

'MAKING THE MOST OF TIME:

**A GROUNDED THEORY TO EXPLAIN WHAT
FACILITATES NURSING HOME STAFF TO
CONNECT WITH RESIDENTS LIVING WITH
ADVANCED DEMENTIA**

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‘Making the most of time’:

A Grounded Theory to explain what facilitates nursing home staff to connect with residents living with advanced dementia

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Abstract

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Keywords: advanced dementia, care home, nursing home, social isolation, connecting, interacting, social exclusion, staff, nurses, care assistants,

Background: People living with advanced dementia in nursing homes often spend the majority of time alone, with little contact with anyone. The need to connect with others is a central part of a philosophy known as Person Centred Dementia Care. A significant body of literature demonstrates the effectiveness of a range of approaches that facilitate connections, yet, we know little about staff perspectives on what facilitates them to connect on a daily basis.

Aim: To develop a Grounded Theory to explain what facilitates nursing home staff to connect with residents living with advanced dementia.

Methods: Semi structured interviews were conducted with nursing home staff (n=21) and relatives (n=5) from seven nursing homes. Following Strauss and Corbin’s (1990, 1998) Interpretivist Grounded Theory methodology, data collection and analysis proceeded iteratively, and theoretical sampling was used to develop the emergent theory.

Results: The Grounded Theory ‘making the most of time’ explains that most connections occurred during personal care. Interdependent contextual and individual factors facilitated staff to make the most of time. Effective leaders were described to create a caring culture in which informal leaders (experienced staff) acted as role models. Staff were then more likely to understand, accept and tolerate dementia, know connections were part of their role, get to know residents and express caring values. In the right

physical environment, this then facilitated staff to make the most of time during personal care. Increased training and education from specialised dementia units and experiential knowledge from family engagement then supplement such contexts

Implications: Future research could empirically test the theory 'making the most of time'

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1 Chapter 1: Background

1.1 Introduction

In this chapter I will explain my reasons for choosing this topic. I will describe how my personal experiences led to my concern that people living with advanced dementia in nursing homes do not routinely have the opportunity to connect with those around them. I set the scene for the thesis by providing the background about people living with advanced dementia in nursing homes. Next I define connections and their relevance to this thesis. I then spend most of the chapter describing the theory of Person Centred Dementia Care (PCDC) and its key tenets including: personhood, psychological needs, positive person work and malignant social psychology. I highlight the importance of connections in Person Centred Dementia Care and the significant role nursing home staff play in ensuring connections happen in nursing homes. I demonstrate that whilst the theory of Person Centred Dementia Care is embraced in policy, it has not been implemented in practice some 20 years on. I discuss some of the challenges of implementing Person Centred Dementia Care. I conclude the chapter by suggesting that we need to better understand the experiences of the nursing home staff tasked with connecting, in the relation of the individual and contextual factors that influence them. I end the chapter with an overview of the thesis structure.

1.2 My personal interest and passion

This PhD journey began with my personal passion to make a difference to the lives of people living with dementia. The realisation that I wanted to make a difference came from personal experience of visiting a relative living with dementia in a nursing home. I was frustrated about not being able to communicate or do anything to help my relative. I wanted that to change. I had a background in biomedical sciences research, which did not allow me to make a difference in the day-to-day lives of people living with dementia

Consequently, I decided to pursue research in applied health and social care.

I began working in nursing home research with the National Institute of Health Research Clinical Research Network (NIHR CRN) in 2013. My role was to develop a network of 'research ready' care homes in Yorkshire and Humber. I enjoyed working in this role with staff, residents and their families. I was involved in a range of research studies during this time, many of which aimed to improve the quality of life and quality of care of those working in, living in and visiting nursing homes. Whilst doing this research I noticed that people living with advanced dementia were usually excluded from the research projects on our portfolio. My relative therefore, would have not been given the opportunity to participate. I saw that residents with advanced dementia spent most of the time in their bedrooms, having little or no contact with others. They were moved from their bedrooms and put in front of the television and staff did tasks around them. Staff and family only rarely established any meaningful engagement with them. I began to feel that people living with advanced dementia lived silent and invisible lives.

I noted from talking to and observing staff that they were not actively ignoring residents but they did not know what to do or had written the residents off as unresponsive to human interaction. It seemed to me that staff lacked the support they needed in order to engage with residents with advanced dementia. It also became evident to me that relatives were unsure about how to connect with, and improve how they cared for, their loved one. Many nursing home managers said they felt they were isolated from wider health and social care organisations, not knowing who to turn to for help. There was a consensus from nursing home managers, from the nursing home forums I attended, that training for staff was scarce. The training that was available was too expensive and time consuming.

I also often observed good practices and saw examples of where staff had managed to connect with residents with advanced dementia. One particular memory which stands out was when a staff member brought a doll to a person living with dementia, I remember she said she had read somewhere that it could be useful. I was doing some observation as part of a research

project. The resident, who was usually unresponsive looked at the doll with a big beaming smile and grabbed it before closing her eyes and going to sleep. It was not a big or sustained reaction, but I could see how the doll had made a difference to that resident. It was situations like this one which enabled me to see that residents with advanced dementia could live well and relatives and staff could be supported to connect. I therefore set out to explore this further. The glimpse of passion and drive in that staff member, along with my own desire to make a difference, are what motivated me to pursue this thesis. I applied for this PhD specifically because the funder, Bupa Care Homes, shared my vision to improve care for people with advanced dementia.

1.3 The background: people living with dementia in nursing homes

In the UK there are approximately 850,000 people living with dementia. Throughout Europe we have an ageing population and as dementia is more prevalent with increasing age, the numbers of people living with dementia are growing (Wu et al., 2016). We expect there to be over one million people living with dementia by 2025 and over two million by 2051 (Laing and Buisson survey, 2016). In 2014 the Alzheimer's Society highlighted the social and economic impact of dementia, estimating costs at £26 billion per year in the UK (Alzheimer's Society, 2014).

This research project is focused on care for people living with advanced dementia in nursing homes. The term 'advanced dementia' tends to be used interchangeably in the literature with 'severe dementia' and 'end stage dementia'. These terms refer to the point at which a person is living with profound functional, cognitive and physical impairments (Burns et al., 2006), including incontinence, recurrent respiratory and chest infections and swallowing difficulties, often leading to pneumonia (Mitchell et al., 2004). People with advanced dementia have varying levels of mobility and abilities to communicate. When I use the term 'advanced dementia' in this thesis I am

referring to those residents who are unable to verbally communicate and spend most of their time in bed or in a chair in their room.

Care homes have an important role in providing care for dependent older people, particularly those living with advanced dementia (Spilsbury et al., 2011). In the UK, around 486,000 older people live in 18,000 care homes (Alzheimer's Society, 2013). Approximately 280,000 of these older people are living with dementia, 70% of all residents (Alzheimer's Society, 2016). Increased longevity and prevalence of complex chronic conditions, such as dementia, means people are entering care homes older, sicker and frailer.

There are two types of care homes in the UK. 'Care homes with nursing' provide personal care and 24 hour on-site nursing care by nurses employed by the care homes. 'Residential care homes' provide personal care only, with nursing care provided as required, by local NHS primary care services (Luff, 2011). Due to the significant level of impairment people living with advanced dementia experience, many reside in nursing homes rather than residential homes. This thesis therefore focuses on nursing homes. For clarity, I will use the term nursing home for the remainder of this thesis. When I use the term 'nursing home staff', I am referring to the collective group of staff including: the manager, nurses, senior care assistants, care assistants and activities coordinators. When describing individual staff I will use their individual title (manager, nurse, senior care assistant, care assistant and activities coordinator).

Residents living with dementia in nursing homes often have complex needs and require high levels of care. A recent report showed many people living with dementia (198,000) were also living with other health conditions. Twenty seven percent (27%) of people living with dementia in nursing homes were living with heart disease, 18% had experienced a stroke and 13% were living with diabetes (Alzheimer's Society, 2016). The quality of care provided to residents in nursing homes is dependent on staff being adequately prepared to meet the medical, physical, psychosocial and palliative needs of people living with dementia (Corcoran et al., 2011; Jackson et al., 2017). This requires staff to be motivated and skilled which is not easy, particularly in a

society where nursing home work is viewed as unattractive, is underpaid and where the support is minimal (Wild et al., 2011). Working in a nursing home can be difficult. Staff often work long hours and provide complex care for little reward or recognition. The nursing home sector as a whole receives little support from primary and secondary health care services. It is often up to each organisation to ensure staff receive adequate support, in a culture where they feel valued (Nazarko, 2009).

There is a significant body of research internationally demonstrating that nursing home residents often spend their days alone with little interaction with anyone (Ward et al., 2008; Palese et al., 2016; den Ouden et al., 2015; Morgan-Brown et al., 2011) It has been suggested that many nursing homes do not offer enough opportunities for residents with advanced dementia to get involved in meaningful activities (Clare et al., 2008). Most activities are directed towards the more active or cognitively intact residents (Fossey, 2014). Residents with advanced dementia may therefore spend the majority of their time confined to their rooms having little contact with anyone (Kovach and Magliocco, 1998). A lack of connection with those around them puts residents living with advanced dementia at risk of isolation.

1.4 Defining connections

In this thesis I use the term 'connection' to refer to verbal or non-verbal meaningful interactions between residents living with advanced dementia and nursing home staff. In most situations connections are through the medium of spoken conversation and/or non-verbal communication such as gestures, changes in posture and facial expression (de Vries, 2013). For people living with advanced dementia, however, the ability to speak is often limited and connections often manifest as non-verbal communication only.

As human beings we have an innate need to connect with others and engage with the social environment. Connections between nursing home staff and residents therefore provide the foundation of any caring situation. (Brownie and Horstmanshof, 2011). Meaningful enhancing connections can

address loneliness and are integral to quality of care. Indeed a prerequisite to meeting the needs of people with advanced dementia is the ability of those providing support to meaningfully connect with those for whom they care. Connections however, can have harmful consequences, as described later in the chapter in section 1.5.5. In this thesis the emphasis is on learning how to support nursing home staff to provide meaningful enhancing connections, with less attention on connections which led to negative consequences. I took this approach because I felt taking a positive view would be more useful for practice.

1.5 The philosophy of Person Centred Dementia Care (PCDC)

The need to connect with others is a central part of a philosophy of care known as Person Centred Dementia Care (Kitwood, 1997; Sabat, 2001; Sabat, 2008). Indeed, one of the most important developments in the field of dementia care in the last 20 years has been the almost universal embrace of the philosophy of Person Centred Dementia Care.

In this section I will present Person Centred Dementia Care as the philosophy guiding this thesis. I will begin with a description. I will then consider Person Centred Dementia Care in relation to other related philosophies of care. I will argue that Person Centred Dementia Care with its focus on connections, is the most appropriate to guide this thesis. I will end the section by introducing key ideas of Person Centred Dementia Care that are important for this thesis such as personhood, psychological needs, positive person work and malignant social psychology.

Person Centred Dementia Care was developed to challenge the dominant medicalised view of dementia. Kitwood (1997) suggested that while dementia is a condition that affects the brain, the person's social environment, personal biography, health, and place in society all play a role in the nature of the connections and interactions they have with others. Rather than focusing on what the person has lost, Person Centred Dementia Care

focuses on the biopsychological factors which can improve the experience of living with dementia (Sabat, 2008; Kitwood, 1997).

This broad, holistic understanding of dementia has encouraged care providers to create environments that foster connections. It has revolutionised the way we conceptualise the challenges of living with dementia. In particular it has raised the possibility of living well with dementia. Twenty years since it was first put forward, Person Centred Dementia Care is still relevant. Brooker's recently edited volume of Kitwood's *Dementia Reconsidered Revisited: the person still comes first*, offers a contemporary understanding of some of Kitwood's key ideas, highlighting the progress made in dementia care in recent years, but also challenging and further developing some of Kitwood's key ideas (Brooker, 2019). Further discussion of recent developments in Person Centred Dementia Care is given later in the chapter.

1.5.1 Consideration of Person Centred Dementia Care in relation to other related philosophies of care

Whilst Person Centred Dementia Care was considered to be the most appropriate to guide this thesis, there are related philosophies that could have been used. For example Person Centred Dementia Care has much in common with, and can be encompassed within the broader philosophy of Person Centred Care (Manthorpe and Samsi, 2016; McCance et al., 2011).

Person Centred Care is a global term used in healthcare. There is no one definition. It is generally used to describe a standard of care that ensures the person is at the heart of care delivery (McCance et al., 2011). Person Centred Care is about doing things with people rather than to them. There are many different aspects to Person Centred Care, depending on the discipline. However, the focus generally is to help people entitled to health and/or care services to plan and express their choices about the care they would like. This enables patients to be involved in planning how the care they receive is organised and delivered (McCormack et al., 2017; Manthorpe and Samsi, 2016).

Given the broad use of Person Centred Care, there is critical debate regarding the conceptual development and operationalisation of the concept (McCance et al., 2011). Person Centred Dementia Care and Person Centred Care are often used interchangeably in the literature. Whilst it may be argued the terms are synonymous, it is important to note there are also distinctions between them.

McCormack et al (2012) acknowledge the many variations to Person Centred Care in existence in their paper 'Appreciating the person in long term care'. They suggest a number of Person Centred Care models have emerged based on a misunderstanding of the primacy of the person. In their opinion such models fail to embrace the person beyond superficial decisions about activities of daily living. McCormack et al (2012) warn that a number of Person Centred Models have become confused with the notion of consumerism. The emphasis is on independence and choice, rather than interdependence and negotiated choice in relation with others. They argue that such models are not concerned with connections and relationships (McCormack et al., 2012).

This research project is specifically focused on Person Centred Dementia Care. This is because Person Centred Dementia Care was developed to recognise the cognitive impairment people living with dementia face, and how that may impact the way they are perceived. Person Centred Dementia Care highlights the importance of connections for well-being and the significant role care staff play in ensuring such connections.

The significance for this thesis is that Person Centred Dementia Care explains how dementia manifests differently in different people thus enabling those who support people to understand their behaviour and state of mind.

Reflecting on my experiences of working in a nursing home, Person Centred Dementia Care seemed the most relevant to guide this thesis because I have seen first-hand how dementia affects people in different ways. For example I can recall observing a gentleman as part of a research project. He used to be very subtle in his reactions. Most of the time he only communicated using eye contact. I later found this was because he had a lot of pain. I often saw

staff rush by him doing jobs. This man experienced very little interaction. Because his communication was so limited, his attempts to communicate often went unnoticed. In contrast there was a lady who was very vocal and received a lot of interaction. Both were living with dementia, but experienced it in very different ways. Person Centred Dementia Care allows staff to understand the different elements that make up a person's experience of living with dementia.

To my knowledge, other models encompassed within the broader concept of Person Centred Care do not provide clear guidance on how to pay attention to these idiosyncrasies in the same way as Person Centred Dementia Care.

More specifically, Kitwood (1997) created a formula which described the mutual contribution of biomedical and social/psychological processes on the development of dementia as a 'dialectical process' and expressed it as an equation:

$$D = NI + PH + B + P + MSP$$

D = Dementia

NI = Neurological impairment

PH = Physical health

B = Biography

MSP = Malignant social psychology

He also placed fundamental importance on overcoming the stigma and the idea that people living with dementia were less than human, or something 'other' than human. This phenomenon has been described by Glaser and Strauss as 'social death'. Glaser and Strauss noted that people, who were expected to die were already treated as if they were dead (Glaser and Strauss, 1966). This generally included people with a terminal illness, very old people and people with cognitive impairments (Brannelly, 2011).

Sweeting and Gilhooly (1997) demonstrated social death to be a common experience for older people living with dementia. In their exploratory study, which examined the extent to which social death occurred before biological

death among people with dementia, a third of relatives either perceived or behaved as though their loved one was already dead (Sweeting and Gilhooly, 1997). It was this depersonalisation that Kitwood (1997) challenged. Kitwood (1997), was clear that Person Centred Dementia Care was a philosophy of care which recognised and nurtured the essential humanity in all people regardless of the level of their cognitive impairment.

It is because of this clear focus on connections and attention to the idiosyncrasies of individuals that Person Centred Dementia Care was deemed relevant to this research with people living with advanced dementia.

There are a number of key ideas in Kitwood's (1997) Person Centred Dementia Care, which influenced this thesis namely: upholding personhood, meeting psychological needs, the use of positive person work and malignant social psychology.

1.5.2 Upholding Personhood

Personhood is the status of being a person with unique characteristics and feelings. Being a person is what makes us human. Ensuring we remain a person is therefore essential for our well-being. The way people understand and relate to each other contributes to personhood. It is through our social interactions (connections) that we experience humanity. Personhood is therefore sustained by interactions and good quality relationships.

People with a diagnosis of dementia, who experience memory loss and disorientation, become reliant on others to maintain their sense of personhood. In his work, Kitwood (1997) suggested for people with dementia personhood was awarded to the person by another.

He argued that the greatest threat to someone living with dementia is the loss of connection with other human beings, and thereby personhood. In my experience this is common for people living with advanced dementia in nursing homes. I have seen many examples of where people spend time on their own, with little contact with those around them. There is also a

significant body of research internationally supporting this observation (Ward et al., 2008; Palese et al., 2016; den Ouden et al., 2015; Morgan-Brown et al., 2011). That said I also saw excellent examples of where personhood was maintained, for example through music or massage, depending on what the person enjoyed.

Twenty years on personhood is still relevant and the concept continues to be developed (McCormack et al., 2012; McCormack and McCance, 2010). In a recent commentary, Dewing (2019) sought to challenge and develop Kitwood's (1997) idea of personhood. She argued that rather than it being awarded as an 'optional gift', it is a moral right. She suggested we should stop searching for definitions of personhood, but instead should consider personhood as capturing shared humanity (Dewing, 2019).

In moving forward Kitwood's (1997) ideas about personhood, she suggests we should include concepts such as: body consciousness, a moral entitlement, dignity and difference, diversity and becoming. She also considers personhood as being influenced by the culture around the person living with dementia and their care partner, which has implications for the staff as they are the ones who are fostering connections (Dewing, 2019). Dewing and McCormack (2017) extended Kitwood's (1997) assertion that culture influenced personhood in their editorial on defining Person Centredness (Dewing and McCormack, 2017).

