haven't done before but on the whole we do use that data to try and assess their needs and wants. I guess, yes I do rely very heavily on family input but on saying that I think that also builds up a great relationship with the family and we always extend all our activities and events and things so the family can come and join in their social life too. We try and do that, encourage them to come in as much as possible. Because sometimes when we can't occasionally get through to them maybe their family can jolly them along and get them to do something.
15. I: I know people with dementia sometimes become worried and agitated. Are there things that you do or don't do to help prevent that kind of thing?
16. P: Again it's all down to the individual. Some respond really well to distraction and we've got a huge range of things going on here which may help or a calming walk or sitting them down in a quiet area, gently talking to them. Some respond well to music therapy or some just like to be left alone. We've got one particular lady at the moment where if she becomes upset or anxious we find that if we take her to her room, she has a cup of tea, sit and chat with her she'll calm down, she'll probably want a little time on her own and then she's ready to come back and join the community group. However, some residents if they work themselves into a real stew for want of a better word there's sometimes no trigger and there's no pacification techniques and sometimes we just have to withdraw and allow them to settle in their own time. I mean you need to make sure that everyone's safe and there's not gonna be any negative impact from their behaviour but sometimes you just have to see that your

input is only going to escalate the situation and again you have to look at each individual situation on merit. Certainly with dementia there is absolutely no way you can have an across the board thing. You have to look at each and everybody as a person and again that's only through observation, something I do quite a lot in my role to try and develop the care plans and how we can move forward with that.

17. I: Have you ever seen a situation where someone was trying to communicate in a way which you actually thought hindered it? Are there things that you think definitely don't work when you're communicating?
18. P: Oh without a doubt. And I think it's sometimes only a lack of experience. It would certainly never be done in a way that would be, or could be conceived as wrong. I think sometimes people are sometimes misinformed in the fact that they might carry on trying to diffuse a situation where to me I can see that it's not going to work. But as I say, all the staff here have amazing training opportunities and everybody is quite happy to take on board what everybody else is saying. So very rarely but sometimes, if there's a younger member of staff and they're not particularly experienced you might say, "Do you think we should step away from this situation and try something else?" or, "Perhaps leave this person for a little while and have a bit of a rethink." But like I say everybody's really good here and works together as a team so it's not so much of an issue I don't think.
19. I: What kind of situations do you tend to communicate most with residents? Are there things you're doing or do you get to just sit down and have a chat?

## Appendix 5. Screen shot of NVivo coding of interview transcript



## Appendix 6. One theme

### All quotes for sub-theme 'Touch'

#### Participant 01

1. Some of the patients it's not medication they want it's just patience and care and guess what, touch. All this rubbish about you must not hold people, touch people, because they'll sue you for this and that, and that's where we're going wrong because these people need touch.
2. they need to be touched. Sometimes when they're going really agitated and wild and screaming all they need to do is to be held, hugged, held. You can even do it backwards as well as forwards, just held. Sometimes, just to calm them. Rock, gentle rock, hold and rock. All those things I don't see done anymore and that's why we're getting it all so wrong. You rock and you hold and say "Shall we sit down now?" You know? It's not a degree thing.
3. Some people, they are difficult to touch. Some, you might find that people who want, who really didn't mind about being touched get very nervous about people coming to touch them. Sometimes it's because they have had some experience of, you know, people touching them roughly and they're frightened, even though they're in dementia they are frightened.
4. what I usually do is go and touch them and say "Have you had a good morning this morning? Because I've had a lousy morning, a lousy morning and I'm still having a lousy morning."
5. And that's it but touch them, don't just go and sit. Touch them, let them know you're talking to them.

#### Participant 03

6. It's like, or when we do everything could be seen to be task orientated but really they might want you go and speak to them and maybe they might not want you to be cheerful, they might want you to be sympathetic, to understand. They might be in pain and they don't want you to make jokes they want you to be there for them and maybe hold their hand and whatever. That varies as well.
7. It can be just, we've got this new thing. We're starting this new aromatherapy and hand massage thing, I'm doing it with another girl. So we're gonna have the, I don't know what it's called, is it called diffuser or something? Yeah where you put the oils and things. And at the same time that will be for the people who can't really speak or who don't speak much or who, you know who just don't have a conversation with you basically. So that will be for them it's that, touch thing and sense thing.

#### Participant 05

8. I mean I watched, a young girl I think you interviewed her this morning and we've got a lady here who's fixated at the moment on her babies dying. We've had a look through the care plans and they never did, in fact they come to visit her. But, the girl this morning she spent 10 minutes sat with her, with her arm around her. You know, then she calmed down and got back on with eating. But she had that time.

#### Participant 06

9. Because if she's started agitating and if you raise your voice it will be worse. So I think if they've started you've got to lower your voice. Try to pat her back, try everything...
10. I: Physical contact as well.
11. P: Yes. She'll be alright. We do have another lady, she just, unexpected but if you try to pat her back, poor lady talking, she'll be alright. "Do you need a cup of tea?" and then if you make a cup of tea she'll be alright.