Ensuring personhood is maintained for people living with dementia is a key idea that guided this thesis. During my study, my aim was to find out what facilitated nursing home staff to connect with residents with advanced dementia. I therefore was mindful of the powerful position staff were in and tried to uncover what facilitated staff to connect so they could maintain the personhood of residents. Taking recent developments in to consideration, I also paid attention to the culture around the person living with dementia and the staff

1.5.3 Meeting psychological needs

Kitwood (1997) suggested that as humans we have psychological needs, which if not met, mean we struggle to function. These 'needs' are often experienced as desires and are expressed through our behaviour. In presenting his model, Kitwood (1997), suggested we should consider a cluster of five needs, which are closely linked and come together in the central need for love. They are the need for: comfort, attachment, inclusion, identity and occupation. According to Kitwood (1997), these needs are not evident in everyone all of the time and often our needs are sufficiently met in order for us to function. It is when we are faced with stress or trauma that our psychological needs become apparent, and any gaps become evident.

Kitwood (1997) suggested these needs are heightened when a person is living with dementia and intensify with the level of impairment. This, he argued, is because people with dementia are less able to take the necessary steps to ensure their needs are met. Each person's particular constellation of psychological needs varies and is dependent on who they are as a person, their past history and life experiences. The task of those using Person Centred Dementia Care is to meet this cluster of psychological needs. If one need is met, it will have an impact on the others. For example, a person who feels secure in attachment, is more likely to engage in occupation, which will make them feel included, this will encourage them to engage in higher levels of occupation, which will maintain their sense of identity. Connections form the route for meeting the psychological needs of a person. In his work Kitwood (1997) argued that by the very nature of the care they provide and therefore the connections they have, staff in nursing homes are in a powerful position to ensure the psychological needs of people living with dementia are met.

Reflecting on my experiences of working in nursing homes I can recall many examples of staff meeting the psychological needs of residents living with dementia. For example I saw staff address residents by name, I saw staff sat with residents, soothing them or trying to engage them in something they might enjoy. I saw staff attending to residents who they saw were distressed

or upset, with kindness and affection. I saw staff talk about themselves and their families and ask residents about their families. For those residents who were unable to communicate I saw staff showing residents family pictures. My aim for this study was to pay attention to how staff met the psychological needs of residents being mindful to consider how staff perceived their position during this time and how that might impact the interaction.

Other academics have also recognised the importance of meeting the needs of people living with dementia. Nolan (2004; 2006) focused on the needs of all parties in the relationship i.e. family, care staff and the wider community, however, rather than focusing exclusively on the needs of the person living with dementia (Nolan et al., 2004; Nolan et al., 2006). More specifically he suggested that in order to experience well-being, the person living with dementia, the staff member and the relative should have the following needs met: a sense of belonging, security, significance, continuity, purpose, and achievement (Brown Wilson et al., 2013). This overlaps with ideas posed in Person Centred Dementia Care.

The emphasis on meeting the psychological needs of people living with dementia continues to be utilised. Indeed there is a general recognition that a persons' experience can be improved through development of individual care plans that tap in to and address psychological needs, which is embedded in practice and policy documents (Department of Health, 2009; NHS England, 2015).

1.5.4 Positive Person Work

A major contribution of Kitwood's (1997) Person Centred Dementia Care theory is Positive Person Work. Positive Person Work describes interactions that affirm personhood and meet the psychological needs of people living with dementia. These interactions, described in Table 1, are termed 'personal enhancers'. According to Kitwood (1997), understanding the therapeutic potential of interactions is essential for providing supportive

environments where people living with advanced dementia feel included and can flourish.

Kitwood (1997)'s contention that good dementia care consists, in essence, of a series of high quality interactions, taking place in the context of a stable and secure relationship remains influential. He argued that emotional support should be at the centre of dementia care (Kitwood, 1997). Since then, much work has been done, particularly on increasing the emotional security of people living with dementia using attachment theory. In his recent commentary in *Dementia Reconsidered Revisited: the person still comes first*, Cheston (2019) suggests this taps in to some of the ideas in positive person work such as validation, holding and facilitation. Studies looking at how psychosocial interventions can improve the well-being of people living with dementia (Oyebode and Parveen, 2019) also tap in to some of the ideas of positive person work. Whilst making progress however, there is much to still to be done to ensure people living with advanced dementia remain connected (Cheston, 2019). I considered understanding what facilitates staff to perform positive person work as a useful next step for the field. My aim in this thesis therefore was to pay attention to examples of where positive person work was used, and what facilitated it.

Table 1 Positive Person Work: connections which affirm personhood and meet psychological needs (Kitwood, 1997)

Personal enhancers	Description
Recognition	Recognising people with dementia as unique individuals.
Negotiation	Asking people living with dementia about their wants, needs and preferences, then making a concerted effort to meet those needs.
Collaboration	Working in partnership with the person with dementia or another person to achieve a shared objective.
Celebration	Working in a way that achieves a positive, joyful experience.
Play	Being spontaneous, embracing self-expression.
Timalation	Interacting in a way that stimulates, reassures and gratifies the person with dementia, not in a way that challenges or tests them.
Relaxation	Slowing down the speed and intensity of the interaction.
Validation	Supporting the person, acknowledging their importance.
Holding	Providing an environment where people with dementia can feel safe, comfortable and happy.
Facilitation	Assisting a person living with dementia to do something they may not usually be able to do.

1.5.5 Malignant Social Psychology

In contrast to positive person work, malignant social psychology refers to styles of interacting which undermine personhood and prevent psychological needs from being met. Kitwood (1997) suggested seventeen categories of malignant social psychology which he referred to as personal detractors.

They are described in Table 2

Table 2 Personal Detractors: failure to meet psychological needs (Kitwood 1997).

Personal detractors	Description
Treachery	Deceiving a person living with dementia in order to get them to do something you want them to do.
Disempowerment	Interrupting a person living with dementia, making them feel they are unable to do something thus obstructing them from using their remaining abilities.
Infantilization	Belittling a person living with dementia, making them feel like a lesser person, often using childlike terminology.
Intimidation	Bullying a person living with dementia, making them feel scared or frightened.
Labelling	Categorising a person according to their condition, blaming their condition for how they act.
Stigmatization	Excluding a person with dementia, treating them as if they were an outcast
Outpacing	Interacting in a way that is too fast for the person with dementia so they are unable to understand or keep up.
Invalidation	Rejecting, ignoring or judging the person living with dementia diminishing their feelings. There is no attempt to try and understand their experience.
Banishment	Excluding the person from day to day interactions, either physically, emotionally or socially
Objectification	Treating the person with dementia as if they were an object, rather than a person
Ignoring	Not acknowledging the person with dementia, carrying out daily tasks as if they were not there, disregarding the person
Imposition	Acting in an unwelcome or demanding way that creates burden for the person with dementia i.e. expecting them to do something, rather than giving them a choice
Withholding	Ignoring or refusing to give something to a person with dementia
Accusation	Blaming a person with dementia, making them feel like they have done something wrong.
Disruption	Interrupting a person with dementia breaking their frame of reference
Mockery	Teasing or making fun of a person with dementia particularly if they are expressing strange behaviour
Disparagement	Speaking to a person with dementia in a negative or belittling way, damaging their self-confidence.

These socially malignant behaviours' may stop a person from feeling connected to their social environment. Regular exposure to these behaviours can lead to people feeling disconnected on a regular basis (Page, 2007). In his recent commentary, in *Dementia Reconsidered Revisited; the person still comes first*, Sabat (2019) highlights how malignant social psychology continues to pose a problem to people living with dementia. He highlights what we have learned since *Dementia Reconsidered* was first published. For example the value of non-pharmacological approaches such as social positioning and validation therapy, as strategies for eliminating socially malignant behaviours in the future (Sabat, 2019). In this thesis I paid less attention to malignant social psychology, because I felt taking a positive approach would be more useful for practice.

1.6 The reality of implementing Person Centred Dementia Care in nursing homes

While the rhetoric of Person Centred Dementia Care is universally embraced in policy (National Institute for Health and Clinical Excellence, 2018), the implementation in practice lags behind. In this section I suggest implementation studies of Person Centred Dementia Care indicate effectiveness. However, I argue that many of these studies sought to import a formal already designed intervention into care settings, rather than asking staff their perspectives how best they connect, along with what helps. I re-emphasise the significant role nursing home staff play in connecting with residents, but suggest we know very little, from nursing home staff perspectives, about what facilitates them to connect with residents with advanced dementia on a daily basis, particularly the individual and contextual factors that influence how they connect and how such factors interact.

Kitwood's (1997) extensive work on Person Centred Dementia Care has led to the development of a range of Person Centred Dementia interventions. Person Centred interventions vary, but are largely focused on implementing

the principles of Person Centred Dementia Care that were described earlier in the chapter.

Recent publications have shown Person Centred Dementia Care interventions to be effective (Ballard et al., 2018; Kim and Park, 2017; Chenoweth et al., 2014). In their cluster randomised controlled trial of Person Centred Dementia Care and Person Centred Dementia Environments, Chenoweth et al (2014), demonstrated a significant improvement in agitation and quality of life in the intervention group compared with the non-intervention group. These findings are supported by a systematic review and meta-analysis evaluating the impact of Person Centred Dementia Care interventions (n=19). Kim et al (2017) reported significant results for quality of life, depression and distressed reactions such as agitation. This was echoed in a recent randomised controlled trial aiming to improve well-being and health for people with dementia in nursing homes (n=69). The WHELD study demonstrated a significant improvement in their primary outcome of quality of life. They also reported a significant reduction of distressed reactions such as agitation, and an improvement of positive care interactions (Ballard et al., 2018).

Whilst research has shown Person Centred Dementia Care to be effective, implementation lags behind, as demonstrated by a systematic review and meta-analysis evaluating the impact of Person Centred Dementia Care interventions (n=19). Kim et al (2017) suggested the effects were significant but short lived, many lasting only six weeks on average. This suggests Person Centred Dementia Care interventions do not last much beyond the life of the trials.

The implementation of social interventions is complex. There is often a limited understanding of why interventions may or may not be effective (Surr, 2018). The difficulties in sustaining interventions beyond the period of training have been widely discussed in the literature (Livingston et al., 2014; Surr, 2018)

Reflecting on my own experiences of working in a nursing home, I can see how it might be difficult to implement such interventions. For example there

are limited staff to address unlimited needs and requests from: residents, relatives, management, external staff, and regulatory bodies. I have seen many instances where a staff member is doing something and has to be pulled away because they were short staffed or another resident required attention. Understanding these factors is important for the implementation of Person Centred Dementia Care.

Seeking the experiences of the staff tasked with delivering Person Centred Dementia Care seems essential if Person Centred Dementia Care interventions are to be implemented. Yet when designing Person Centred Dementia Care interventions, researchers have often overlooked the experiences of such staff. Facilitators and barriers to implementation are often identified retrospectively as evidenced by qualitative studies exploring the factors that influenced the adoption and outcomes of their Person Centred Dementia Care interventions. Individual and contextual factors were identified (Chenoweth et al., 2015; Fossey et al., 2019).

Individual factors included staff attitudes, which were identified as important in a study seeking to understand staff perspectives of the implementation and outcomes of Person Centred Dementia Care and environments. Resistance was reported when staff (at all levels) disagreed with the recommendations of the Person Centred Dementia Care intervention. Comments included 'this is not what we had in mind'. Other examples were when staff felt the principles underpinning the intervention were not always suitable for people living with dementia. This led to a lack of cooperation and interest in implementing the intervention. Such staff were reluctant to change their practice because did not see the value of doing so (Chenoweth et al., 2015). This is echoed in a study exploring the sustainability of a Person Centred Dementia Care intervention. Being able to recognise the value of the Person Centred Dementia Care intervention had a significant effect on whether they implemented it. Staff who understood the benefits of the intervention and felt involved in the process were reported to be more likely to implement it in practice (Fossey et al., 2019).

Barriers and facilitators to implementation, such as leadership, culture and team work, also operated at the contextual level. In their mixed methods

study of an educational intervention to reduce the use of restraints and implement Person Centred Dementia Care in nursing homes, Jacobsen et al (2017) suggested the culture of the nursing home was important, particularly ensuring that good relationships existed between the team (Jacobsen et al., 2017). This echoes the findings from a qualitative study exploring the factors that influenced the adoption and outcomes of a Person Centred Dementia Care intervention. Chenoweth et al (2015) found that successful implementation relied on a culture with an effective leader, ongoing training and staff teams who communicated well (Chenoweth et al., 2015). In their recent qualitative study exploring what influenced the sustainability of a Person Centred Dementia Care intervention, Fossey et al (2019) reported that the culture of the nursing home was important. They suggested effective leadership and team working allowed staff to take ownership of delivering Person Centred Dementia Care (Fossey et al., 2019).

Evidence suggests there are a range of factors operating, at the individual and contextual level, that influence the implementation of Person Centred Dementia Care. The combination of these factors, their interdependence and potential association with greater or poorer implementation, however, have not yet been explored. Seeking the experiences of the staff tasked with implementing such interventions seems an important next step, and one which aligns with Kitwood's (1997) philosophy of Person Centred Dementia Care, which emphasised the powerful role the care partner played (in this case nursing home staff) in ensuring meaningful connections were achieved.

In this section I have looked at the effectiveness and implementation of Person Centred Dementia Care interventions. Whilst showing evidence of effectiveness, I argued that many of the existing studies sought to import an already designed intervention into care settings, rather than asking staff their perspectives how best they connect, along with what helps. I went on to emphasise the significant role nursing home staff play in connecting with residents, and suggested that we need to better understand the experiences of the nursing home staff tasked with fostering connections, particularly the individual and contextual factors that influence how they connect and how these factors interact with each other.

1.7 Structure of the thesis

In this first chapter, I have described how my personal experiences led to my concern that people living with advanced dementia in nursing homes do not routinely experience human connections. I set the scene for the thesis by providing the context about people living with advanced dementia in care nursing homes. Next I defined connections and their relevance to this thesis. I then spent most of the chapter describing the theory of Person Centred Dementia Care (PCDC) and its key tenets including: personhood, psychological need, positive person work and malignant social psychology. I highlighted the importance of connections in Person Centred Dementia Care and the significant role nursing home staff play in ensuring connections happen in nursing homes. I demonstrated that whilst the theory of Person Centred Dementia Care is embraced in policy, it has not been implemented in practice some twenty years on. I ended the chapter by discussing some of the challenges of implementing Person Centred Dementia Care.

In Chapter 2, the literature review, I specifically focus on people living with advanced dementia. I systematically review the evidence to see what research has focused on connecting with residents with advanced dementia, the aim of which is to understand the experiences on staff. I argue that most research in the area has examined the use of psychosocial interventions to facilitate connections. I group the approaches to connect with residents with advanced dementia that have been studied into five types: arts-based approaches, turn-taking, the use of physical objects, connecting through the senses and day-to-day care. I conclude that the evidence on the effectiveness of psychosocial interventions of how staff connected with residents with advanced dementia is mixed. Not all studies demonstrate conclusive results due to small sample sizes and methodological limitations. I go on to suggest that a limitation of the evidence base is that few of the studies included in the review sought staff members' experience to understand how contextual and individual factors influence the use of psychosocial interventions and how such factors interact. I end the chapter by outlining my overall research aim and research questions.

In Chapter 3, Methodology, I present the philosophical assumptions about the nature of knowledge which underpins this thesis. I provide a rationale for why Interpretivist Grounded Theory using a Critical Realist lens was the most appropriate to address the research questions. This involves critical analysis about the range of approaches available and justification for the chosen approach of Interpretivist Grounded Theory.

In Chapter 4, Research Methods, I describe the overarching research design and the methods used to address the research questions. I begin with an overview of the overarching research design. I go on to discuss ethical considerations, including the process for gaining ethical approval, how I dealt with ethical issues and how data were managed. Next I describe the data collection procedure in detail, defining my sampling and recruitment strategy for nursing homes, nursing home staff and relatives. I describe how data collection occurred through semi-structured interviews and outline the data analysis procedure. Finally the criteria for ensuring quality is described.

In Chapter 5, I describe the characteristics of the nursing homes and participants who took part in the study. I then go on to explain the process of open coding, axial and selective coding. Through each section I weave in where data collection occurred in relation to analysis, along with key decisions and changes I made along the way. I aim to unfold the way my Grounded Theory developed to give transparency to the process I followed, and to provide an overview of the Grounded Theory.

In Chapter 6, I address research question one by describing the contextual factors that facilitated nursing home staff to use their time effectively to connect with residents with advanced dementia. These include: effective leadership, specialised dementia units, a caring culture, experienced staff, a suitable physical environment and family engagement. Throughout the chapter I highlight the interdependence between contexts. I also present examples of contexts that are perceived to prevent staff from using their time effectively

In Chapter 7, I address research question two: what individual staff factors facilitated nursing home staff to make the most of time to connect

with residents with advanced dementia. I present individual factors such as: accepting, tolerating and understanding advanced dementia, perception of connecting as a legitimate part of their role, caring qualities and knowing the person. I go on to acknowledge that the process of using time to connect with residents with advanced dementia is not linear and illustrate the interdependence between individual and organizational factors.

In Chapter 8, I focus on research question three: how and when do nursing home staff connect with residents with advanced dementia. Introducing the core category of 'using time', I suggest that nursing home staffs main opportunity to connect was non-verbal interactions during personal care. I suggest that staff who used their time effectively during personal care were most able to connect. Throughout the chapter I continue to highlight how contextual and individual factors interact with each other to generate the theory of 'making the most of time'. I end the chapter by suggesting the optimal conditions for making connections is for all of the contextual and individual factors to be present.

In Chapter 9, the discussion, I begin by summarising the Grounded Theory I proposed to explain what facilitates nursing home staff to use their time effectively i.e. 'make the most of time' to connect with residents with advanced dementia. I spend most of this chapter considering my findings in relation to the broader literature. I go on to argue that this thesis makes an original contribution by considering both contextual and individual factors and how they interact to influence staff making meaningful connections with residents with advanced dementia. I discuss the implications of the results for policy, practice and research, before considering the limitations of this thesis.