#### Participant 07

12. But you can reassure them just by physical touch sometimes and things like that or by guiding them somewhere,
13. Some of them because of the nature of the dementia and the lack of communication it might be on a passive level but even if I sit and do a hand massage or a manicure for somebody or just sit and chat to them about their family or what I know about them something might be going through.
14. P: Oh absolutely, contact is amazingly important. There was a school of thought at one time that you shouldn't be too touchy feely but to be honest a lot of the residents do respond greatly to love, cuddles, hugs, holding their hand. Some of them are very tactile and a lot of the families make that known when they're admitted. They actually say "If it's not beyond your call of duty they deeply relish cuddles and loves." And it's just like having heaps and heaps of grandmas and grandpas really. And yes it's an extremely important. I would say touch is quite key really.

#### Participant 08

15. We do a lot of hand massages and feet. I don't really like it (shaking her head) but tonguing their hairs and...

#### Participant 09

16. P: I think again with some people it's different forms of communication coz some people don't respond particularly well to touch but with other people it's a way of getting over that barrier with them.

17. I: Right so touch is something that you'd use. What kind of touch do you mean?
18. P: I mean it depends what the person's like or what kind of mood they're in. If they're upset it's a bit of comfort or something like that.
19. I: Arm round their shoulder or something like that?
20. P: Yeah, yeah. But if like, say if you're guiding someone and they don't necessarily understand what you're trying to communicate to them, if you just like placing your hand on them, showing your way kind of thing, it's sometimes more effective doing it like that.

#### Participant 12

21. There's also in the culture, the political culture that we live in there's nervousness about things like physical contact and other ways of connecting with a person so if a person is presenting in a very childlike very vulnerable way there are, I think, a proportion of people who would feel uncomfortable even hugging that person or holding their hand would be seen as inappropriate. Whereas I don't accept that I've regularly hugged patients and regularly, in an interaction with a patient have physically held their hand. I don't see anything wrong with that provided it's, provided you're not imposing that on the person.
22. if I imagine myself, through no fault of my own, being consigned to a ward where I wasn't allowed to make physical contact with another human being outside of very invasive personal care, that just sounds like hell. To never hold a hand, to never hug, to never, it's just horrific. You could almost, not condoning it, but you could almost understand it in a hospital setting with hospital rules when we're still very governed by those conventions and it's not intended that people stay for any length of time though often they do. But in permanent residences in permanent cared for environments there's got to be a different way to see that. I know there's got to be checks and balances that need to be put in place and people's safety and vulnerability need to be dealt with but it just seems horrific to me.

#### Participant 14

23. So you simplify your language and you have to be aware of non-verbal communication issues so body posture, body tone and facilitating things like hand-shakes and touch.
24. So if you come up to a patient and you talk to your junior doctor but you do not talk with the patient you are denying them their personhood, it's discourteous. However, going and shaking their hand and saying who you are can make the experience less frightening.
25. So, you know, we have a mental health specialist physio. And you'll find analogies in learning disabilities and the way, you know, I don't know if you have a stereotype of a learning disabilities physio? No? Lots of hugs,



lots of touch, lots of games, lots of fun. And there are very definite analogies about being very up-beat.

Participant 16

26. So in terms of communication we're looking for eye contact. Often some physical touch, though there's some people who don't like being touched, but getting some sort of engagement. Using physical prompts and using non-verbal cues if you want somebody to stand up and walk.
27. So very often you resort to observation and certainly a lot of the time resort to eye contact and maybe a thumbs up or a smile. Or a physical cue to sort of wave your hand to stand up or a hand behind the back.
28. I find a lot of the time when I'm working with carers, with staff in care homes and they're walking with somebody towards a chair and the person's spatial awareness is impaired by their dementia and they start to sit down long before they get to the chair. And you hear this rising panic in the voice of the carer going, "No, no, no, take two steps back, two steps back, now step to the side, step to the side." And when I'm doing falls training I'm saying to them; does two steps backwards, does stepping sideways, does that mean anything to that person? And would you be better to actually stand next to that person and nudge them to where that person needs to be? So sometimes it might be just simplifying it down to what might almost sound a quite bossy instruction and not then flowering it up with loads of, 'could you', 'can't you' and 'the weather's nice' and, you know, not too much other sensory information going in really.
29. I might suggest some hand cream and rubbing some hand cream and maybe, you know tactile stuff. Maybe a gentle bit of music where somebody might respond and suddenly start singing which you see so often with people who are given the opportunity.
30. So there will be some people who respond very well to an arm round the shoulder. Some really tactile stuff. If somebody feels that that's not allowed, that we haven't got time to do that then they're not gonna do it.
31. Is there just something, and my gut feeling and this isn't based on any evidence or anything scientific but sometimes, sometimes eye contact and gentle touch can take you on a slightly different journey with someone.

## **Appendix 7. Evolution of coding scheme: 3 iterations**

### **Coding scheme 09/01/12**

1. Alheimers and dementia
2. Individualized care
3. Know the individual
4. Personhood
5. Carer attitudes
6. Things that shouldn't be done
7. Problems associated with dementia
8. Independence
9. Extra resources
10. Dementia care has changed over time
11. It's just protocol
12. Work to their abilities
13. Drifting in and out of reality
14. Non-verbal communication
15. Effect of communication on residents
16. Being attentive to resident
17. Strategies to care
18. The right environment
19. Going against guidelines to care
20. Dealing with distressed behaviour
21. How carers become skilled
22. What's the disease and what's the person?
23. Change the person
24. Assumptions about dementia
25. Activities
26. Sense of reward for care worker
27. Task oriented care
28. You have to be realistic
29. Providing opportunities for communication
30. Personal disclosure
31. Dissatisfaction with the present system
32. Expect the challenge
33. Issue of age gap
34. Change the way you speak
35. The job is hard
36. Frustration
37. There's no rule to it
38. They're just like us
39. People with dementia knowing their care workers
40. It doesn't have to make sense

## Coding scheme 08/03/12

- 2) Barriers and facilitators to communication
  - a. Relationship building
    - Personal history (family history, diagnoses, preferences and habits)
    - Developing rapport (humour, appropriate topic for communication)
    - Individualized communication (catering for individual differences and abilities, including not uncovering weaknesses of the individual)
  - b. Verbal
    - I. Language (choice of words, going down to their level)
    - II. Speech characteristics (volume, pitch, speed)
    - III. Explanation of actions
    - IV. Tone of voice (happy, calm, stress, importance of carer mood, controlling)
    - V. Repetition
    - VI. Questioning
  - c. Non-verbal
    - I. Eye contact
    - II. Touch (gaining attention, affection, guiding, comfort)
    - III. Communication aids, demonstration and pointing (signs, gestures, picture cards)
    - IV. Facial expression (smiles, friendliness)
  - d. Utilising opportunities for interaction and altered expectations.
    - During ADLs
    - Additional opportunities
  - e. Pacing (matching speed to verbal/non-verbal behaviour to that of the resident)
  - f. Disengagement
  - g. Distraction and rewards
- 3) Attributes of care worker to facilitate communication
  - a. Patience
  - b. Respect and upholding dignity (politeness and actions that indicate respect)
  - c. Attention and sensitivity to residents' needs, responses, abilities and mood
  - d. Ability to engage with residents' reality
    - Includes expectations about what can be understood in interactions and engaging with emotions rather than factual content.
    - Empathy
  - e. Honesty/integrity (just mention this, small node)
  - f. Creativity (just mentioned, small node)
  - g. Appropriate beliefs about dementia (Need to compare this with cognitions and attributions regarding dementia.)
  - h. Fluidity of personal and professional boundaries (voluntary personal disclosure, distinction between job-role and personal relationship)
- 4) Physical characteristics of the home
  - Noise
  - Space
  - Temperature
- 5) Organisational factors
  - a. Staff training
  - b. Staffing and time constraints
  - c. Best practice (most of these quotes could be distributed into other nodes, however it seems like it's a point that should be made)
  - d. Organisational culture and leadership
  - e. Schedules and targets
- 6) Psychological impact of communication on staff
- 7) Staff perceptions of residents
  - a. Cognitions and attributions regarding dementia (including personhood)
  - b. Problems associated with dementia related to communication
    - I. Short term memory loss
    - II. Drifting attention
    - III. Confusion
    - IV. Dysphasia
    - V. Unpredictability (mood, health, abilities)
    - VI. Degeneration
    - VII. Resident choosing the wrong words
    - VIII. Mental capacity
  - c. Challenging behaviours
    - Paranoia
    - Aggression
    - Agitation
    - Vocalisations
    - Wandering
  - d. Problems associated with the elderly
    - Visual and auditory acuity
    - Co-morbidity

## Coding scheme 28/03/12

1. Attributes of care worker to facilitate communication
  - a. Personal characteristics
    - i. Patience (including tolerance)
    - ii. Attention to residents' needs, responses, abilities and mood
    - iii. Honesty
    - iv. Creativity
  - b. Skills
    - i. Relationship building (including stereotypes and assumptions)
    - ii. Initiating and using opportunities for interaction
    - iii. Ethics, respect and dignity (including care worker values)
    - iv. Engaging with resident's reality (validation, reality orientation and emotional salience)
    - v. Not exposing the deficit
  - c. Understanding about dementia and communication
    - i. Realistic expectations,
    - ii. Appropriate attributions of resident behaviour
    - iii. Misc (inc. ABC model, role of amygdale, use of person-centred care, emotional memory, lack of communication assessment, belief in brain processing without external responses, differences between types of dementia)
  - d. Knowledge
    - i. Problems associated with dementia related to communication (short term memory loss, drifting attention, confusion, dysphasia, unpredictability, degeneration, loss of mental capacity)
    - ii. Challenging behaviours (paranoia, aggression, agitation, vocalisations, wandering)
    - iii. Problems associated with the elderly (visual and auditory acuity, co-morbidity)
2. Strategies to facilitate communication
  - e. Verbal
    - i. Language (choice of words, going down to their level)
    - ii. Speech characteristics (volume, pitch, speed)
    - iii. Explanation of actions
    - iv. Tone of voice (happy, calm, stressed, importance of carer mood, controlling)
    - v. Repetition
    - vi. Questioning
  - f. Non-verbal
    - ii. Eye contact
    - iii. Touch (gaining attention, affection, guiding, comfort)
    - iv. Communication aids, demonstration and pointing (signs, gestures, picture cards)
    - v. Facial expression (smiles, friendliness)
  - g. Pacing (matching speed of verbal/non-verbal behaviour to that of the resident)
  - h. Disengagement (knowing when to withdraw and had the situation to another person)
  - i. Distraction and rewards
3. Organisational factors
  - a. Culture, leadership and management
  - b. Staff training
  - c. Staffing establishment and workload
  - d. Best practice (including fluidity of personal and professional boundaries)
4. Physical characteristics of the home (noise, space and temperature)
5. Impact of communication quality on staff (job satisfaction, frustration, helplessness, rewards)

## **Appendix 8. Segment of reflective journal**

7/1/12

The care worker interviews seem to all have a person-centred care basis. Personhood is discussed quite regularly and also individualised care. Also the care workers often stray from communication and talk about generalised care, or they embed communication in care so that good quality care is all about communicating effectively.