2 Chapter 2: Literature Review

2.1 Introduction

In Chapter 2 I systematically review the evidence on how nursing home staff connect with residents with advanced dementia and what facilitates them to do so. I begin by providing the background to the review. I then describe the methods used including the systematic search strategy, study selection and quality appraisal. I go on to provide a description of the findings suggesting most studies examined the effectiveness of interventions. I group the included studies in to five types: arts-based approaches, turn-taking, the use of physical objects, connecting through the senses and day-to-day care to connect with residents with advanced dementia. I conclude that the evidence on the effectiveness of psychosocial interventions on how staff connected with residents with advanced dementia is mixed, with not all studies demonstrating conclusive results due to small sample sizes and methodological limitations. I go on to suggest that a limitation of the evidence base is, that few of the studies included in the review sought staff members' experience to understand the contextual and individual factors and how they interact. I end the chapter by outlining my overall research aim and research questions.

2.2 Background to the review

Searches for studies addressing connections with people with advanced dementia identified two relevant reviews. The first, Kverno's et al (2008), was a review of the literature, which focused on the effectiveness of non-pharmacological strategies on people living with advanced dementia. Kverno et al (2008) reviewed 21 studies. None of the studies were considered relevant to this review of the literature as the participants in the studies had to be mobile and be able to verbally communicate to take part (Kverno et al., 2008). The second was Clare's (2010) review and integration of studies on the awareness of people with advanced dementia. Clare (2010) assessed

thirteen empirical studies published up until 2008. Only four of these focused on connecting with residents with advanced dementia who were unable to verbally communicate or move around on their own (Asplund et al., 1991; Asplund et al., 1995; Norberg et al., 2003; Götell et al., 2003). The other nine studies required participants to be mobile and be able to verbally communicate and were therefore not considered to be relevant. Of these four relevant studies, two were not considered relevant as their focus was on demonstrating connections were possible, where the aim of this review is to understand the how best to connect (not if connections are possible). The two relevant studies (Norberg et al., 2003; Götell et al., 2003) are included in the findings of (Clare, 2010)'s review.

To date there has been no systematic review which summarises how best to connect with residents living with advanced dementia in nursing homes. The aim of this review was to understand how nursing home staff connected with residents with advanced dementia and what facilitated them to do so.

2.3 Methods

2.3.1 Search Strategy

A comprehensive search of the literature was carried out in January 2015 and updated in December 2018. Key words from journal articles that explored connections were included in the search strategy. To identify studies focusing on people with advanced dementia, the following key words were used: advanced dementia, severe dementia, end stage dementia, late stage dementia, advanced Alzheimer disease. To locate those with a focus on connections key words included: stimulat*, interact*, engage*, occupation, participat*, involve*, communicat*, attach*, activit*, include, inclusion, social inclusion, approach*, supportive, supportive relationship, supportive environment, non-pharmacological intervention, meaningful, attachment, occupation, comfort. Database searches included: CINAHL, Medline, AMED, PsychINFO. Free text terms of known approaches such as Namaste as well as lateral searches of reference lists and authors to include those doing

research in the field for example Julie Watson and Brendon McCormack were conducted.

2.3.2 Study Selection (inclusion and exclusion criteria)

Included in the review were empirical studies that aimed to understand how nursing home staff connected with residents with advanced dementia and what facilitated them to do so. I also included studies that had explored terms associated with connections such as: responsiveness, non-verbal communication, and meaningful engagement, as these serve as indicators of enhancing connections. I wanted to get a broad overview of any work that was relevant thus minimal exclusions were applied. I did not place date limitations on the search. I excluded papers that were not written in English and those that relied on verbal communication from participants. Please see Table 3 for a list of inclusion and exclusion criteria.

Table 3 Inclusion and exclusion criteria

<p>Inclusion Criteria</p> <ul style="list-style-type: none">• A focus on connecting with people with advanced dementia (see key words in the search strategy)• Peer reviewed evidence OR reviews OR opinion papers OR academic books OR grey literature' <p>Exclusion Criteria</p> <ul style="list-style-type: none">• Not in English language• Where the primary focus was on addressing unmet needs characterised by agitation or aggression.

2.3.3 Quality Appraisal

The Critical Appraisal Skills Programme (CASP) tool were used to assess the quality of the studies (Critical Appraisal Skills Programme, 2018). CASP

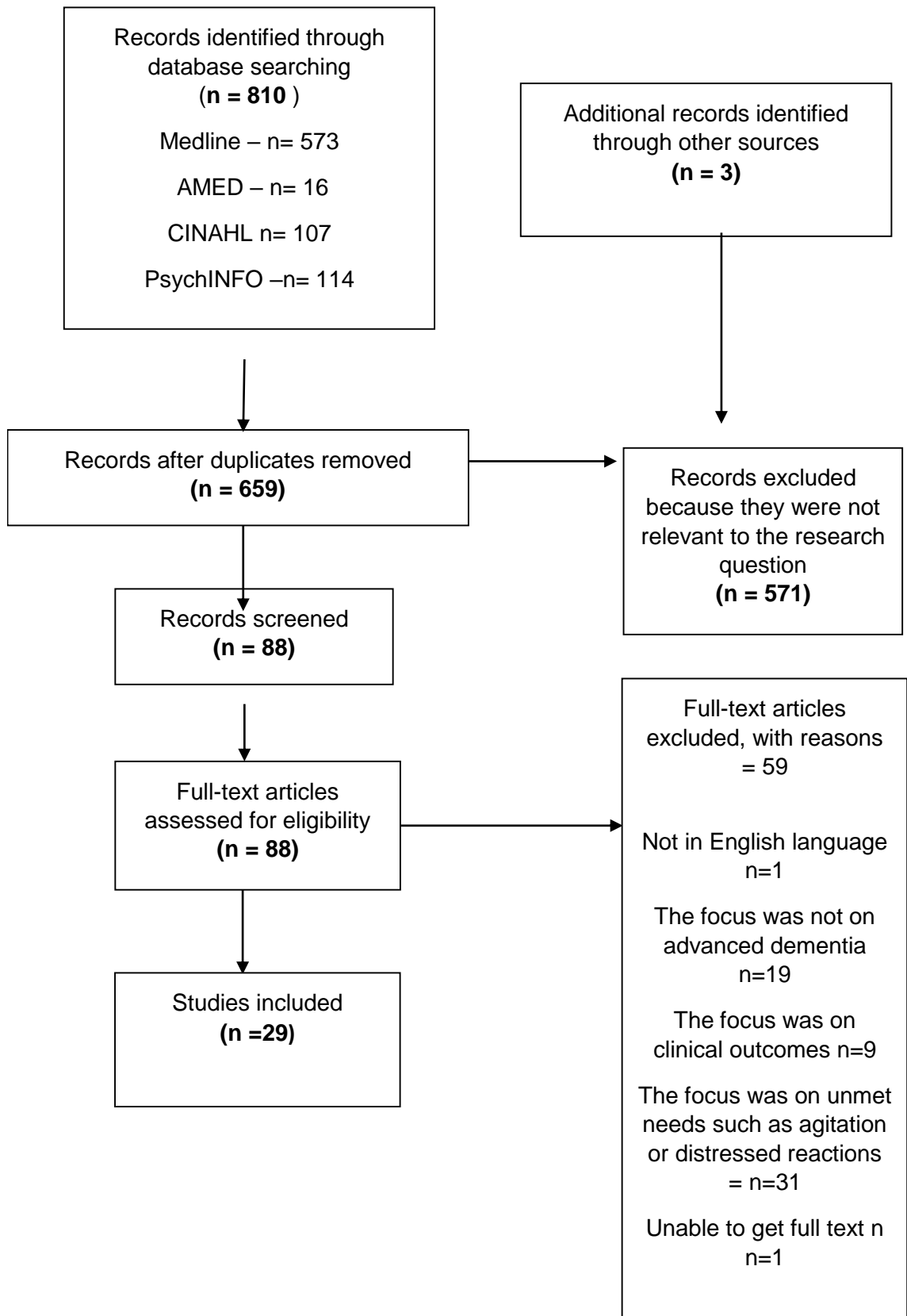
tools are validated instruments which ask detailed questions about the elements of a study in order to assess its trustworthiness, results, relevance and credibility (Hanne, 2011). I used a range of the tools depending on if the study was a randomised controlled trial, case study, qualitative study, cross sectional study, or intervention study.

Using the CASP tools I allocated scores of quality to each study. Supervisors (JO and MD) cross checked a sample of the included studies. The quality assessment identified a wide range of 'quality' across the studies. No studies were excluded on the basis of poor quality, instead the limitations of particular studies are woven into the description of findings. See Appendix 1: Literature Review Quality Rating System for details of the rating system used. See Appendix 2: Literature Review Data Extraction Table for the score each study was given.

2.4 Results

Twenty nine papers were included. Four were randomised controlled trials (RCT), two quasi-experimental designs, nine pre and post intervention studies, four observational studies, seven qualitative studies and one case study. Figure 1 details the PRISMA flow chart describing the process of finding literature.

Figure 1- PRISMA flow chart describing the search process of finding literature



2.4.1 Synthesis of findings

There was considerable variation in methodologies, approaches and outcomes measures used in the 29 studies. As such it was not possible to perform a meta-analysis. The next section presents a narrative description of findings.

Most studies evaluated interventions to foster connections. However, there were studies that explored connections through day-to-day care. Papers have been organised in to five themes:

- Arts-based approaches
- Turn-taking as a way to develop a shared language
- The use of physical objects/props
- Connecting through the senses
- Connecting through day-to-day care

2.4.2 Arts-based strategies to form connections

Music and elder clowns were two arts-based approaches that were used to connect with people with advanced dementia.

2.4.2.1 The use of music with people living with advanced dementia

Eight studies used musical interventions to connect with people with advanced dementia. They included: one randomised controlled trial (Holmes et al., 2006), one quasi experimental study (van der Vleuten et al., 2012), two pre and post-test studies (Hammar et al., 2011; Sherratt et al., 2004), one observational study (Clair, 1996), two qualitative studies (Götell et al., 2003; Götell et al., 2009) and one case study (Norberg et al., 2003). Three types of music situations were identified: staff (staff already employed in the nursing home) singing during routine care, pre-recorded music and playing of live music by professional singers. Some studies compared approaches

Nursing home staff singing

Overall the response to nursing home staff singing during routine care was positive. Clair (1996) observed residents who were no longer ambulant or able to verbally communicate (n=26) in response to: singing, background music, reading the newspaper and silence. After a series of video recorded sessions over four sequential days, residents gave significantly more frequent responses (indicating connections) during nursing home staff singing compared with sitting in silence. Evidence of connections included: eye movements, head movements, changes in facial expressions and vocalisations. There were no significant differences between nursing home staff singing and reading the newspaper.

In their qualitative studies, Gotell et al (2003, 2009) supported these findings describing the development of close and intimate connections as a result of nursing home staff singing during care tasks. Participants (n=9) with advanced dementia and nursing home staff (n=5) were observed on 27 different occasions (either nursing home staff singing, background music or usual care). Nursing home staff singing was described as heartfelt and sincere, with staff noticeably connecting with residents through eye contact. The live singing element tended to alter the tone of the connection in a positive way, with the change in emotion and mood being more apparent compared with the other types of music intervention.

Authors described a sense of 'mutual vitality' with both interventions, but in addition to the light heartedness resulting from background music, nursing home staff also suggested their singing resulted in sincerity, openness and intimacy. People living with dementia appeared to listen attentively, moods were solemn, sincere and residents expressed pleasure. Nursing home staff singing also appeared to enhance connections more readily compared with the other types of music intervention including background music and silence (Götell et al., 2003; Götell et al., 2009). Intimacy and reciprocity from residents was a recurrent theme.

In a later study the emotions of residents (n=10) in response to nursing home staff singing were observed. Connections were noticeable with explicit expression of visible pleasure. Residents were more alert and receptive to personal care. In video recordings capturing 20 hours of interaction, residents were described as joyful and attentive. In the absence of nursing home staff singing, participants were observed to have a slumped posture, sluggish motion with minimal evidence of connections (Hammar et al., 2011).

Gotell et al. (2009) suggest that without musical intervention, care was often disjointed with staff being enthusiastic, energetic and warm while residents with dementia were resistant, confused and misunderstood. Musical intervention, particularly nursing home staff singing however, led to a change in posture (straightened and engaged). These effects were far reaching having a positive impact also on the staff members who were reported to appear more relaxed and satisfied in their role (Götell et al., 2003; Götell et al., 2009).

Background music

Background music has also been shown to increase the nature of connections between nursing home staff and people with advanced dementia (Götell et al., 2003; Götell et al., 2009; Norberg et al., 2003). In their qualitative studies, Gotell et al (2003, 2009) observed a positive change in the emotional expression of people (n=9) living with advanced dementia. Connections were often wordless, but articulated through playful and humorous actions. Positive changes in posture and sensory awareness were also reported. Residents were reported to be much more alert compared to their usual care giving situation. In their case study, Norberg et al. (2003) set out to connect with people (n=2) living with advanced dementia using background music, touch and object presentation. Over 12 consecutive days, both participants responded more favourably to background music compared with touch and object presentation. Participants were observed to be significantly more connected to those around them. This was measured by

the frequency of eye blinking and mouth movements. The authors noted connections were subtle and different in each person. In a later study, Holmes et al (2006) compared live music, background music and silence in participants (n=32) living with advanced dementia. Two methods of music were compared to each other in this RCT, with silence being the control. Whilst background music did not have any negative impact on people living with advanced dementia, it did not significantly alter levels of apathy in residents. Apathy was measured by the level of observed attempts at positive connection (Holmes et al., 2006).

Live Music

Live music performances have been shown to have a significant impact on the frequency of connections with people living with advanced dementia and those around them (Sherratt et al., 2004; Holmes et al., 2006; van der Vleuten et al., 2012). In their continuous time series analysis, Sherratt et al. (2004) revealed participants (n=29) spent significantly more time connected to those around them when presented with live music than other music conditions (background music and silence). This was characterised by eye contact, head movements and changes in facial expression. A significant decrease in the amount of time spent in meaningless activity or sleeping was also noted. Connections were observed for longer during live music, followed by background music and then silence. Holmes et al. (2006) presented a similar picture. In their RCT involving people (n=32) living with advanced dementia, the observational tool Dementia Care Mapping, revealed live music had a significant impact on the frequency of connections between people with advanced dementia and those around them, compared with background music and silence (which had no significant effect). Similarly to the former study connections were characterised by changes in facial expression and emotional responses for example smiling, appearing happy and stimulated. The impact of live music on people with advanced dementia was further investigated in a later study. In their quasi experimental study Van-Der-Vleuten et al (2012) replicated these findings. They found that

intimate live music made a significant difference to the frequency of connections in people (n=16) living with advanced dementia. Increased human contact and communication were also significant.

There is evidence to suggest music is beneficial for facilitating connections between nursing home staff and residents with advanced dementia. Some studies compared musical approaches and indicated live music and care giver singer were the most effective. Without a meta-analysis however, it is not possible to know. A limitation of the studies is their lack of attention on the individual and contextual factors that might influence the use of music in practice, particularly from the staff's perspective. For example live music and care giver singing may not be an option for some nursing homes.

2.4.2.2 Elder clowns

The use of elder clowns to connect with people living with dementia is a relatively recent development. Elder clowns are external specialists who use humour with the aim to bring happiness and joy to people with advanced dementia (Kontos et al., 2017). Connections are usually spontaneous and include: playing, dancing, touch and imitation. A recent ethnographic study by Kontos et al. (2017) examined the practice of elder clowns with residents (n=23) with advanced dementia over a 12 week period. Video recordings were used to observe the connections between residents and elder clowns. Researchers focused on non-verbal communication, affective expression and embodied engagement as ways of connecting. Findings revealed that connections were achieved through reciprocal playfulness and imagination. Residents radiated joy and delight in response to elder clowns. Residents responded with smiles and eye contact, which were more frequent as the interaction went on. The authors reported a state of mutual connectedness.

Whilst demonstrating effectiveness, only one study, conducted in Canada evaluated the effects of elder clowns in people living with advanced dementia. Further research testing its effectiveness and feasibility in practice, from a staff perspective, is required

2.4.3 Turn taking and imitation to form connections

One case study investigated the impact of turn taking on communicating with people with advanced dementia (Astell and Ellis, 2006). Imitation is a mode of communication that has been used to facilitate connections in people with advanced dementia. Astell and Ellis (2006) conducted a case study with a participant with advanced dementia to explore its effects. By mirroring the actions of the participant, researchers attempted to connect with her, drawing her in to a social world from which she was once socially excluded. The resident and the researcher sat side by side at a table, the chairs tilted towards each other, but not directly facing one another. The researcher initiated a conversation and mirrored her reactions. Sessions were video recorded and analysed using event coding. Events such as nodding, head shaking, shrugging shoulders, muttering, eye contact and looking away were considered attempts at connecting. Sessions lasted approximately 35 minutes.

Findings revealed that the participant's emotional state remained neutral in both sessions for most of the time (79%). 16% of time was spent in a happy state. No signs of sadness were noted at any time. The participant was able to connect through imitation in both sessions. This was typically through verbal muttering, but also through non-verbal communication such as eye contact, head nodding and head movement. Through turn-taking researchers were able to demonstrate that while the participant was unable to connect through conversation, she retained the urge to connect with spontaneous sounds and movements. The researcher then imitated this and a shared language was created.

Imitation appears to be an effective way to connect with residents with advanced dementia. However, only one study has explored its effectiveness and this was 13 years ago. The authors did not report on any individual or contextual factors that may affect its use in practice. The approach appears to be time intensive which indicates it might be tricky for staff to implement in practice. Further research testing its effectiveness and feasibility, from a staff perspective, is therefore required.

2.4.4 The use of physical objects

A number of researchers have reported on the use of physical objects as vehicles to facilitate connections with residents with advanced dementia. The first approach is the use of Paro-seals. Three pre and post intervention studies (Moyle et al., 2013; Takayanagi et al., 2014; Valentí Soler et al., 2015) and one randomised controlled, trial were found in the literature search (Joranson et al., 2015). The second approach was the use of dolls (Braden and Gaspar, 2015).

2.4.4.1 Paro-seal

A Paro-seal is a therapeutic robotic seal that can act as a companion for people with cognitive impairments and other physical disabilities. Paro-seals display life-like behaviours and can express emotional states similar to humans. They are a unique way of connecting with people who struggle to verbally communicate (Moyle et al., 2013). Studies showed that the Paro-seal had a significant impact on the frequency of connections with people living with advanced dementia (Takayanagi et al., 2014; Moyle et al., 2013; Joranson et al., 2015; Valentí Soler et al., 2015).

In a pre-and-post cross-over study, people living with mid to late stage dementia (n=18) were assessed at three time points. Researchers rated the frequency of connections through: positive affect, apathy, signs of anxiety and depression using verbal and non-verbal responses as a guide. Participants were observed to connect by having significant pleasant and engaging reactions such as laughing and smiling when they received the seal compared with the control group of reading (Moyle et al., 2013).

These findings were replicated in a later pre-and post-test study using continuous time sampling analysis (a method where an observer records behaviour at timed intervals). Residents (n=19) with mid to late stage dementia were given a Paro-seal or a stuffed lion in their room. Responses were recorded and video and behavioural analysis was used to interpret findings. Researchers looked for instances of connection through evidence

of: positive engagement, talking, muttering, touching, stroking and emotional expression. In both groups (moderate and severe dementia) participants connected significantly more with the Paro seal than the lion. This was characterised by smiling and laughing. Participants in the advanced dementia group gave neutral expression more frequently with the lion than the seal, suggesting more connection when presented with the seal (Takayanagi et al., 2014).

In a pilot cluster randomised controlled trial participants (n=221) were assigned to receive either a humanoid robot, Paro-seal or trained dog, two days per week, for three months. Assessments included quality of life. There was a statistical difference between the humanoid robot, Paro-seal and trained dog in the first phase of the study. There was, however, no statistical difference during the second phase (Valentí Soler et al., 2015).

The most recent study was a cluster randomised controlled trial. Nursing home units (n=10) received either Paro-seal or a control. Participants were followed up at three time periods over 12 weeks. Findings revealed that participants who had interaction with the Paro-seal had significantly lower scores for agitation and depression (Joranson et al., 2015).

The studies evaluating Paro-seals were pre-and post-studies or randomised controlled studies and had larger sample sizes than the studies described thus far. Randomised controlled trials in particular are considered to be the gold standard of evidence, thus it could be argued that findings from randomised controlled trials carry more weight. Given the different methodologies in the approaches presented thus far, it is impossible to know which approach is the most effective however. Asking the nursing home staff tasked with implementing such approaches in practice seems an important way to gain further understanding of this, yet nursing home staff's views were not sought.

2.4.4.2 Dolls

Dolls have also been used to encourage connections between nursing home staff and people with advanced dementia. Two studies explored their effects in people living with advanced dementia (Braden and Gaspar, 2015; Pezzati et al., 2014). In their pre-and post-test study, Pezzati et al. (2014) recruited people with advanced dementia (n=10) in a specialised dementia unit to receive doll therapy. Participants underwent ten sessions over 30 days. This involved being presented with either a doll or a non-anthropomorphic object such as a rubber cube. Sessions were videotaped and analysed through an observational grid focusing on six behaviours that indicated they were connecting with those around them. They included: acceptance of the doll/object, eye gaze, moving, smelling, hugging and smiling. Findings suggested that participants who received doll therapy were significantly more connected with those around them than the control group, this was characterised by eye gaze. Participants in the doll group shifted their gaze back and forth from the doll to the nursing home staff members, whereas in the control group their eyes were simply fixed on the object. Participants in the experimental group also appeared to explore areas of the doll, moving it around. No other significant findings were reported.

Braden and Gaspar (2015) conducted an observational study that looked at the effects of dolls on residents living with advanced dementia in nursing homes (n=16). Observers rated resident behaviour in response to receiving the doll. The only significant finding was levels of happiness. Qualitative field notes from the study reported staff perceptions of the intervention. Staff suggested residents appeared to connect with the doll and those around them. They were much happier, more active and socially engaged. Field notes did not consider the feasibility of doll therapy in practice, nor did they consider the contextual influences highlighted in Chapter 1. While indicating positive effects, both studies used small sample sizes thus findings should be interpreted with caution.

2.4.5 Connecting through the senses

2.4.5.1 Sensory stimulation

Sensory stimulation (SS) is an approach whereby items such as: fibre-optic lights, aromatherapy, music, screen projectors, are used to stimulate one or more of the five senses (visual, auditory, tactile and olfactory). The method was first designed for people with learning disabilities, but has since been adapted as a way to facilitate connections with people with advanced dementia and those around them. The idea is to present residents with stimulation in a calm and relaxing environment to evoke positive and stimulating responses that lead to connections with nursing home staff (Fowler et al., 2007). Five studies explored connections and responses of people living with advanced dementia to sensory stimulation. Two were randomised controlled trials (Sanchez et al., 2016; Hutson et al., 2014). One was a quasi-experimental study (Sposito et al., 2017) and two were observational studies (Cruz et al., 2013; Materne et al., 2014).

The results presented a mixed picture. While indication of connections (increased eye gaze, alertness and smiling were reported), none of the RCTs were able to show this in a significant way (Sanchez et al., 2016; Hutson et al., 2014). Other studies reported residents going from a sleepy 'eyes closed' state, to an alert and attentive state gazing, smiling and making eye contact with staff (Sposito et al., 2017; Materne et al., 2014). None of the studies considered how nursing home staff could use sensory stimulation on a day-to-day basis to form connections with residents with advanced dementia. Sensory stimulation equipment may be expensive, it may require extra staff time, resources, specialised rooms etc. Such factors should be considered for future research.

2.4.5.2 Massage

Massage is an approach that aims to stimulate the tactile sense. It has been used to connect with people living with advanced dementia with the aim of

improving pleasure and mood. Whilst an RCT suggested foot massage did not have an effect on the mood of people with advanced dementia (Moyle et al., 2014), a study describing the experiences of staff who massaged people with advanced dementia (n=5), revealed an optimistic perception of massage. Nursing home staff perceived massaging as a way of connecting with people in a positive way. Staff reported signs of positive emotion and relaxation. Staff were asked questions about how they thought the person responded to the intervention, how they expressed it verbally/nonverbally, what they did during the session and how they experienced the session. Each of the participants (n=5) were reported to connect through positive emotions such as joy, happiness and pleasure. Nursing home staff described massaging as a helpful tool that enabled them to be close and spend time with people (Skovdahl et al., 2007). Staff thought massage was effective for the resident and helped them to find a way to connect, however, they were not asked about the contextual factors that might influence its feasibility in practice.

2.4.5.3 Namaste

'Namaste' is the Indian greeting meaning 'to honor the spirit within'. Developed by Joyce Simard in the 1970s, the programme is described as being based on the power of love and touch, Namaste was developed for care home residents with advanced dementia who can no longer engage in conventional group activities. It combines compassionate care with meaningful activity in a dedicated, peaceful environment together with 'loving touch' Care home staff deliver the Namaste programme seven days a week (Simard, 2013).

Two studies quantitatively explored the impact of Namaste on residents with advanced dementia (Simard and Volicer, 2010; Stacpoole et al., 2015). In a pre-and post-test study, nursing home residents (n=86), with advanced dementia (n=14) and with very advanced dementia (n=23), were enrolled in the Namaste programme for 30 days. There were no significant differences in depression scores or behavioural and psychological symptoms before or

after enrolment (Simard and Volicer, 2010). Stacpole et al (2015) however, reported a significant decrease in neuropsychiatric symptom severity and occupational disruptiveness in 4/6 care homes. In one home behavioural symptoms increased. This was attributed to poor leadership and inadequate staffing (Stacpoole et al., 2015; Stacpoole et al., 2017).

Qualitative findings suggested Namaste had a positive impact on residents with advanced dementia. According to staff, residents reacted to Namaste by speaking, smiling, interacting and generally being more connected (McNiel and Westphal, 2018; Magee et al., 2017; Stacpoole et al., 2017). This state of connectedness is characterised in the following quote:

“When asked to articulate the purpose of the programme, a care worker wrote, ‘to enable us to reach out to each other’. This theme of connection, re-connection and shared humanity is the foundation of the relationship-based care that Namaste fosters. Many care staff and families talked about the emotional significance and power of touch. Namaste gave people (care staff and families) permission to touch residents that seemed to be a catalyst for change” (Stacpole et al, 2017, p 334).

In a qualitative study asking staff members (n=14) and family members (n=1) their personal experiences of providing Namaste care, the response was positive. Six themes emerged that indicated connections occurred. They included Namaste providing: a peaceful sanctuary, a platform to allow staff to connect to residents on their level, a way of transforming the experience of living and working in a nursing home, connections and community and increasing frequency of positive moments formed. Positive moments were a thread that ran throughout all the themes. Examples of positive changes included residents (who prior to the intervention did not communicate verbally): speaking, smiling, interacting with dolls, stuffed animals and generally being more interactive. Residents were also described to be less anxious. The program prompted residents to connect with those around them creating positive moments and new possibilities (McNiel and Westphal, 2018).

In another qualitative study of residents with advanced dementia (n=31), the Namaste program evoked the act of touch. Two broad themes were revealed: touch by others and touch by the person. The outcomes were reciprocal connectedness and awareness. Touch for people living with advanced dementia was deemed important, and Namaste was suggested as a vehicle for doing this (Nicholls et al., 2013). When testing the feasibility of the Namaste program in an Irish context, Magee et al (2017) reported that Namaste had the potential to improve experiences of people living with advanced dementia. Furthermore it was well received by staff (Magee et al., 2017). In one study, staff described how Namaste changed how they felt about their work. Namaste was suggested to provide structure, purpose and permission to spend time with residents (Stacpoole et al., 2017).

2.4.6 Connecting through day-to-day care

Two studies were identified that connected through day-to-day care rather than the use of interventions (Ericsson et al., 2013; Watson, 2015; Watson, 2019).

In a Grounded Theory, Ericsson et al (2013) proposed a theory to describe how relationships were created between nursing home staff and residents with moderate to severe dementia. Individual factors of assigning time, establishing security and trust and communicating equality were strategies that allowed nursing home staff to get residents to open up to form relationships. There was no focus on the contextual influences that impacted the implementation of such strategies (Ericsson et al., 2013) .

Watson et al (2019) conducted an ethnographic study examining the caregiving/receiving relationships between nursing home staff and residents with advanced dementia. She reported findings about what shaped relationships between staff in nursing homes and residents with advanced dementia on a day-to-day basis. Key facilitators for connecting with residents with advanced dementia in nursing homes included: promoting connections during personal care, learning about and supporting embodied aspects of personhood and supporting interconnections between residents and care

staff. This study provides insight in to the nature of connections arising from day-to-day interactions between nursing home staff and residents with advanced dementia. Similarly to Ericsson et al (2013), there was little attention to the contextual factors that facilitated relationships. Thus whilst staff were asked what they did to connect, they were not asked how or why they were able to do this or what might help.

2.4.7 Critique of included studies

Whilst showing benefits for people with advanced dementia, the findings, were mixed and not all studies demonstrated conclusive results. There were a number of possible reasons for this, which will be discussed in this section.

2.4.7.1 Small sample sizes used in the quantitative studies.

10/27 studies included in this review used a sample size of less than ten participants. Of those, four were music studies (Hammar et al., 2011; Norberg et al., 2003; van der Vleuten et al., 2012; Sherratt et al., 2004) two were those using physical objects (Takayanagi et al., 2014; Pezzati et al., 2014) and one sensory stimulation (Cruz et al., 2013). Three studies had a sample size of less than 20 (Valentí Soler et al., 2015; Materne et al., 2014; Holmes et al., 2006). The highest sample size was n=221 (Valentí Soler et al., 2015). Small sample sizes reduce the power of a study, which in turn can question the meaningfulness of the findings.

2.4.7.2 Time since publication

7/27 studies were conducted prior to 2010. Six of these were music intervention studies (Holmes et al., 2006; Sherratt et al., 2004; Norberg et al., 2003; Clair, 1996; Götell et al., 2003; Götell et al., 2009). The case study using imitation was conducted in 2006 (Astell and Ellis, 2006), with no further research done in the area since. It is important to consider time since

publication when considering the relevance and feasibility of strategies in practice.

2.4.7.3 Use of theory

Many of the interventions in this review did not refer to having a theoretical basis for their use. Whilst a number of papers alluded to using theory to underpin their interventions i.e. Person Centred Dementia Care (Simard and Volicer, 2010; Sherratt et al., 2004; Sposito et al., 2017; McNiel and Westphal, 2018), and Bowlby's attachment theory (Braden and Gaspar, 2015), the explicit use of theory in the papers was scant. For example the authors often only referenced a theory, rather than discussing the logical argument of why the theory led to their predictions. A good theory is comprised of a set of interconnected and convincing arguments. It should consider the processes to understand why things happen (Sutton and Staw, 1995). Authors must explain how the theory informs the work. Simply mentioning theory is not the same as explaining the causal logic they contain. Explaining data patterns alone does not constitute as theory as observational patterns rarely demonstrate causal pathways (Sutton and Staw, 1995).

2.4.7.4 Applicability to practice

Many of the studies presented in this chapter referred to named therapeutic approaches such as, music, sensory stimulation, imitation and Namaste care, which were often conducted by special staff such as music therapists, activities coordinators and other qualified professionals. Where nursing home staff did get involved, it required prior training by specialist staff (Namaste) or specialist skills e.g. ability to sing. Only one of the studies explicitly addressed how suitable the strategies would be in day-to-day practice (Magee et al, 2017). Whilst in the qualitative studies nursing home staff were

asked their views on the effectiveness of the interventions, their views about feasibility in practice were not sought.

2.5 Discussion

The aim of this review was to understand how nursing home staff connected with residents with advanced dementia and what facilitated them to do so. I was particularly interested in nursing home staff's perspective on the individual and contextual factors that influenced how they connected with residents.

Findings suggest that psychosocial interventions including, arts-based approaches, turn-taking and imitation, use of physical objects, connecting through the senses and connecting through day-to-day care, could be effective in facilitating nursing home staff to connect with residents with advanced dementia.

The different methodologies among the studies meant it was not possible to directly compare the effectiveness of the interventions. However, whilst it is important to understand which interventions are most effective, effectiveness alone does not align with the Person Centred Dementia Care principles guiding this thesis (outlined in Chapter 1). For example different interventions are likely to be effective for different residents (and staff members) at different times, on different days. There is no one size fits all approach. The interventions described in this study should therefore be viewed as a range of tools that facilitate nursing home staff to connect with residents with advanced dementia.

Given that there are a range of interventions that seem effective in assisting staff to connect with residents with advanced dementia, it seems more important to ask staff how best they connect in practice. Whilst some of the studies sought nursing home staff perspectives, it was in relation to the effectiveness of an intervention, rather than asking their perspectives on their feasibility in practice or indeed if they considered these interventions were the best way to connect.

Few of the studies considered the individual and contextual factors associated with connecting with residents with advanced dementia and how such factors interacted. This is an issue that has been reported in the broader Person Centred Dementia Care implementation literature. A systematic review of the acceptability of psychosocial interventions for dementia also supports this limitation. Authors in the review reported a lack of information from the included studies (n=42) about the acceptability and feasibility of the interventions in practice. One of the critiques of the studies was that researchers placed more attention on effectiveness than implementation and had rarely sought the views of nursing home staff (Qiu et al., 2019).

The fact that few of the studies sought staffs views about how best to connect with residents with advanced dementia and what helped them to do so, is a major limitation of the literature. People living with advanced dementia are particularly reliant on nursing home staff to initiate connections. Nursing home staff are therefore in powerful positions to ensure connections happen. Seeking the perspectives of those tasked with ensuring connections occur, therefore seems essential.

In their study exploring how to close the gap between research and practice, Rahman et al (2012) highlighted the importance of involving the end users in the design of interventions to ensure they are feasible (Rahman et al., 2012). Vikstrom et al (2015) echoed this in their implementation guidelines for Person Centred Dementia Care in nursing homes. The guidelines encourage staff involvement as it is perceived to empower staff, promote shared ownership and identify areas of most value. Involving nursing home staff in implementation also highlights important individual and contextual barriers from the outset (Vikström et al., 2015).

In their study about how to sustain complex interventions in practice, nursing home staff Colon-Emeric et al (2016), also highlighted importance of including staff in the design. For example interventions that were perceived by nursing home staff themselves to be useful and effective were most sustainable. Group sessions in particular, allowed staff to learn from each other and build confidence to keep momentum going. Contextual factors

were integral to ensure this happened. Staff described the notion of being given permission to implement interventions. Effective leadership was therefore described as key for sustainability (Colón-Emeric et al., 2016).

Whilst seeking staff perspectives in the design of interventions is important, it is important to acknowledge the challenges of doing so. There is a growing literature outlining the difficulties researchers face in involving nursing homes and nursing home staff in research (Tzouvara et al., 2016; Shepherd et al., 2015; Jenkins et al., 2016; Luff, 2011). Barriers for nursing homes include: additional workload, mistrust and scepticism (Tzouvara et al., 2016), managers acting as gate keepers (Shepherd et al., 2015), and disempowered staff (Jenkins et al., 2016). Researchers may also face barriers. In a methods review on research in care homes, Luff et al (2011) outline how important the experience, skills and readiness of a researcher is to engage in care home research.

However, whilst seeking nursing home staff perspectives may be challenging, barriers can be overcome with open communication and quality relationships between the researcher and the nursing home (Tzouvara et al., 2016). Luff et al (2011) highlighted key skills for conducting nursing home research including: an ability to relate to others, communicate effectively, empathise, remain flexible, be patient and, importantly, ensure the wellbeing of the residents, relatives and staff are central at all times.

Despite this critique, it is clear that there are a number of interventions that are effective in assisting nursing home staff to connect with residents with advanced dementia. Reflecting on the evidence reviewed above, national guidance supports the use of a variety of approaches including: aromatherapy, multi-sensory stimulation, music, paro-seals and massage for people with dementia who demonstrate distressed behaviours (National Institute for Health and Clinical Excellence, 2018). Findings from this review suggest these approaches are also useful for connecting with people with advanced dementia, something that is not currently emphasised in national guidance.