10/2/12

The participants often talk about stepping out of their own reality and into the reality of the person with dementia, though a couple seem to say this is impossible, others say this is very necessary. This seems to be a therapeutic skill maybe?

16/2/12

Discussion of challenging behaviour is quite dominant in the interviews but I need to make sure I'm not just describing dementia but how these relate to communication. Participants do seem to think that effective communication can prevent challenging behaviour or calm someone down enough to stop it.

## **Appendix 9. Participant information sheet for care workers**

### **Better communication with people with dementia**

In your line of work you have a lot of experience communicating with people with dementia. This is why I am inviting you to help with this research. It is being undertaken at the University of Nottingham. Its aim is to find out what type of communication style works best.

I would like you to take part in a project where I will look at interactions between you and one of the care home residents. This will take place during morning care as the resident is washed and dressed. I would like to video this same slot a total of 6 times. On most occasions I will ask you to communicate to the resident as you would normally. On two occasions I will ask you to slightly change the way in which you communicate. For these two care episodes I will run training and practice sessions so you can get used to communicating in this way. I will not fully explain the exactly what I want you to change until the training session so that it does not accidentally interfere with how you would normally communicate.

- You would be free to stop being involved in the research at any time. Any data we have collected would not be used in the research and could be destroyed if you wished
- Only members of the research team will have access to the videos. The videos will be stored securely in a locked cupboard at the university.
- Any publication as a result of the research will not contain any information that could identify the participants.

This research is being conducted by Miriam Gray and supervised by Professor Amanda Griffiths, Dr Shirley Thomas and Dr Adam Gordon. If you would like to know more about the research, please contact Miriam (email: [lwxmlg@nottingham.ac.uk](mailto:lwxmlg@nottingham.ac.uk) tel: 0115 8467543). If you have any concerns please tell me, or feel free to contact my supervisors.

## Appendix 10. Mental capacity form

### Mental Capacity Act Two Stage Test

Name:

Address:

Date of Birth:

Hospital No:

Date of test: .....

#### **Decision to be made:**

.....  
.....

To support the named person to make a decision about their care/treatment, I have given them relevant information to make a decision using:

☐ Simple Verbal Language   ☐ Picture Information   ☐ Leaflet

☐ Other: Please

State.....

#### **Two Stage Test:**

##### **Stage 1**

The named person has an impairment of, or a disturbance in the functioning of their mind/brain due to:

- |  |   |
|--|---|
| <input type="checkbox"/> Dementia                        | <input type="checkbox"/> Long Term Brain Damage |
| <input type="checkbox"/> Mental Illness                  | <input type="checkbox"/> Delirium               |
| <input type="checkbox"/> Symptoms of Alcohol/Drug Abuse  | <input type="checkbox"/> Head Injury            |
| <input type="checkbox"/> Significant Learning Disability | <input type="checkbox"/> Other                  |
|  | Please  |

State.....

##### **Stage 2**

They lack capacity to make this particular decision as they have been unable to:

- |   |  |   |  |
|---|--|---|--|
| <input type="checkbox"/> Understand<br>the<br>Information | <input type="checkbox"/> Retain<br>Information | <input type="checkbox"/> Weigh up<br>Consequences | <input type="checkbox"/> Communicate<br>Decision |
|---|--|---|--|

Please provide your evidence for your stage 2 conclusion:

NOTE: An **Independent Mental Capacity Advocate (IMCA)** should be involved where the person is believed to lack capacity, has no-one appropriate to consult and faces:

- ✓ **Long Term Accommodation Change** (e.g. moving into residential care on discharge) and/or
- ✓ **Serious Medical Treatment** (e.g. 'Allow Natural Death').

There is a statutory duty on NHS bodies to refer **by law** those who meet the criteria. This should be done before any best interest decision is made. Further details can be found on the intranet MCA policy, NUH safeguarding Adults website or the MCA Code of Practice.

### **Mental Capacity Act - Best Interest checklist**

1. **Advance Decision**  
Has an Advance Decision to refuse treatment been made about the decision in question and is it valid and applicable. Yes ☐ No ☐  
Comments:.....
2. **Lasting Power of Attorney**  
Is a Lasting Power of Attorney (LPA) in place for the decision in question? Yes ☐ No ☐  
If yes, who holds this and is it registered.  
.....
3. **Court of Protection Deputy**  
Has any deputy been appointed by the Court of Protection for the decision in question? Yes ☐ No ☐  
Comments:.....

**If the answer is yes to question 1, the checklist need not be completed. If the answer is yes to questions 2 and 3, the LPA or Deputy will be the decision maker. Please refer to the Code of Practice for further information on how to proceed in these circumstances. If the answer is no, continue through the checklist below:**

These factors that **must always be considered** when trying to work out someone's best interests:

- Working out what is in someone's best interests cannot be based simply on someone's age, appearance, condition or behaviour.
- All relevant circumstances should be considered when working out someone's best interests
- Every effort should be made to encourage and enable the person who lacks capacity to take part in making the decision.
- If there is a chance that the person will regain the capacity to make a particular decision, then it may be possible to put off the decision until later if it is not urgent.
- Special considerations apply to decisions about life-sustaining treatment (see paragraphs 5.29–5.36 of the Code of Practice).
- The person's past and present wishes and feelings, beliefs and values should be taken into account.
- The views of other people who are close to the person who lacks capacity should be considered, as well as the views of an attorney or deputy.