2.6 Conclusion

Most research about staff connecting with residents with advanced dementia has examined the usefulness of psychosocial interventions. The evidence for their usefulness is mixed. Not all studies demonstrate conclusive results due to small sample sizes and methodological limitations. A limitation of the evidence base is that few of the studies in the review considered the staff members' experience, particularly their perspective on the individual and contextual factors that influenced how they connected and how such factors interacted.

2.7 Research aims

To develop a Grounded Theory to explain what facilitates nursing home staff to connect with residents living with advanced dementia.

2.8 Research questions

This aim will be addressed through answering the following research questions

1. What contextual factors facilitate connections?
2. What individual staff factors facilitate connections?
3. How and when do nursing home staff connect with residents with advanced dementia?

An extra research question, research question 4, was added retrospectively. This was as a result of re-analysis of my data following my viva. Re-analysis of my data led me to the realisation that I could use the Grounded Theory methodology to theorise about how individual and contextual factors interact. This was not something I had originally considered. My original approach was to add a staff perspective (something I argue was missing from the literature). However, re-analysis of the data highlighted that there was interdependence between factors. After re-reading literature I was unable to

find studies that had attempted to do this. I therefore added a fourth research question (retrospectively) and felt this was another way my thesis could make an original contribution.

4. How do individual and contextual facilitators interact to facilitate connections?

3 Chapter 3: Methodology

3.1 Introduction

In this chapter I present the methodology guiding this thesis. I begin by outlining philosophical assumptions about the nature of knowledge. I provide a rationale for using the ontological and epistemological assumptions of critical realism. I go on to propose the use of Grounded Theory as the chosen methodological approach. I describe Grounded Theory in detail, beginning with a historical overview of the versions of Grounded Theory, before arguing that Interpretivist Grounded Theory with its emphasis on abduction and use of theory was most aligned with critical realism and the research aims and questions of this thesis. I end the chapter by presenting the broad steps and processes of Interpretivist Grounded Theory.

3.2 Ontological and Epistemological Position

3.2.1 Definition of philosophical paradigm

Social inquiry is underpinned by how the researcher views the world. As researchers we hold a set of beliefs, also known as a philosophical paradigm, that influence the research process and the subsequent conclusions made (Lincoln and Guba, 2000). These views are instilled in us throughout our lives, from our early experiences, through our education, by scholarly communities and associated professionals (Creswell, 2013a). In its broadest sense a philosophical paradigm is a set of beliefs or underlying ideas about the world, which guides our actions (Creswell, 2013b).

The term 'paradigm' was first used by Thomas Kuhn who suggested it enabled differentiation between the ways people viewed the world (Kuhn, 1970). The term 'paradigm' has been used in a number of different ways, even by Kuhn himself, which has left it open to interpretation (Guba, 1990). There is a common consensus however, that a philosophical paradigm


consists of three components: 1) the ontological question: what is the nature of reality, 2) the epistemological question: how do we know what we know and 3) the methodological question: how do we obtain knowledge about the world (Guba, 1990). Answers to these questions reveal the worldview of the researcher and either knowingly or unknowingly guides their philosophical position and subsequent research methods.

3.2.2 Consideration of philosophical paradigms

There are a number of philosophical paradigms which can be thought of as occupying positions on a spectrum. These perspectives range from realism to idealism. Realism considers reality or 'truth' to be objective and something that can be independently observed. In contrast idealism considers 'truth' to be constructed through our minds and the meanings we attach to things. In-between these extremes are more nuanced perspectives, which while having many distinctive features, also considerably overlap making it difficult to delineate their boundaries. There are four main views spanning the realism/idealism spectrum that are widely used in health and social sciences. They include: positivism, constructivism, pragmatism and critical realism. An overview of these world views are illustrated in Table 4 (Guba, 1994).

Table 4 Philosophical paradigms adapted from Guba (1990)

Realism Idealism



Item	Positivism	Critical realism	Pragmatism	Social Constructivism
Aim	Explanatory, researchers intend to determine cause and effect	Researchers find the most likely explanation to explain phenomena	Researchers aim to determine what is useful and what is practical	Exploratory, researchers understand phenomena through co-construction
Ontology – the nature of truth	Researchers take a realist view. There is one reality governed by natural laws and forces. Scientific methods are used to discover this reality (Guba. 1990, Willig. 2001).	Researchers take a realist view but ontology is stratified in to three layers. An empirical layer, an actual layer, and a real layer (Wainwright. 1997)	Researchers do not concern themselves with ontology. Reality is what is useful and what is practical (Seale et al. 2007, Creswell. 2013).	Researchers are subjective, and idealist. There are multiple realities which are constructed through our interactions, experiences and the meanings we attach to them (Creswell. 2013).
Epistemology – how knowledge is acquired	Researchers take a deductive approach, knowledge is often acquired in a controlled environment. Sources of bias and confounding factors removed (Guba 1990, Willig. 2001)	Knowledge is fallible, findings are fluid, flexible and subject to constant change. Researchers use abductive reasoning to find the most likely explanation (McEvoy. 2006).	Knowledge is derived from interaction among individuals and their environment - both of which create reality	Knowledge is co-constructed between the researcher and the participants through interaction. Usually inductive, findings are not objective or value free (Ritchie. 2014)
Methods	Quantitative methods are used to establish: who, what, where and when. Often randomised controlled trials.	Mixed methods, exploratory allow the researchers to focus on underlying structure and mechanisms	Mixed methods are often used.	Qualitative methods are used to establish the 'why'. Often using interviews, observations and focus groups

3.2.2.1 Positivism

In considering which paradigm was the most appropriate to guide my research, I considered a number of aspects.

First the limitations of existing empirical research on connections with people with advanced dementia (van der Vleuten et al., 2012; Snow et al., 2004; O'Connor et al., 2013; Takayanagi et al., 2014) led me to reject positivism as the paradigm to guide this thesis. Given that positivist methods were developed for experimental research in natural sciences, they are often not directly transferrable to the social sciences. For example, experimental designs are often focused on identifying cause and effect (Scotland, 2012). However, the results in Chapter 2 suggest connections do not unfold with a singular cause and effect. It seems connections are much more complex, and likely to be influenced by multiple factors not observable through experimental research (Luff, 2011). Thus I felt applying quantitative methods that focused on single cause and effect would not capture the complex nature of the nursing home environment.

Second it seemed unrealistic to assume researchers conducting nursing home research could remain wholly objective. My experience of carrying out research in nursing homes in particular has highlighted to me the way my values and beliefs may influence participants' behaviours. The idea that there is an unquestionable truth which exists and is waiting to be discovered did not sit comfortably with me. In my personal and professional experience of visiting and conducting research in nursing homes, I have regularly been confronted with different realities. In particular, working with nursing home staff, with different views and understandings, has highlighted very different interpretations of the same event. It is indeed what drove me to pursue this thesis.

The research projects I conducted in my previous role often excluded people with advanced dementia, as it was assumed they were unable to participate. In my observations I often saw residents, particularly those living with advanced dementia, alone in their bedrooms, having little or no contact with others. Other residents were moved from their bedrooms and placed in the

lounge. I noted some staff attempted to interact with those residents, other staff did not. Such different reactions to the same situation fascinated me, but also highlighted the many different interpretations in existence. It seemed to me a positivist approach would not identify these different interpretations which would be at the heart of my research inquiry (Guba, 1994). Thus when re-considering the nature of my research questions, I noted that positivist research, often associated with methods that look for effectiveness of an intervention (Lincoln and Guba, 2000), was not appropriate. A view point that accommodated the complexity of the nursing home environment and that would prompt me to examine connections from a nursing home staff perspective appeared more appropriate. This observation raised the potential for social constructivism as the paradigm of choice. Indeed the idea of seeking participants 'perspectives' to find out 'how and why' connections occurred immediately evoked ideas of social constructivism.

3.2.2.2 Social constructivism

Social constructivism is sensitive to the individual meanings and multiple realities I sought to explore. However, there were a number of issues which I felt made it unsuitable as the paradigm of choice for this thesis. Firstly constructivist research often neglects to explore external structural forces which influence behaviour (Cohen et al., 2011). For example different interpretations of the same event could be due to wider influences. Participants may be unaware or may not understand invisible influences or ideologies which guide their actions (Creswell, 2008; Creswell, 2013b; Guba, 1994). As such their explanations of knowledge could be considered as incomplete (McEvoy and Richards, 2006).

In nursing homes these external structural forces (or contextual factors) are important. The resident population in a nursing home represents the frailest and most vulnerable members of society who have complex care needs due to multiple long term conditions (Luff, 2011; Alzheimer's Society, 2016). Staff are often under trained, poorly paid and undervalued (Trinkoff et al., 2017; Han et al., 2014). Staff often work long hours for little reward or recognition (Wild et al., 2011; Bowers et al., 2003). There may therefore be a

number of external factors which influence their perspective on connecting with residents with advanced dementia. These might include: whether the nursing home is a profit or non-profit business, as this impacts things such as pay, hours, and staff levels. The size of the nursing home may also influence a staff member's ability to connect. For example, a large nursing home may have a higher number of residents to care for and connect with, there may be many more staff, more managers, rigid structured approaches to care to ensure efficiency (Backhaus et al., 2014; Spilsbury et al., 2011). Staff may not be aware of these factors that impact their attitudes and behaviours.

The second reason for discounting social constructivism was because the aim of my thesis was to produce findings that had real world application for nursing homes. I wanted to produce guidance that nursing homes could practically use to maximise connections between staff and residents. Knowledge produced from social constructivist projects, however, have limited transferability. Generalisations are rarely possible because findings are often highly contextualised. Interpretation of findings involves subjective individual constructions which may be difficult to convey in practical guidance (Guba, 1994; Creswell, 2008).

3.2.2.3 Pragmatism

In discounting social constructivism, I explored other paradigms. Consequently I explored whether pragmatism should inform my work. As pragmatism is generally not based on an explicit philosophy and researchers adopting this approach are concerned with 'what is useful' and 'what is practical', it was an attractive choice. In taking this view I would have been able to produce real world research with findings, which were valid providing they were useful in practice (Creswell, 2013b; Ritchie et al., 2014). From a pragmatic perspective, knowledge can be created using tools which include both qualitative and quantitative approaches, which would fit with the approach in this thesis (Ritchie et al., 2014; Creswell, 2013a). However, as a pragmatic view tends to discount philosophy and theory in favour of 'what works' it was discounted. Following the usual practice of pragmatism, I would

not have aimed to build theory about underlying processes from my findings, and my findings would have lacked conceptual discussion, whereas I was hoping to build some understanding of the processes at play.

My experience of working in nursing homes has highlighted that no day is the same, no hour is the same, no resident is the same and no staff member is the same. Each person experiences similar events, in different ways. Despite this observation, the idea of focusing my research only on different subjective understandings did not sit comfortably with me. I realised that I was more of the view that the differences in interpretation of similar events could be due to wider influences shaping our experiences. Thus I believe that we share a reality, but feel that we interpret this reality in different ways based on external influences, most of which are beyond our control. This view most aligns with critical realism.

3.2.3 Rationale for critical realism

Critical realist studies are based on an assumption that an external reality exists beyond people's interpretation of it, as is the case in positivism. However people access and interpret this reality in different ways (McEvoy and Richards, 2006).

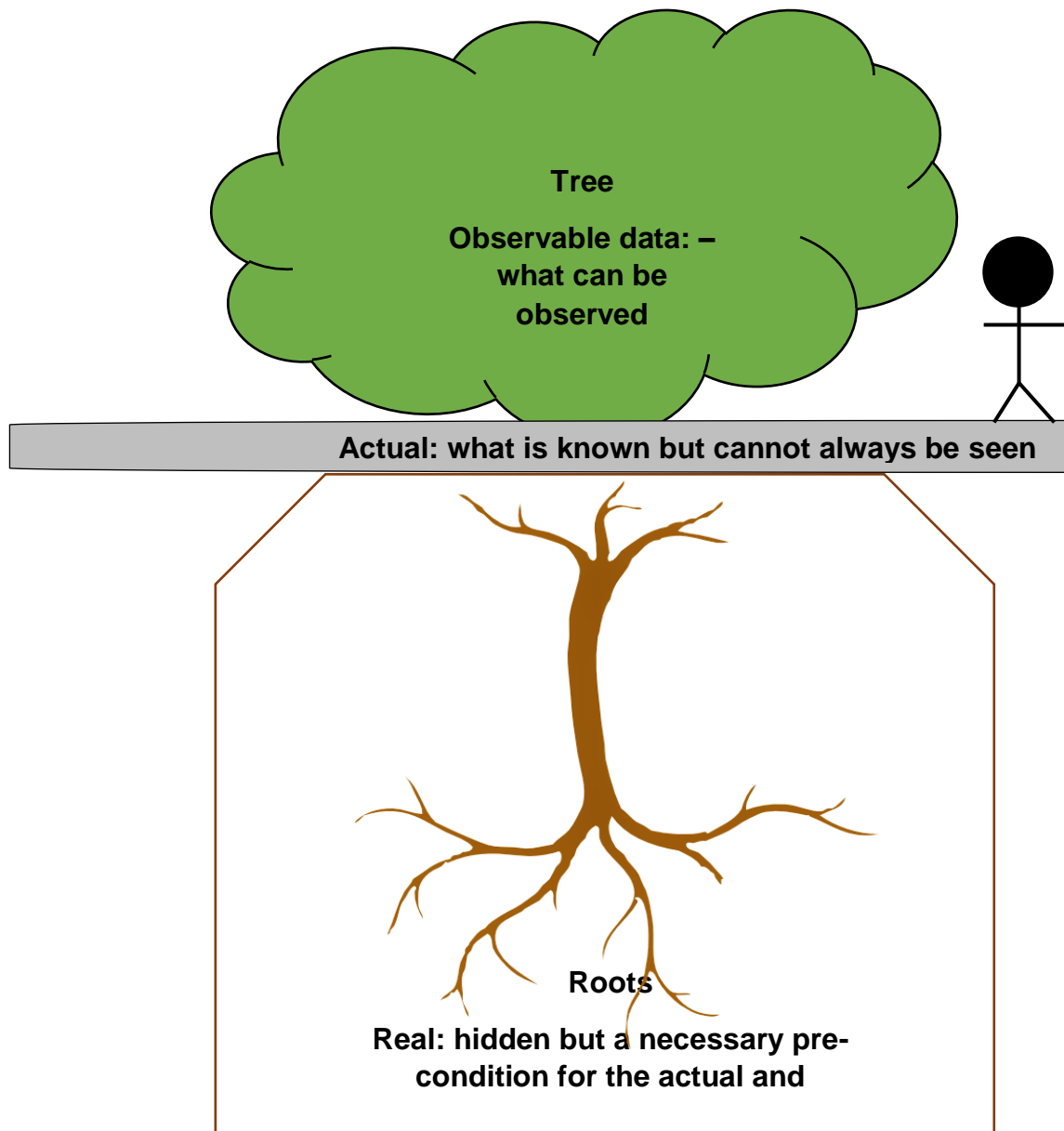
Knowledge is considered to be limited by the senses and intellect we have to access reality and to develop our understanding of it. Knowledge is therefore imperfect (fallible), and should be understood through logical thought, by considering the range of possible explanations (Bygstand, 2011). Critical realism combines a realist ontology (a shared reality exists) with a constructivist epistemology (it is accepted that reality is seen through the lens of the person, their views and beliefs and is therefore imperfect). Consequently the aim of critical realism is to further understand and explain the world we live in by looking for patterns that highlight the most likely explanation for what is observed (McEvoy and Richards, 2006). Similarly to research projects that take a pragmatist stance, critical realist research places emphasis on what is useful and what is practical (Ritchie et al., 2014).

For researchers taking a critical realist view, empirical accounts alone are incomplete, as they do not take in to account the complex nature of a social situation or the underlying forces that may be influencing a person's behaviour. Thus a critical realist perspective suggests that creating knowledge is about more than simply describing empirical data, it involves reference to mechanisms, structures or individual factors that attempt to explain what has been observed. This perspective is often described as conceiving ontology (our shared reality) as being layered across three levels:

- The observable layer: which involves the researcher recognising the interactive messages conveyed during the time spent with participants
- The actual layer: the process of analysis whereby the researcher looks for connections between what they have observed.
- The real layer: where researchers look for patterns and make interpretations about the mechanisms (factors) that could be responsible for the observed effect. Mechanisms in the real layer might not be directly observable or accessible, but exist, and it has been suggested that it is the job of science and social science to understand and gain reliable knowledge of them (Bhaskar, 1997).

A retroductive framework to help navigate through this stratified ontology may be used when researching from a critical realist position. Researchers use the retroductive framework, illustrated in Figure 2, to ask questions about what they are researching (in this case how staff connect and what helps). This allows researchers to uncover causal mechanisms for what they have observed (Danermark et al., 1997).

Figure 2 Tree diagram illustrating the stratified ontology of critical realism, which is characterized in the retroductive framework (Dyson and Brown, 2006)



Critical realism was considered the most appropriate for this thesis. Firstly my experience of working and visiting nursing homes, along with the literature I reviewed in Chapter 2, led me to believe connections between nursing home staff and residents were likely to be influenced by multiple factors. For example I thought each participant's view may have been influenced by contextual factors, reflected in their behaviours, feelings or attitudes. By taking a critical realist view, I was: 1) able to navigate through

the 'messy' interrelationship between contextual factors and individual behaviours and 2) I was able to ask questions of the data, to 'scratch beneath the surface' in search of the most likely explanation for how connections were enacted and what helped. Other research, highlighting the influence of contextual factors on individual behaviours (Kitson, 2001; Estabrooks et al., 2004; Kontos and Poland, 2009), also contributed to this decision. A study that used critical realism to navigate the complex relationship between multiple factors in nursing homes (Kontos et al., 2011), further strengthened my argument for its use in this project. The final reason for choosing critical realism was that my previous experience has highlighted the complex and dynamic nature of a nursing home environment. The notion of accepting reality as what is useful, practical and the best explanation at the time, fits with this type of environment and will provide useful findings for nursing home providers.

3.2.4 Critiques of critical realism

Despite being a good fit for the aims and objectives of this project. There are limitations to critical realism. One of the reasons I rejected social constructivism was because findings would be context-specific and would have limited transferability. This could also be argued when conducting research through a critical realist lens. For example I interviewed participants within their context alone so in theory, findings would not be transferrable. However, one of the aims of a realist researcher is to create an abstract mid-level theory that is general enough to transfer from one context to another. More specifically realist approaches adopt a generative approach to causation, which means they rely on theory to, make sense, frame problems and create tentative suggestions for what they have observed.

I therefore intended to look for patterns in my empirical data, which I would then compare to similar patterns in other research and theory. By doing this I would be able to validate the patterns observed in my data, thus addressing concerns of limited transferability (Bygstand, 2011).

Other critiques, particularly those with a positivist world view, have suggested critical realist research is at risk of bias. However, all research projects, whether acknowledged or not, are likely to be subject to some interpretation from the researcher (and are therefore at risk of bias). As such I aimed to take responsibility, as the researcher, to be mindful of this and ensure my interpretations were as informed as possible (Hammersley, 2009). In emphasizing the importance of searching for mechanisms, it is also important to highlight that data analysis can become stuck at the descriptive empirical level, with researchers not considering the range of mechanisms that might explain why something has occurred. It is therefore important to address findings at a deeper level if conducting research through a critical realist lens (Oliver, 2012). I addressed this through sense checking hunches with participants and resident participation groups, regular supervision, I also looked in the literature for clues for comparable patterns in search for the most likely explanation for my observations.

Finally given that our understanding of reality is provisional, constructivist researchers have challenged how a layered ontology can identify mechanisms with any certainty (DeForge and Shaw, 2012). These arguments are apparent in the health care literature where the exploration and examination of a critical realist framework for research has had nearly two decades of discussion (Porter and Ryan, 1996; Angus and Clark, 2012). However, it can be argued that mechanisms are real, because their effects are real. It is up to the researcher to undercover mechanisms (and indeed reality) as comprehensively as possible. A critical realist researcher therefore acknowledges that they are providing the most likely explanation, rather than a definitive explanation. In this thesis I used the aforementioned strategies to uncover mechanisms at the real level.

3.3 Methodological Approach

3.3.1 Introduction

In order to achieve an in-depth understanding of how nursing home staff connected with residents living with advanced dementia, along with what facilitated them to do so, a qualitative approach was considered the most appropriate. The lack of research that directly explored nursing home staff perspectives about the contextual and individual factors that facilitated them to connect, further supported this decision. For example research in this area has largely used experimental designs to understand the effectiveness of interventions (van der Vleuten et al., 2012; Hammar et al., 2011; Holmes et al., 2002; Moyle et al., 2013; Moyle et al., 2011). Using such designs, however, does not answer the 'how' and 'why' elements of my research questions. Research designed to understand staff perspectives of how best they connected seemed more appropriate. A number of qualitative studies, identified in Chapter 2, were able to yield rich findings about the effectiveness of specific interventions which further supported this decision (Götell et al., 2009; Watson, 2015; Watson, 2019; McNeil and Westphal, 2018).

3.3.2 Consideration of the methodological approach

When considering which would be the most suitable for this project I considered three approaches, Ethnography, Phenomenology and Grounded Theory (Ritchie et al., 2014).

I initially considered Ethnography as this focuses on culture. Indeed this approach would allow me to observe and understand the experience of nursing home staff (Al-Busaidi, 2008). However, reflecting on the research questions developed in Chapter 2,

1. What contextual factors facilitate connections?
2. What individual staff factors facilitate connections?
3. How and when do nursing home staff connect with residents with advanced dementia?
4. How do individual and contextual facilitators interact?

I realised I required an approach that would uncover a social process. Ethnography is emic in that it focuses on describing a culture or language in terms of its internal elements. It does not pay attention to individual or contextual factors or how they interact (Reeves et al., 2008). This approach would therefore not allow me to understand the social process I sought.

Interpretive Phenomenology Approach (IPA) was next considered as an approach. IPA places emphasis on understanding a social process. However, whilst IPA seeks to understand and map social processes, relationships and their consequences for participants, IPA projects are often more psychologically focused. Research projects using an IPA approach often pay attention to the experience (thoughts, beliefs, and feelings) of participants over the social context, causes and consequences (Reid, 2005). This approach would not be the most useful for paying sufficient attention to research question 1 or 4, what contextual factors facilitate staff to connect with residents with advanced dementia, and how individual and contextual factors interact. IPA was therefore discounted.

IPA shares many features with Grounded Theory, particularly the emphasis on understanding a social process. Indeed Grounded Theory has been described as: 'a systematic method that seeks to explain the social processes about a phenomenon'. The aim of Grounded Theory is to generate a theory from the systematic analysis of primary data (Glaser, 1992), which outlines the main concern of participants in the study (Mediani, 2018). While IPA proceeds from the 'inside out', Grounded Theory takes the view from the 'outside in' (Charmaz, 2000). Most importantly the approach fosters attention on the individual and contextual factors that influence connections and allows the researcher to make causal links about how they interact. Grounded Theory has many unique features, which will be discussed later in the chapter. However, one that was particularly helpful for

this project was the inductive/abductive approach. In Grounded Theory, questions are open and guided by the participants themselves so they are able to highlight their main concern. Data are collected and analysed concurrently, successive data collection (which is informed by continuous data analysis) is called theoretical sampling (Parahoo, 2014). Further description of the Grounded Theory process is discussed later in the chapter. I will first focus on the development of Grounded Theory as it has changed since its original inception, which has had implications for the data in this thesis.

Classic Grounded Theory was first written about in 1967 (Glaser, 1967). However, since its original development, there has been divergence by its pioneers about the nature of its methods. Most significantly, original authors Barney Glaser and Anselm Strauss parted company due to the differing ways they thought Grounded Theory should be applied. It has been suggested that this divergence was due to contrasting views about the world (philosophical assumptions), which had implications for how Grounded Theory studies were conducted. There are currently three prevailing versions of Grounded Theory, all with differing philosophical positions. Classic Grounded Theory (Glaser, 1967; Glaser, 1992; Bryant, 2002), Interpretivist Grounded Theory (Strauss and Corbin, 1990; Strauss and Corbin, 1998; Corbin and Strauss, 2008) and Constructivist Grounded Theory (Charmaz, 2000; Charmaz, 2006)

There is a lack of critical debate about the philosophical underpinnings of classic Grounded Theory (Urquhart, 2002; Bryant, 2002; Holton, 2007). This can be attributed to the way classic Grounded Theory was developed. The method, first presented by Glaser and Strauss in *Awareness of Dying* (1965), was formulated and utilised in a study that explored dying as a social ritual that permeated the lives, and care, of terminally ill patients. The methods used in this study were later refined into a research methodology in: *The Discovery of Grounded Theory* (Glaser, 1967). The book, was a retrospective account of the techniques used when developing their qualitative methods and was not explicit or exhaustive in its explanation about the emergence of theory (Glaser, 1978).

When considering classic Grounded Theory in relation to my research questions I soon realised classic Grounded Theory did not fit well with realism. For example though Glaser (Glaser and Holton, 2004; Glaser, 1967) claims Grounded Theory is a general method that lends itself to any paradigm, his insistence that researchers should remain objective suggest features of positivism. For example Glaser (1967) suggested researchers should keep an empty mind by refraining from viewing literature in the project area until the end. He also created a rigorous and systematic coding procedure aimed at eliminating bias (Urquhart, 2002; Kelle, 2005). I have already suggested that as a critical realist researcher, I might make claims about what I think is happening. However, I accept there is an independent reality beyond my interpretation of it. I therefore recognise my knowledge, along with participants' knowledge may be incomplete. The findings from this project are one perspective. I looked for the most likely explanation for what I had observed.

Glaser (1967) suggests classic Grounded Theory is a purely inductive method. The researcher should start the research without any assumptions or expectations. Whilst I took an inductive approach to data collection, my previous experience of working and visiting nursing homes, along with the findings of my literature review (a step that allowed me to identify gaps in the field) means I began the project with some knowledge. Although this occurred prior to my decision to use Grounded Theory, it compromised my ability to remain wholly objective (although this is an argument of any constructivist researcher). Thus the idea of the researcher maintaining full objectivity (as suggested in classic Grounded Theory) did not align with the philosophical underpinnings of this project.

Retroduction is a key idea in critical realism which, focuses on uncovering structures, processes and outcomes (Bygstand, 2011). As already suggested the use of some strategies can help the researcher delve deeper than the empirical level of data. For example in my case I was able to turn to the literature and draw on my experiences to find similar ideas or patterns, which

helped me identify comparable mechanisms. This did not mean using the literature or my experience as data per se, instead it meant using examples to stimulate thinking about how to understand the empirical data. By doing this, I let participants guide the research in an inductive manner, but took the view that there was a difference between an empty mind and an open mind (Strauss and Corbin, 1998). It appears my views and approaches were more closely related to the views of Anselm Strauss, who diverged from Glaser and classic Grounded Theory to introduce his own version of Interpretivist Grounded Theory (Strauss and Corbin, 1990; Strauss and Corbin, 1998; Corbin and Strauss, 2008).

This divergence was thought to be due to Strauss's background in pragmatism and symbolic interactionism, approaches which both embrace a critical realist ontology (Blumer, 1986; Mediani, 2018). Indeed Interpretivist Grounded Theory is punctuated with critical realist features (McCann and Clark, 2003; Jones and Alony, 2011; Kelle, 2005; Bryant, 2002; Strauss, 1994; Strauss and Corbin, 1990; Strauss and Corbin, 1998). This is evidenced by Strauss's acknowledgment that the participant's story is an interpretation (rather than a definitive account) of reality. Strauss recognised the limitations of relying on interpretations to explain reality and created methods that encouraged researchers to use some theory to find the most likely explanation (as with critical realism) (Strauss and Corbin, 1990; Ghezeljeh and Emami, 2009).

This meant moving away from the purely inductive approach in classic Grounded Theory to include deduction (Glaser, 1998; Strauss and Corbin, 1998; Strauss and Corbin, 1990). This is termed abduction. Abduction is a type of thinking where a researcher starts by looking at the empirical data, but makes use of research evidence, theory and their own experiences if the observation cannot be explained from the data alone. The researcher must think about all of the possible theoretical explanations for the data and come up with the one that is most likely (Bygstand, 2011). This move away, from pure induction to abduction, allows ideas and hunches to become a good foundation from which theory can be built (Corbin and Strauss 2008).

Strauss reformulated the original coding procedure to accommodate abduction (details of which is discussed later in the chapter).

In practice using 'abductive thinking' meant I was able to use theory to "ask effective questions of the data" (Strauss and Corbin, 1990). I used cognitive reasoning as well as the empirical data to look for the most likely explanation. I was able to modify or reject concepts during and due to observations (Reichertz, 2010). I validated findings through structured techniques such as axial coding (to be discussed later).

Strauss and Corbin continued to develop their diverging position of Interpretivist Grounded Theory (1990, 1994) until Strauss's death in 1996. Corbin then continued developing the approach publishing a second edition of the Basics of Qualitative Research in 1998, a third edition in 2008 and a fourth edition in 2014. Corbin's later writings relaxed Strauss's analytical coding procedure, and adapted the underlying philosophical assumptions (Corbin and Strauss 2008), moving away from a position consistent with critical realism to one closer to an underlying constructivist ontology.

This aligns with a third version of Grounded Theory, which is more clearly constructivist in its ontological underpinnings. Researchers using this version of Grounded Theory assume multiple realities exist and that it is the job of the researcher to co-construct knowledge with the participants. Charmaz (2000), a former student of Glaser and Strauss, reconfigured what she termed Grounded Theory's positivist and rigid methodology into a flexible, intuitive and open-ended methodology. This had implications for the coding procedure which was a more flexible and adaptable procedure, which she suggested encouraged researchers to imaginatively engage with the data. This third configuration was discounted because of its constructivist underpinnings.

3.3.3 Rationale for choosing Interpretivist Grounded Theory

Interpretivist Grounded Theory in its original inception, underpinned by critical realism was most suitable for this project because:

- The methodological tools used in Interpretivist Grounded Theory (abduction rather than induction) are compatible with the retroductive tenets of critical realism (Bunt, 2018).
- The structured approach of Strauss and Corbin (1998) helps novice researchers by providing a clear, structured coding process which allows researchers to uncover conceptual categories while identifying links between them (McCallin, 2003). Explicit guidelines for data analysis are provided. Whilst Charmaz (2000, 2006) has suggested this might be restrictive, it was considered helpful for the purposes of this project. Axial coding examples will be further discussed in Chapter 5.
- There is a clear focus on contextual factors.
- Interpretivist Grounded Theory is able to produce a theory which is relevant to practice.

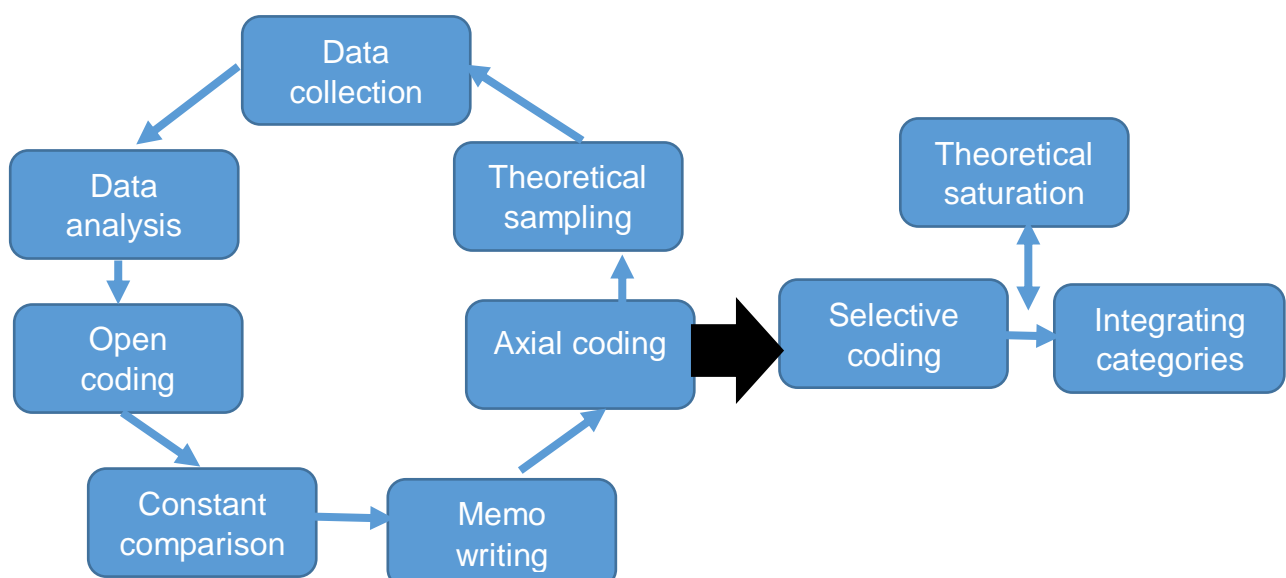
Interpretivist Grounded Theory has been subject to criticism. For example there is the argument that the introduction of abduction creates an entirely different method to classic Grounded Theory (Glaser, 1992). Strauss's reformulation of coding procedures to include abduction have also been described as rigid and over complicated (Charmaz, 2000; Goulding, 1999). Such complicated coding procedures have been suggested to force data in to preconceived concepts thereby coercing a theory (Glaser, 1992; Kendall, 1999; Melia, 2010). The emphasis on constructivism by the later works of Corbin (Corbin and Strauss, 2008) also suggest incompatibility with critical realism. Whilst valid points, firstly I felt that whilst the coding procedure could be considered complicated, life is complicated thus coding procedures should be applied flexibly and adjusted depending on context (Strauss and Corbin, 1990), and secondly despite Corbin's move towards constructivism in

recent years, I felt Strauss's original inception of Grounded Theory aligned nicely with the aim and research question of this project.

3.3.4 Interpretivist Grounded Theory steps

I will now describe the steps involved in Interpretivist Grounded Theory. The aim of Grounded Theory is to create a theory about a social process, in this case, what facilitated nursing home staff to connect with residents with advanced dementia. Figure 3 demonstrates that the route for doing this is not linear. I simultaneously collected, coded and analysed data to understand how and when connections occurred, along with what helped. There are three coding steps (i) open coding, (ii) axial coding and (iii) selective coding. In open coding the aim is to break apart the data and dig beneath the surface of the empirical data. In axial and selective coding the data is reassembled and hypotheses developed. During this time the researcher needs to know what data to collect next and where to get it. There are analytical tools of Grounded Theory designed to assist with this, which occur during the cycle of data collection, coding and analysis. They include, constant comparison, memo writing and theoretical sampling. I will first describe these analytical tools, before describing the coding steps.

Figure 3 Steps of Interpretivist Grounded Theory (Corbin and Strauss, 2008)



3.3.4.1 Analytical Tools

3.3.4.1.1 Constant comparison (occurs throughout all steps)

The aim of constant comparison is to compare similarities and differences in the data. Similar ideas are grouped according to patterns. I engaged in constant comparison throughout the data collection process and at each stage of coding. At the beginning of the process constant comparison was used after each interview. This allowed me to create a set of categories. Categories were not created by one idea from one piece of data, but required involvement of a number of ideas relating to similar things (Strauss and Corbin, 1990; Strauss, 1994; Strauss and Corbin, 1998). I developed each category by looking at similarities and differences under various conditions. This allowed me to add details about its features and dimensions. Details of the properties and dimensions of categories are available in Table 11, p: 105. Open Coding, Exploring Properties and Dimensions. At times this was obvious in the data, other times it was necessary to get more data to explore this further. Categories were refined and developed when new data was collected and analysed. This was a continuous process which allowed the categories to become saturated in a systematic way, thus validating their existence (Strauss and Corbin, 1998). Progressive constant comparison led to a set of connecting ideas which explained the social process of what facilitated staff to connect with residents with advanced dementia. This abstract description is illustrated with examples in Chapter 5.

3.3.4.1.2 Theoretical sampling

The aim of theoretical sampling is to identify what data to collect next and where to find it. During Grounded Theory, data collection, coding and analysis occurs simultaneously. Theoretical sampling is a step that enables data to be collected for the specific purpose of developing the theory. It is controlled by the emerging theory (Glaser, 1967).