*(Taken from Mental Capacity Act Code of Practice point 5.13 pages 71-72)*

### **Please document your evidence of how you have considered these factors:**

1. **Taking into account the above points and any other relevant factors, the best interest decision made for this patient is:**
2. **How the decision was reached?**
3. **What the reasons for reaching the decision were?**



**4. Who was consulted to help work out best interests?**

**5. What particular factors were taken into account?**

Name:.....Sign.....  
Job Title:.....

## **Appendix 11. Participant information sheet for residents**

### **Better communication with people with dementia**

Communication is often difficult with dementia. I am doing some research with the University of Nottingham. I want to find out what type of communication works best.

I want the care worker to try different ways of talking with you.

I will film the care worker talking with you during morning care as you are washed and dressed to see how the care worker communicates.

Would you like to take part? You may like to talk to a friend or relative to help you decide.

You would be told every time we collect data. If you do not want to be involved we will stop.

Only me and my researchers will see the videos. The videos will be kept in a safe place.

Results of this research will not contain any information that could identify you.

This research is being conducted by Miriam Gray and supervised by Professor Amanda Griffiths, Dr Shirley Thomas and Dr Adam Gordon. To contact Miriam (email: [lwmg@nottingham.ac.uk](mailto:lwmg@nottingham.ac.uk) tel: 0115 8467543).

## **Appendix 12. Participant information sheet for consultees**

### **Better communication with people with dementia**

As a friend or relative of a person with dementia, you know that communication becomes more difficult as time goes on. I am doing some research at the University of Nottingham. It aims to find out what type of communication style works best.

Because of their dementia, your relative/friend's ability to make an informed decision about being involved is limited. So I am asking you, as a person who knows them well, to consider whether they would be likely to consent to being involved if they were able to make the decision themselves.

In this study I would like to look at interactions between your relative/friend and a care worker. This will take place during morning care as they are washed and dressed. On most occasions the care worker will be asked to communicate as they would normally. On two occasions I will ask them to slightly change the way in which they communicate. These changes in communication are very subtle and are based on the advice of care workers and others who work with people with dementia. They should not distress those participating in any way. I would like to put a very small video recorder in the corner of the room so I can catch all the small details.

- If your relative/friend showed any indication of distress due to the research we would withdraw.
- Only members of the research team will have access to the videos. The videos will be stored securely in a locked cupboard at the university.
- Any publication as a result of this research will not contain any information that could identify participants.

This research is being conducted by Miriam Gray and supervised by Professor Amanda Griffiths, Dr Shirley Thomas and Dr Adam Gordon. At the end of the research a summary will be available. If you would like to know more about the research, please contact Miriam (email: [lwmg@nottingham.ac.uk](mailto:lwmg@nottingham.ac.uk) tel: 0115 8467543). If you have any concerns please tell me or feel free to contact my supervisors.

## Appendix 13. Consent form for consultees

### Better communication with people with dementia

#### CONSENT FORM

1. I have read and understand the information sheet.
2. I understand that I can stop being involved at any time.
3. I understand that I will be videoed but only the researchers will see the film.
4. I agree to take part.

☐☐☐☐

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of consultee	Date	Signature

## **Appendix 14. Participant profiles**

### **Resident 1 (K)**

The first participant (K) was a woman in her 80s who had been diagnosed with dementia only three months previously, though, according to her daughter, in that time her memory had deteriorated dramatically. She had been living in the care home for three months prior to the start of the project. Her daughter described her a 'local lass' who had always lived just down the road from the care home. She had married young and had two daughters. She was described by her daughter as a loving wife and mother who enjoyed making her home comfortable.

The care workers report that she has made a good and quick transition to the life of the care home and enjoys interacting with the care workers and other residents. She is frequently visited by her daughters and grandchildren. K is still able to walk with a walking aid but needs assistance from care workers to remind her what to do during activities of daily living. She was described by care workers as polite and mostly cheerful though her level of awareness was said to be changeable.

MMSE score: 6/30

### **Resident 2 (N)**

The second participant (N) was a woman in her 90s who had been diagnosed with dementia eight years previously and had been living in residential care for six years. Her daughter described her as a woman who had had a hard life who was always at home keeping house for the family though she found showing maternal affection difficult. The second of two sisters she was born with a curvature of the spine, with one leg shorter than the other and spent 7 years of her childhood in hospital. She was told she would die at the age of 30 but her daughter maintained that, although physically weak, her mother valued emotional strength and that is why she is still going now. She married and had three children. She would mostly stay at home as her physical disabilities made it difficult to go out. Her husband died 40 years previously and she lived independently for many years before developing dementia.

At the time of the study her care workers describe her as a woman with a real strength of personality but her awareness is often changeable. Sometimes she will

talk happily with care workers but sometimes she can be aggressive. She has difficulty focussing when there is more than one person in the room. She will occasionally be transferred into a wheelchair and spend the day in the lounge though she mostly prefers to stay in her bed. She needs assistance with all aspects of daily living including eating and drinking.