A key concern of many researchers using Grounded Theory is who to interview next to develop the emerging theory. Strauss and Corbin (1998) encourage researchers to ask themselves, who, what, where, when, how and why. Doing this gives the researcher a basis for sampling additional participants so they can make comparisons in different conditions.

Theoretical sampling of the type of participants to be interviewed, along with the content of the interview questions in this thesis was guided by the output from the coding phases and memo writing. Initially I used very broad questions about connections and included all nursing home staff. This allowed me to gain a broad understanding of the area. As the theory emerged I sought to recruit particular groups of staff who would be able to provide better insights about how and when connections occurred, along with what helped (Ritchie et al., 2014). Further description of how this was done is detailed in Chapter 5. A clear and detailed audit trail was used to keep track and monitor the direction of my theoretical sampling.

3.3.4.1.3 Memos (occurs throughout all steps)

The aim of memo writing is to keep track of ideas and thoughts about the data and how it contributes to the developing theory as it occurs.

Memo writing happens simultaneously with data collection and analysis (Strauss and Corbin, 1998). Memos serve as written records of considerations about the data. They vary in length, content and degree of conceptualisation. Initial memos are short and brief. Memos that occur later in the coding process are known as theoretical memos and are conceptually focused.

Initially memos consisted of my thoughts on the empirical data. They were recorded as bullet points, which served as a reminder of my thought process. I began doing this on interview transcripts but soon realised it was difficult to write memos of length. I found there was insufficient space to develop my ideas. As the process went on and my thinking changed, it was also difficult

to write memos at a conceptual level. I therefore switched to Microsoft word to record my memos digitally. This made them easier to organise and retrieve. After transcribing interviews I recorded my reflections.

An advantage to memos is that they force the researcher to work with concepts rather than empirical data. Each memo was dated and linked to the corresponding transcript(s).

In axial coding, discussed later in the chapter, memos were more organised than the short, brief, bullet pointed memos written in open coding. Each category was subject to thinking around: who, what, why, where, when. Memos were still uncertain at this stage. Throughout the coding processes I made a number of unsuccessful attempts to explain the phenomenon of connections, which were recorded in memos. Details of this are captured in Chapter 5.

A helpful function of memos is that they informed my analytical thinking. One idea often stimulated another. As conceptual categories were formed, memos were raised to the conceptual level (theoretical memos). Eventually in selective coding they integrated individual categories around a core category about the emerging theory. Memos were more specific and directed. Memo writing and theoretical memo writing were a pivotal step between recording ideas from the empirical data and writing early drafts.

3.3.4.1.4 Saturation

The aim of saturation is to identify the point at which data collection should stop. Indeed saturation is the point at which no new categories or properties within the categories are being derived from the data. That means if new data were collected constant comparison would not alter the conceptual understanding. The theoretical model proposed however, is not an end point and is still open to change (Glaser, 1967).

Having described how steps such as: constant comparison, theoretical sampling and memo writing are woven in to the simultaneously cycle of data

collection, coding and analysis to help develop the theory, I will go on to describe the coding procedure in detail: (i) open coding, (ii) axial coding and (iii) selective coding.

3.3.4.2 Step one: open coding

Open coding refers to the first step in the coding procedure. Empirical data are first systematically analysed and categorised, the aim of which is to explore what is being said by whom (Strauss and Corbin, 1990; Strauss, 1994; Strauss and Corbin, 1998).

Similar segments of empirical data are labelled with the ideas they represent to create categories. They will share common characteristics or meanings which allows them to be grouped in to a category. Analytical tools such as memo writing and constant comparison are used to determine the range of potential meanings contained in the words used for those labels. This develops them more fully in terms of their properties and dimensions. (See Table 11, Open Coding, Exploring Properties and Dimensions p 105). In practice this meant looking across and within transcripts, also termed constant comparison, to group similar open codes in to categories. Close inspection of the similarities and differences highlighted the distinctions between ideas. In later steps of the coding procedure, i.e. axial coding and selective coding, data are reconstructed with ideas about how the various categories relate to one another. I focused on gerunds to highlight processes and action.

The abductive nature of Interpretivist Grounded Theory meant I was not expecting categories to be immediately obvious. Instead I used abductive thinking to look for the most likely explanations for each category. Using this logic, meant I was able to turn to the literature and draw on my own experiences to find examples of similar ideas. This did not mean using the literature or my experience as data, but instead used examples from the literature and my own experiences to stimulate thinking about how to understand the empirical data (Strauss and Corbin, 1998, p 44). Chapter 5,

section 5.3 shows how this was done in practice. I ended this coding step with a list of major categories which summarised the empirical data.

3.3.4.3 Step two: axial coding

Axial coding is the next step of data analysis. The aim of axial coding is to reassemble the data that were pulled apart during open coding. In axial coding, categories are related to their sub categories. This means each category is expanded, by elucidating the process around each category. Careful attention is paid on: when each category occurs, where it occurs, why it occurs, how it occurs and with what consequences it occurs. By answering these questions for each of the major categories, the social process of what facilitates staff to connect with residents with advanced dementia can be described more fully and the influence of any underlying mechanisms addressed.

Whilst axial coding is different to open coding, these are not sequential steps. Researchers may move back and forth across coding steps. Researchers must make decisions, about which steps to take and when.

The process of axial coding allowed me to move from the initial list of categories identified in open coding, to create a complex, coherent pattern of categories that highlighted a process, a requirement of axial coding.

Figure 4 details a template which I used to assist with this (Scott and Howell, 2008). Chapter 5, section 5.4 shows how I did this in practice

Figure 4 Conditional relationship guide template (Scott and Howell, 2008)

Conditional relationship guide						
Major Category	What (collective definition based on codes using participants words)	When (during what process does the category occur)	Where (in what setting does the category occur)	Why (the category occurs... because)	How (by what means does the category occur)	Consequence (with what result does the category occur)

3.3.4.4 Step three Selective coding and emergence of the core category

The aim of selective coding is to develop a story line that logically explains the many patterns discovered during axial coding. A core category is first identified. The core category is the central phenomenon considered to be at the heart of the overall social process. Once a core category is identified the researcher should reflect on how/where all of the other major categories fit in the overall story line.

The central purpose of a Grounded Theory is the development of a process, its sub components, the relationship among them and the influencing conditions (Strauss and Corbin, 1990)

The researcher must engage in five steps as part of selective (not necessarily in sequential order) to identify the core category and how it links to other major categories to develop the emerging theory (Strauss and Corbin, 1990).

1. Storyline: in a few sentences the researcher gives an overview of the Grounded Theory.
2. Connecting major categories to the core category: the researcher demonstrates how the core category links with the other major categories (identified in open coding). For example some of the categories were defined as the conditions or contexts needed for connections to occur. Other categories referred to the actions or processes that led to connections. There were categories that were considered to be modes for understanding consequences (i.e. process outcome). The remaining categories were properties and dimensions which added depth to the story
3. Relating categories at a dimensional level: the researcher describes how they developed the core category giving details about its features and dimensions and how it links to other major categories.
4. Validating relationships against data: the emerging theory is provisional until it is validated (See Chapter 9).

5. Filling in categories that may need further refinement: if there are any remaining gaps in the categories, the researcher undertakes theoretical sampling to fill such gaps and ensure saturation.

Table 5 details the template I used to assist with steps 2 and 3 (Scott and Howell, 2008). In practice I transposed each major category (identified in open coding) on to the reflective coding matrix template according to whether it was the core category, a process, a property, a dimension, a context or mode for understanding consequences

Further description of how I did this is detailed in Chapter 5.

Table 5 Reflective coding matrix template (Scott and Howell, 2008)

Core Category				
Processes (actions/interactions) that lead to using time				
Properties (of the process)				
Dimensions (property location on continuum)				
Contexts				
Modes for understanding consequences (process outcome).				

3.4 Conclusion

In this chapter I presented the methodology guiding this thesis. I began by outlining philosophical assumptions about the nature of knowledge. I provided a rationale for why the ontological and epistemological assumptions of critical realism most aligned with the research aims and questions in this thesis. I went on to propose the use of Grounded Theory as the chosen

methodological approach. I described Grounded Theory in detail, beginning with a historical overview of the versions of Grounded Theory, before arguing that Interpretivist Grounded Theory with its emphasis on abduction and theory was most aligned with critical realism and the research aims and questions in this thesis. I ended the chapter by presenting the broad steps and processes involved in Interpretivist Grounded Theory.

4 Chapter 4: Research Methods

4.1 Introduction

In this chapter I describe the overarching research design and the methods used to address the research questions. I begin with an overview of the overarching research design. I go on to discuss ethical considerations, including the process for gaining ethical approval, how I dealt with ethical issues and how data were managed. Next I describe the data collection procedure in detail, defining my sampling and recruitment strategy for nursing homes, nursing home staff and relatives. I talk about how data collection occurred through interviews and discuss the data analysis procedure. Finally the criteria for ensuring the quality of this qualitative research is described.

4.2 Overarching research design

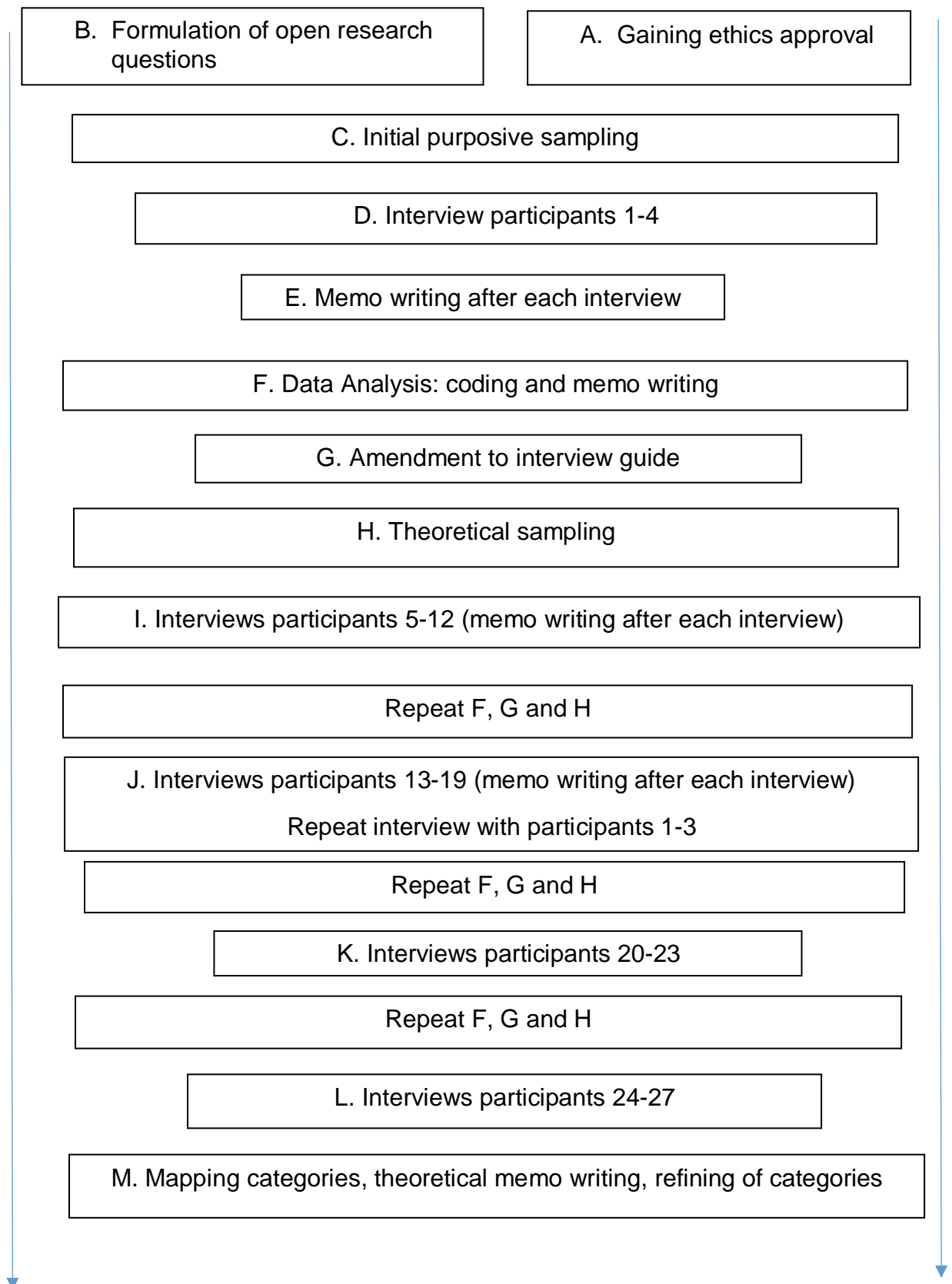
As described in the previous chapter, a qualitative design was planned, using Interpretivist Grounded Theory underpinned by critical realism.

4.3 Interpretivist Grounded Theory

Interpretivist Grounded Theory proposes technical and rigorous procedures for collecting and analysing data (Strauss and Corbin, 1998). Figure 5 below outlines the specific Grounded Theory process I engaged in to explore the research questions identified in Chapter 2

The data were collected through interviews. I conducted data analysis concurrently (Creswell, 2008; Parahoo, 2014). This occurred between June 2016 and August 2017. I will give a detailed description concerning each of the steps later in the chapter.

Figure 5 Overview of the research design



4.3.1 Ethical considerations

4.3.1.1 Ethical approval

The protocol for this thesis was reviewed by the University Ethics Committee and ethical approval granted by the chair of Humanities, Social and Health Science Research Ethics Panel at the University of Bradford on 17 June 2016.

4.3.1.2 Informed consent

Written informed consent was obtained from individual staff and relatives taking part in the interviews (see Appendix 7: Nursing Home Staff Consent Form and Appendix 9: Relatives Consent Form).

4.3.1.3 Right to withdraw

Participants were advised that they could withdraw from the project at any time. However, their contributions, up to the time of withdrawal, would be included in the data analysis/transcription.

4.3.1.4 Participant protection and well-being

None of the methods proposed were thought to pose any risks or harm to participants. The aim of the project was to identify best practice, which was the focus throughout. Despite this, it was possible that poor or potentially abusive practice might have been witnessed or uncovered during data collection. The Department of Health issued some guidance on how to protect vulnerable adults from abuse (Department of Health, 2000). In their

report they reached a common consensus of different forms of abuse which included:

- Physical abuse: including hitting; slapping; pushing; kicking; misuse of medication; restraint; or inappropriate sanctions.
- Sexual abuse including: rape; sexual assault; or sexual acts to which the vulnerable adult has not consented, or could not consent or was pressured into consenting;
- Psychological abuse including: emotional abuse; threats of harm or abandonment; deprivation of contact; humiliation; blaming controlling; intimidation; coercion; harassment; verbal abuse; isolation or withdrawal from services or supportive networks.
- Financial or Material Abuse including: theft; fraud; exploitation; pressure in connection with wills; property or inheritance; financial transactions; the misuse or misappropriation of property, possessions or benefits;
- Neglect and acts of omission including: ignoring medical or physical care needs; failure to provide access to appropriate health and social care or educational services; the withholding of necessities of life such as medication, adequate nutrition and heating.
- Discriminatory abuse including: racist; sexist; based on a person's disability and other forms of harassment, slurs or similar treatment.

“All or any of these types of abuse may be perpetrated as the result of deliberate intent, negligence or ignorance” (Department of Health, 2000, p 9)

This definition was followed during data collection. If there had been any incidence of abuse, local reporting procedures for safeguarding would have been followed, with support from my supervisors.

4.3.1.5 Confidentiality and Anonymity

Participants' details remained confidential at all times. Physical data collected, including, documents and transcripts, were held securely in a locked cabinet, in a locked room separately from consent forms. Electronic data, for example audio files, were downloaded digitally and were held securely on password protected computers in accordance with the Data Protection Act. Recordings were deleted as soon as the files had been transcribed. Data were only handled by the researcher on University premises. All paper documents were anonymised to ensure confidentiality and were only accessed by myself and my supervisors. Personally identifying information was kept separately in a secure location and was only linked to individual's data using numerical codes (Gov.uk, 1998). When writing up the thesis all participants and organisations were given pseudonyms.

4.3.2 Recruitment

4.3.2.1 Nursing home sampling strategy

Purposive sampling was used to select the initial nursing home sites. The intention was to begin with three nursing homes, and then to continue to recruit through theoretical sampling as required, to develop the Grounded Theory.

There were two inclusion criteria:

- Each nursing home should provide care for people living with advanced dementia
- At least one nursing home should provide outstanding care, as indicated in Care Quality Commission (CQC) inspection reports. This was to maximise the likelihood of uncovering best practice and identify what facilitated nursing home staff to connect with residents with

- advanced dementia. The Care Quality Commission (CQC) is the independent regulator for health and social care services in England. They ensure health and social care services provide safe, effective, responsive and compassionate care by monitoring and inspecting services to make sure they meet key quality standards. Ratings range from outstanding to inadequate care. Inspection reports are published and are available in the public domain (Care Quality Commission, 2016).

Selection of nursing homes was also influenced by my capacity as a researcher working for the National Institute for Health Research (NIHR). My involvement with the Enabling Research in Care Homes (ENRICH) network meant I was already familiar with a number of nursing homes. This knowledge in addition to CQC reports helped me to achieve variation. For example I was able to select nursing homes where I had previously observed connections between staff and residents with advanced dementia.

Care was taken to ensure nursing homes ranged in size and setting. This ensured diversity was achieved. Within the nursing homes that agreed to participate, all nursing home staff and relatives who cared for, or observed care of people living with advanced dementia were invited to take part. For example: nursing home managers, nurses, care assistants, activities coordinators, kitchen staff, maintenance staff and relatives.

4.3.2.2 Recruitment of nursing homes

The nursing homes were part of the NIHR ENRICH initiative which meant they had previously expressed an interest in taking part in research. I initially approached homes through a phone call. I briefly explained the reasons for approaching them and what was entailed if they took part. After an initial phone call I then sent further written information by email (See Appendix 3: Nursing Home Invitation Letter). The email was followed up by a phone call the following week where questions were answered. A date was then

arranged to visit the nursing home. Nursing home managers who agreed to take part needed to confirm they were able to:

- Identify a lead person to be the key point of contact and take an active role in supporting the research. For example facilitating access to the nursing home and introduction to participants.
- Inform key members of the team and have their agreement in principle to be involved
- Act as a gate keeper and provide support in approaching and speaking to staff and relatives

Once the nursing home agreed to participate, written informed consent from the provider or their nominee was obtained (See Appendix 4: Nursing Home Consent Form).