MMSE score: 1/30

### **Resident 3 (E)**

The third participant (E) was a woman in her 80s who had been a resident at the care home for six months prior to the start of the project. She was described by her daughter as a dominant woman who was a typical homemaker. She had lost her mother at the age of 12. She had been married twice. She lost her first husband at the age of 27 in the war. With her second husband she had four children and devoted herself to the care of her family. Her daughter described her upbringing in a 'typically 50s family' saying that she always remembered her mother 'doing something' such as cooking or baking, washing, gardening or sewing. E had been diagnosed with dementia 18 months previously at which point she moved to a care home. Before this she had been living independently at home with daily visits from carers though had been showing signs of memory loss before her diagnosis. She spent one year in residential care where she showed signs of depression saying she wished to die and fasted. She suffered a few strokes, was admitted to hospital and on discharge was moved to the present care home. Her daughter reported that since her strokes she no longer seemed depressed.

Her present behaviour described by her care workers is that she is a woman who likes things 'just so'. She is generally kind and polite to care workers but when ill can become aggressive. She still has movement in all of her limbs though does not have the muscle strength for standing or walking. She needs assistance for most activities of daily living. Most days she spends in an armchair in the quiet lounge though she sometimes requests to spend the day in bed.

MMSE score: 13/30

## Care worker profiles

### **Care worker 1 (E)**

E was a young man in his late twenties who had been working in residential care from the age of 18 when he left school. He lived at home with his wife and two young children. He worked full-time at the care home. When asked whether he enjoyed care work he said that he enjoyed the work itself and the contact with the residents but often found the nature of the work i.e. the shift patterns, the long hours and relationships with some of the staff difficult. He stated that he wished to go to university and train as a nurse but was worried about being able to support his family while training.

### **Care worker 2 (M)**

M was a woman in her early fifties who had become a care worker after her children had left home. She lived at home with her husband. She worked full-time at the care home. She said that she greatly enjoyed the work, even if she found it stressful sometimes. She said it was especially difficult at present as she was having to look after her grandchildren on her days off so was still very tired when working her shifts. She hoped to retire in a few years as she felt she was beginning to get too old for some of the more physical aspects but she was sure she would miss the work when she left.

### **Care worker 3 (D)**

D was a young man in his late teens who had started care work as soon as he had turned 18. He worked part-time to begin with but became full-time when he finished school. He said that, although he found the work challenging to begin with, he enjoyed care work and said he would probably continue working part-time while at studying at university. He was due to go and study music at university the following September.

## Appendix 15. Care worker training materials for experimental conditions

### Script for A commands: Version 2

- Thanks so much for everything you've done over the past couple of weeks.
- First of all, how have you found the past couple of weeks?
  - Have you found it strange being videoed?
  - Do you think you acted differently to normal?
  - Has it interfered too much with your normal work, taken too much time?
  - Are you happy to continue?
- Today I'd like to tell you about the first way in which I would like you to change your communication style. So up to now you've been communicating just as you would normally communicate and I've been videoing those interactions and this week I would like to introduce a communication style where you change the way in which you give instructions to the resident you're working with.
- So far I haven't told you what we're gonna change because, apparently, if you tell people how you're gonna change things they can start doing it, even subconsciously. So that's why I'm only telling you now.
- To explain this I'm going to have to bring in a piece of research that I read a while back and that this phase is based on.
  - It's by a group of researchers from the USA and they did a piece of research where they videoed interactions between residents and staff during daily care activities similar to what we're doing. They took those videos and they analysed the way in which the staff gave instructions. They wrote out everything that was said, took out all the instructions and 'coded' those instructions into different groups depending on the words they used and the way in which they were said.
- I'm just going to talk you through some of the groups:
  - A commands
    - The appropriate response that the resident has to make is clear



- The appropriate response that the resident has to make is possible
- B Commands
  - The appropriate response that the resident has to make is vague and often means that that person with dementia has to guess what you mean and guess what to do next
  - The appropriate response that the resident has to make isn't possible for the person with dementia.

Examples:

- One other thing to say is that if B commands are accompanied by a gesture that makes it obvious what you're requesting then what could have been an B command is actually an A command.

Some examples, tell me if they're A or B:

Here's a pen - B

Stop it! - B

Stand up! - A

Lift up your right arm for me. - A

Move! - B

Fly around the room. - B

Don't sit down yet – A

Stop hitting! – A

We're going to sit in this chair – B Collaborative though it's impossible for both of us to do it.

Okay? – B

Over there, in the blue chair. – A

Could you help me please? – B

Over there – B

Over there, pointing – A

We're going to sit down and take your shoes off, ok? – B It ended with something vague, it ends up being a B command.

- So I would like you to use more A commands and less B commands (preferably not any)

So, any questions?

So now, just to give you a little bit of practice I have a task, on the back of your sheets. I have scattered around the room a hat, scarf, gloves and coat and I would like you to help me put them on but I'm going to be blindfolded. So I want you to instruct me using A commands, preferably no B commands and we'll talk about it after.

### Condition 1 training hand out

#### Definitions:

1. **A Commands:** Instructions in which a verbal or nonverbal response is appropriate, clear and possible.
  - Examples: “What’s your name?” “Lean forward.”  
“Stop hitting.” “Lift your feet up.”
2. **B Commands:** Commands where co-operation is difficult because it is vague, impossible to fulfil or carried out by the care worker before the resident has chance to respond.
  - Examples: “Move.” “Stop it.” “Let’s go and have a bath.” “Wait.” “Go other there.” “Okay?”

## Script for Condition 2 training

- Thanks for all you've been doing.
  - How have you been finding it?
  - Have you had any problems? Is there anything you would like to feed back to me?
- Today I want to introduce the second way in which I would like you to change your communication. Today is all about pacing.
  - Have you heard the term before? What do you think it means.
  - Definition of pacing something is: "To advance or develop (something) at a particular rate or tempo."
  - The aim of this condition is to carry out your interactions with your residents at the same pace in which the residents themselves are working.
- People with dementia are often much slower at processing something and responding to it whether that's a question or instruction or physical movements. If we are going to interact at the same pace as people with dementia then we need to give them chance to hear, process and to react.
- Do you have any examples where you've seen people working at a different pace to the person with dementia?
- For example, have you ever heard a carer or anyone ask a resident if they wanted a cup of tea and, because they didn't get a reply straight away, they move on but then a few seconds later they say "Yes please." Or you give them an instruction like "lift your feet up" and they don't do it only to find that ten seconds later they start doing it. Or they repeat things you've already done like you've already dried their arms after a bath but a little bit later they're drying their arms themselves because they haven't had time to process that that is what you're doing?
- This pacing is aiming to move and interact at a pace that they can cope with.
- The way in which we're going to do this is that each time you initiate something that needs a response from the person with dementia I want you to wait, either for a response from them or for 5. In that 5 seconds don't talk or do anything else, just wait and be attentive to their responses.
- If they do not respond in 5 seconds then repeat your instruction again and wait for another 5secs. If they don't respond again then do what you would normally do.
- Don't change the speed of your actual speech so don't suddenly start speaking really slowly and try not to change anything else like your facial expression or what you say from normal.
- It might seem quite simple but you could be surprised by how slow 5seconds is so we're going to practice now.
- I'm going to pretend to be a person with dementia and I'd like you to, again, help me put my coat, hat, scarf and gloves on. This time I won't be blindfolded be I might be a bit slower in responding or a might not respond at all. So I want you to wait 5 seconds before either repeating or moving on.

### **Condition 2 training hand out**

When I talk about pacing, what do you think it means?

**Aim:** To carry out interactions at the same pace as the resident you are interacting with.

Do you have any examples where you've seen people working at a different pace to a resident?

In this condition I would like you to:

- Wait at least 5 seconds for a response from the person with dementia every time you initiate an interaction that requires a response.
- If there is a response in that time carry on with the interaction.
- If there is no response after 5 seconds repeat the instruction or action.
- If there is still no response after another 5 seconds move on.
- While waiting be silent and attentive.
- Do not change anything else e.g. the speed of speech, facial expression or language.

### **Exercise: Pacing practice**

I'm going to pretend to be a person with dementia and I'd like you to, again, help me put my coat, hat, scarf and gloves on while following the instructions above. This time I won't be blindfolded but I might be a bit slower in responding or I might not respond at all.

## Appendix 16. Post-intervention feedback form for care workers

### Demographic and participant responses questionnaire

#### The effect of care worker communication style on the behaviour of care home residents with dementia

Name: \_\_\_\_\_

1. Please state your age \_\_\_\_\_ years
2. What is your gender? Male/female (delete as appropriate)
3. What is your ethnic group?  
Choose **one** section from A to E then tick **one** box to best describe your ethnic group or background

- A. White
- ☐ British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other White background
- B. Mixed / multiple ethnic group
- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other mixed / multiple ethnic background
- C. Asian / Asian British
- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background
- D. Black / Black British
- ☐ Caribbean
- ☐ African
- ☐ Any other Black background
- E. ☐ Other ethnic group

4. Is your first language English? Yes ☐ No ☐  
If no please state your first language: \_\_\_\_\_
5. Please state how long you have worked with people with dementia:  
\_\_\_\_\_ yrs \_\_\_\_\_ months

6. How long have you cared for the resident you were filmed with?  
\_\_\_\_\_yrs \_\_\_\_\_months
7. Please state any qualifications you have in the care profession (NVQs, VRQs, certificates):\_\_\_\_\_
8. Please state any thoughts you have on the research in which you participated. Please be as honest and open as possible:
- a) What did you think of the **specific instructions and fewer question commands condition**?
- E.g. Did you think the changes would make any difference before filming?  
Did you feel you acted any differently than you normally would? Was it difficult to change your behaviour? Do you think the resident behaved differently?

## **Appendix 17. Instructions for 2<sup>nd</sup> researcher for inter-observer reliability coding**

### **Instructions for coding of video data**

#### **Introductory brief**

This task involves the analysis of video data by coding (labelling and recording) verbal and non-verbal behaviour according to established measures using the ELAN video analysis computer programme. The video shows excerpts from the morning care routines of three care home residents with dementia and their carer workers. I am interested in the verbal behaviour of the care workers and the verbal/nonverbal responses of the residents. The video is approximately 20mins long and contains representative sections from all of the videos. I would estimate this analysis could be completed in the space of one day. All training and guidance for the task will be supplied. No previous experience is necessary.

#### **How to use ELAN**

ELAN is video analysis software originally for linguistic analysis (so it can do lots of stuff we don't need it to do). This programme allows us to analyse the frequency and duration of certain behaviours.

Explain:

- Tiers
- Selection of data
- Annotation
- Deleting annotation
- Transcription
- Controlled vocabularies
- Altering the display (hiding tiers, altering zoom and font size, volume and speed)

If you have any questions as you go along don't hesitate to ask. You may want to note down any difficulties you have and explain why you coded the way you did.

#### **Transcription of care worker speech**

Start by, in the speech tier, select every instance of care worker speech by clicking on the red time indicator and dragging so that a blue shaded area appears over time when the carer is speaking. Right click on this shaded area and select new annotation here (then escape so that, for now, you don't have to write anything in the annotation). Go throughout the whole video doing this. Once they have all been selected go into Options and select 'transcription mode'. In this mode you can easily listen to each selected section and transcribe it. When this is done, return to annotation mode (Options> Annotation mode).

#### **Coding for command types**



After speech the first tier relates to command type. A command is defined as “a verbal request stated by the care worker in the hearing of the resident which entails a response from the resident (or could be interpreted as requiring a response by the resident i.e. the carer could mean for a statement to be rhetorical but the resident may not realise this)”. Go through all of the speech produced by the care worker and select the instances where commands are given. When a command has been identified select to make a new annotation in the command type tier. It will then give you a number of options. These refer to different types of commands, the definitions are described on the sheet provided. On the other side of the definitions sheet are a few guidelines to follow when it may be difficult to decide which command type to choose. The abbreviations are as follows:

Command type	Abbreviation
Conditional alpha	ca
Conditional beta	cb
Interview alpha	ia
Interview beta	ib
Question alpha	qa
Question beta	qb
Regular alpha	ra
Regular beta	rb
Indirect beta	inb
Exclusionary alpha	ea
Exclusionary beta	eb
Collaborative alpha	cla
Collaborative beta	clb
Compound alpha	cpa
Compound beta	cpb
Sequence alpha	sa
Sequence beta	sb
Context alpha	cta
Context beta	ctb

### Coding compliance

The next tier is compliance. In this tier you must judge how the resident responds to each command.

Compliance is defined as: “an appropriate behaviour initiated within 5secs of the end of the command and terminates with completion of the task”.

Noncompliance is defined as: “the failure to initiate an appropriate response within 5secs following the end of a command”.

Forced compliance is defined as: “the requested response is completed by the care worker instead of the resident within 5secs of the end of the command”.

For each command select the same time period as the command in the tier above and in the compliance tier select either 'c' for compliance, 'nc' for noncompliance or 'fc' for forced compliance.

### **Coding for PRS**

The Positive Response Scale codes the behaviour of the resident. We are only looking at three of the 7 behaviours listed in the original scale: look at carer, initiate interaction and engagement. Here are the definitions for the three behaviours:

**Looks at carer:** When the resident looks at the carer. This could be their whole person if they are far away. If the carer is closer only code for when the resident is looking at the carer's face, attempting eye contact. Do not code if the resident is looking at the carer's hands and what they are doing. Do not code for any carer or individual not involved in the personal interaction e.g. another carer walks into the room.

**Initiate interaction:** Any attempt to initiate interaction or obtain attention by either vocal or non-vocal means (gestures). This also includes contributions to conversations( e.g. Carer: Did you sleep well. Resident: Yes I did thank you. Resident: Did you sleep well?) Although this is part of a conversation initiated by the carer, the resident has offered a new 'contribution' in the conversation which would otherwise have come to an end.

**Engagement:** Any absorbed commitment to an activity shared with the carer where you can see the carer and the resident 'on the same page' e.g. the resident complies with a request, has an appropriate conversation with carer or anticipates the next step in a task. It may be easier to identify 'non-engagement' where the resident is obviously not understanding or not following the same train of thought as the care worker.

There is a separate tier for each of these three behaviours.

### **Coding for RTC**

The Resistiveness to Care Scale measures behaviour that is not positive but more uncooperative, distressed or aggressive. There are 13 kinds of behaviour in all (though there are very few instances of this in the videos in total). The 13 behaviours are:

- **Gegenhalten:** this refers to body movements which are of equal force in the opposite direction from the carer.
- **Grab object:** e.g. bed rails, item of clothing
- **Say no:** this also refers to other wordings of this e.g. 'I won't'.
- **Adduct:** lifting arms or legs to prevent the carer getting near to the resident's body.
- **Grab person:** e.g. grabbing the carer's wrist to stop them getting closer

- Pull away: This refers to the resident's own body, otherwise it would be in the grab object category.
- Clench: When a resident refuses to move limbs or release their grip.
- Cry: This refers to the resident raising their voice and shouting words at the carer.
- Scream: When the resident raises their voice but not using words.
- Turn away: Turning the face or body away from the carer
- Push away: Pushing the carer away.
- Hit/kick: Include biting and pinching here as well.
- Threaten: This can be threatening words or words said in a threatening way or it can be non-verbal such as a raised fist.

With each behaviour, when annotating, judge it for intensity and add the value 1: mild, 2: moderate, 3: extreme. Think about the hardest the resident could kick or the loudest they could scream and judge the amount of effort they are putting into the behaviour.

## Appendix 18. Screen shot of video analysis using ELAN