4.3.2.3 Sampling of participants within sites

Initially I aimed to recruit:

- Nursing home managers
- Nursing home staff including, nurses, care assistants, activities coordinators, kitchen assistants, domestic staff and maintenance staff
- Relatives of residents living with advanced dementia

In line with Grounded Theory methods purposive sampling was carried out in order to ensure diversity across the subsequent participants. A range of participants with: various experience of caring for people with advanced dementia, who worked in various roles, with diverse age and ethnicity were sought with the aim of eliciting similarities and differences.

In addition theoretical sampling was used, informed by ongoing analysis. For example, my initial sampling was completely open in the first home, with recruitment of interested participants. However, as data collection proceeded I refined the selection criteria based on emerging themes and concepts. An example of this was when supervisory support emerged as a theme, which

guided me to recruit nursing home managers and nurses to get their perspectives. (See Appendix 5: Reflexive Diary).

4.3.2.4 Recruitment process of participants at sites

4.3.2.4.1 Recruitment of nursing home managers

Nursing home managers indicated they wanted to take part in the project by responding to an email. They were provided with a staff information sheet (See Appendix 6: Nursing Home Staff Information Sheet) and a consent form (See Appendix 7: Nursing Home Staff Consent Form). This was followed up by a phone call after a minimum of 24 hours to answer any questions. Arrangements were then made to obtain written consent. A written copy of the manager's signature was required and was obtained either during a face to face meeting, in the post or scanned and emailed.

4.3.2.4.2 Recruitment of nursing home staff

All staff who worked in the nursing home were given initial information about the project by the nursing home manager. If they were interested they were asked to contact me independently for further information. This process ensured staff did not feel pressured by the manager to participate. Once staff indicated they might like to take part, a detailed information sheet was provided (See Appendix 6: Nursing Home Staff Information Sheet) and a follow up phone call after a minimum of 24 hours was made to ask questions and obtain written informed consent. A signed copy of their agreement to take part was collected via a consent form (See Appendix 7: Nursing Home Staff Consent Form).

4.3.2.4.3 Recruitment of relatives

All relatives of residents living with advanced dementia were invited to take part in the project in all seven nursing homes. Relatives were directly given a letter by staff. A poster was also displayed throughout the home and information given at relatives' meetings. If relatives were interested they were asked to contact me independently for further information. This process ensured relatives did not feel pressured to participate. Once relatives indicated they would like to take part, a detailed information sheet was provided (See Appendix 8: Relative Information Sheet) and I made a follow up phone call after a minimum of 24 hours. This was to answer any questions and obtain verbal consent. Their agreement to take part was then collected via a consent form (See Appendix 9: Relative Consent Form).

4.3.3 Data collection methods

In this section I will discuss the practical procedures for generating data. I will describe, in detail, interviews as the specific method employed for collecting data. As data collection and analysis occurred concurrently, much of the description about how this was done in practice is given in Chapter 5.

4.3.3.1 Interviews

I chose to use a semi structured interview as the method of data collection. In-depth qualitative interviews were conducted with key personnel in nursing homes and relatives of residents living with advanced dementia. Staff were asked to give rich descriptions about the ways they connected with residents with advanced dementia, along with what enabled such connections. Relatives were asked to give rich descriptions about the ways they observed staff connecting with their relative, along with what they felt facilitated such connections.

In-depth qualitative interviews are a powerful way of gaining insight and interpretation into the social worlds of people, generating rich data (Ritchie et al., 2014). Taking this approach allowed me to gather rich descriptions about care staffs' main concern (Willig, 2008). I developed a flexible interview guide (See Appendix 10: Phase 1 Interview Guide). I began by asking broad questions about how and when staff connected with residents, along with what helped them. This allowed participants to guide the interview according to their own experiences. Answers to these initial questions allowed me to adapt successive interview guides based on new and emerging themes.

Asking for specific examples of instances where staff had connected with residents with advanced dementia helped to gather specific detail of actual moments of connection, rather than generalised or impersonal ideas. The aim of Grounded Theory interviewing is to encourage participants to talk openly about their main concern, therefore asking open questions from the outset allowed this to happen (Alvita Nathaniel, 2008). As part of the process of the development of the interview technique, I considered my own responses as a way of paying attention to possible instances of bias (Birks and Mills, 2015). For example, I was conscious not to look judgemental if staff were unable to easily recall an instance of connection, instead I rephrased my questions and provided an example of what I meant.

Interviews varied in length from 14 minutes to 82 minutes and took place in a private room within the nursing home. Interviews were audio recorded and subsequently transcribed. Field notes were also taken during informal discussions. On occasion follow up interviews were conducted to clarify ideas with staff, relatives or to clarify areas I felt we had not covered. The possibility that this might happen was discussed with staff during the consent process.

Interviews occurred in 4 Phases. Phase 1 began with interviews one to four. Three of these interviews occurred in one day. Interviewing three people in one day is not standard practice for Grounded Theory. It would be more usual to begin coding and analysis immediately after an interview so it could guide the next interview. However, staff were keen to participate and available that day. I felt it was a precious opportunity as I knew how hard at

times it was for nursing home staff to be available. As I did not have time to process and analyse each interview before the next, I conducted follow up interviews with the first three participants.

Following reflection on the first four interviews, the interview guide was amended, refining the questions in line with initial findings. For example I introduced questions asking what staff did to connect, when they connected, why they connect, where they connected and how they connected. This added structure to the open questions that had been used in the early interviews (what staff did to connect and what helped them). This interview guide was used for participants' 5 to 12 (See Appendix 11: Phase 2 Interview Guide).

Analysis of interviews 1 to 12 highlighted the importance of time. Nursing home staff repeatedly talked about the issue of time. I therefore amended the interview guide further to incorporate 'time'. This interview guide was used for participants 13 to 18 (See Appendix 12: Phase 3 Interview Guide).

In Phase 4 contextual factors were incorporated in to the interview guide. I used theoretical sampling to approach participants that would provide insight in to this area. This interview guide was used for participants 19 to 21 (See Appendix 13: Participant Interview Topic Guide Four). This is a brief description of the phases of the interviewing process. As data collection and analysis were conducted concurrently, I have integrated further information into Chapter 5. This shows when decisions about interviewing were made as a result of ongoing analysis, along with the consequences of such decisions.

4.3.4 Data analysis procedure

4.3.4.1 Transcription

I produced verbatim transcripts of all the interviews. I asked participants if they would like to see their own transcript to check it was acceptable or if they would like any content removed. One relative took me up on this offer and was happy with the transcript. I then removed all names and identifying details to ensure confidentiality. I then listened to the recordings repeatedly and made notes on the verbatim transcripts. The abductive nature of Interpretivist Grounded Theory meant this step was useful as I was able to ask myself questions about the data, then go back to reflect on tone of voice, or significant moments or gaps. Electronic versions of transcripts were uploaded on to NVIVO 10 (NVivo, 2010). Recordings were deleted following this process.

4.3.4.2 Process of analysis

Data were analysed according to the Grounded Theory procedures set out in Chapter 3. Table 6 describes the steps I took.

Table 6 Main steps of Interpretivist Grounded Theory (Strauss and Corbin, 1990; Strauss and Corbin, 1998)	
Step	Description
Identification of research problem and initial research questions	Informed by working and visiting nursing homes, and the literature review in Chapter 2
Interviewing	Phase 1, participants one to four (See Appendix 10: Phase 1 Interview Guide)
Step one: open coding	<p>Labelling similar ideas and grouping them in to categories</p> <p>Asking questions of the data to identify actions and processes</p> <p>Ensuring my coding was action focused (use of gerunds)</p> <p>Using an iterative process (coding one interview may lead to returning to another) to explore similar or different ideas, identifying gaps in the data (constant comparison)</p> <p>Recognising that initial open codes were provisional</p>
Memo writing	<p>Recording my informal thoughts and ideas that allowed me to begin to understand and interpret the data early in the process.</p> <p>Coming up with provisional ideas for tentative categories.</p> <p>Looking for links between codes, comparing codes to one another, which guided me to further data collection.</p>
Interviewing	Phase 2, participants five to twelve (See Appendix 11: Phase 2 Interview Guide)
Memo writing	<p>Further reflection about what I was hearing. Taking an abductive approach I looked for clues elsewhere for example in the literature.</p> <p>A tentative emerging model was proposed (Model 1, p 120)</p>

Step two: axial coding	Exploring categories in further detail. What is the category, when does it occur, where does it occur, why does it occur, how does it occur, with what consequences does it occur. Transforming the loose array of flat linear categories into a complex coherent pattern that highlighted processes.
Interviewing	Theoretical sampling to include staff who were not involved in personal care and those in a management position (i.e. activities coordinators) participants 13 to 15
Memo writing	I realised Model 1 did not accurately capture the outcome of interest. I therefore followed up other leads.
Interviewing	Phase 3 participants 16 to 18 (See Appendix 12: Phase 3 Interview Guide) to explore other leads.
Memo writing	Organising thoughts, constant comparison to clarify thoughts, sense checking with nursing home PPI groups, follow up interviews with three staff to clarify their thoughts on new ideas. A tentative emerging model was proposed (Model 2, p 124).
Interviewing	Phase 4 participants 19 to 21 (See Appendix 13: Phase 4 Interview Guide) Theoretical sampling to include senior nursing home staff including nursing home managers and nurses.
Step three: selective coding	Exploring how the categories interacted and influenced one another to bring about change. Identifying a core category (that explained the most variation) then showing how it related to the other categories.
Theoretical saturation	No new conceptual relationships were emerging that added depth or dimensions to the categories that had already been developed.
Memo writing	Further reflection, theoretical memo writing, sense checking with a nursing home PPI group, follow up interviews with participants to sense check. Looking for clues in the literature. Revisiting transcripts and recordings
Emerging theory	Development of an interpretive theory. Model 3, p 128, developing a story line which captured meanings and actions according to participants' experiences.

4.3.5 Ensuring quality

Lincoln and Guba (1985) proposed four criteria when ensuring quality in qualitative research: credibility, transferability, dependability and confirmability (Lincoln and Guba, 1985). These will now be considered in relation to my study.

4.3.5.1 Credibility

Credibility refers to the precision of the research; more specifically how well the data collection process measure what it claims to measure (Gibbert and Ruigrok, 2010). In order to enhance credibility, a number of strategies proposed by (Shenton., 2004) were employed in this project. They included:

- The use of correct terms for the concepts being measured: this began with the literature review and consultation with nursing home managers and evolved during the interview process. Nursing home managers at a care home forum reviewed the participant information sheets, along with interview topic guides prior to the research taking place. Terms were subsequently guided by the participants in the interviews. I also recorded memo so I could see how concepts and terms evolved during the interview process (See Appendix 5: Reflexive Diary).
- Becoming familiar with the culture of the organisation under study before data collection begins: I had already worked with many of the homes prior to conducting this research project during my role at the NIHR. However, as some of this was not recent, I visited each home two or three times prior to starting the research. Doing this allowed me to become immersed in the culture of the nursing home and to re-form trusting relationships with participants.
- Using a systematic and transparent chain of evidence that allows the reader to re-enact the process and understand how the conclusions

were reached: see Chapter 5 for a detailed description of how the Grounded Theory was developed.

- Frequent collaboration with supervisors and/or peers to discuss progress, problems, develop ideas and interpretation: this offered a fresh perspective and shed light on any bias. Monthly and bimonthly supervision sessions were held. I also had the opportunity to present my findings to peers and colleagues in the School of Applied Dementia Studies at the University of Bradford. I also presented my final model to nursing home managers at a care home forum. Questions and observations during these processes allowed me to refine methods and explanations. A reflective diary that detailed events as they happened allowed me to record deviations from the original planned process. This allowed the development of ideas and theories to be recorded as they occurred. (See Appendix 5: Reflexive Diary).

4.3.5.2 Transferability

Transferability refers to the extent to which the findings can be applied beyond the context of the project. It has been argued that qualitative research, with its small numbers, cannot be applied beyond its intended context. It has also been argued however, that while the context of each project is unique, it is an example within a broader group and may be applicable to other contexts (Shenton., 2004). Lincoln and Guba (1990) agree with this view suggesting the researcher should provide the necessary contextual information to support the transfer of knowledge. In my study, this included gathering in depth information about who and where the participants were, and reporting this in the findings chapters, along with information about restrictions on who was involved, the sample size, data collection methods, the number and length of interviews and the time period over which data was collected. This information, along with a description of what enabled staff to form connections with residents with advanced dementia, should enable the

reader to consider the relevance of my study findings to their own situations (Shenton., 2004).

Glaser and Strauss (1967) suggested the notion of theoretical generalisation. They proposed that theories are built about the social world and the practices within it through analysis of data. Theories are then tested by repeated investigation of the data, until that theory sufficiently explains the phenomenon under investigation. In this thesis theories were not repeated by repeated investigation as with positivist informed research, but rather abductive logic was used to look for similarities with other ideas both in the literature and my own experiences. In this way my theoretical concepts related to general structures as opposed to individual practices in individual places. It is in this way findings can become transferrable.

There have been questions as to whether theoretical generalisation could be deemed credible however. Pitfalls that may limit the credibility of theoretical generalisation have been noted (Smaling, 2002) For example stopping sampling before saturation has been achieved, forcing data into neat categories, downplaying data that does not fit, presenting findings that are descriptive rather than theory generating, and offering little discussion about where else the theory might hold. I have aimed to take steps address these pitfalls in my study (See Chapter 5 for an account of how I developed my Grounded Theory, Appendix 5: Reflexive Diary and Table 11: Open Coding, Exploring Properties and Dimensions, p 105).

4.3.5.3 Dependability

Dependability refers to the extent to which findings from the study can be repeated in the same context, with the same methods using the same participants. Lincoln and Guba (1990) suggest dependability is closely linked with credibility and that using overlapping methods such as interviews, focus groups and repeat interviewing helps to address issues of dependability. Other strategies include: reflection and memo writing along with detailed and transparent reporting as this would enable another researcher to repeat the

process if necessary. This thesis provides the reader with a detailed description of what happened. The data collection process was recorded accurately, along with reflective appraisal throughout. Refer to Chapter 5 for a reflective process of developing the Grounded Theory.

4.3.5.4 Confirmability

Confirmability refers to the extent to which findings from the study are a result of the experiences of the participants and not biased or influenced by the researcher. I have already acknowledged I bring some bias to the research from my previous knowledge and experience. However, this can be addressed by ensuring the researcher considers his or her own role and influences they might have on the research. This means views and beliefs of the researcher should be made explicit within the findings, along with the reasons for choosing one approach over another. I have weaved in reflexivity throughout the chapters. The reflective diary (See Appendix 5: Reflexive Diary) was also invaluable for ensuring confirmability as it produced an audit trail with the aim of allowing the reader to follow the course of the research step by step (Shenton., 2004)

4.4 Conclusion

In this chapter I have described the overarching research design and the methods used to address the research questions. I began with an overview of the overarching research design. I went on to discuss ethical considerations, including the process for gaining ethical approval, how I dealt with ethical issues and how data were managed. Next I described the data collection procedure in detail, defining my sampling and recruitment strategy for nursing homes, nursing home staff and relatives. I talked about how data collection occurred through interviews and discussed how the data were analysed. Finally the criteria for ensuring quality was described. The next

chapter provides an overview of the research findings. I begin by providing an overview of the final theory before introducing the core category of 'using time'.

5 Chapter 5: Findings

5.1 Introduction

In Chapter 5, I describe the iterative processes of data collection, analysis of data and the gradual development of my Grounded Theory. First I describe the nursing homes and participants who took part in the study. I then go on to explain the process of open coding, axial and selective coding. Through each section I will weave in when data collection occurred in relation to analysis, along with key decisions and changes I made along the way. I aim to unfold the way I developed my Grounded Theory to give transparency to the process I followed, and to provide an overview of the Grounded Theory. Following this overview, Chapters 6, 7 and 8 each focus in greater depth on one set of findings: contextual factors, individual factors and outcome respectively.

5.2 Description of nursing homes and participants

All of the nursing homes who took part were privately owned. Whilst I tried to recruit nursing homes owned by the local authority and non-profit organizations, none of those I approached responded with a willingness to take part. Seven nursing homes in total agreed to take part. Table 7 shows the demographics of the nursing homes involved.

Once the three initial nursing homes had been selected (NH01, NH02, NH03 in Phase 1), theoretical sampling was performed for the remaining homes (NH04, NH05, NH06 in Phase's 2 and 3, and NH07 in Phase 4). This allowed me to ensure my developing ideas and concepts could be explored. An example of this was when care assistants described nurses as providing them with support. This encouraged me to recruit larger nursing homes with more nurses to ensure this could be explored in further detail.

Table 7 Demographics of the nursing homes

ID	Setting	Type of home	Registered for	No of beds	CQC rating
Initial sampling (phases 1 and 2)					
NH01	Urban	Nursing	Old age, dementia	31	Requires improvement
NH02	Rural	Nursing	Old age, dementia	34	Good
NH03	Rural	Nursing	Old age, dementia	30	Requires Improvement
Theoretical sampling (phase 3)					
NH04	Urban	Nursing	Old age, dementia Specialised dementia unit (SDU)	70	Outstanding
NH05	Rural	Nursing	Old age, dementia SDU	63	Good
NH06	Rural	Nursing	Old age, dementia	69	Good
Theoretical sampling (phase 4)					
NH07	Rural	Nursing	Old age, dementia SDU	22	Good

As can be seen in Table 8, demographics of the nursing home staff, all but one of the 21 nursing home staff were female. There were two nursing home managers, four nurses, three senior care assistants, eight care assistants, three activity coordinators and one kitchen assistant.

Table 8 Demographics of the nursing home staff that were recruited

Home ID	Participant ID	Role	Experience working with older people	Years in home	Ethnicity	Age	Gender
Phase 1 – interview guide 1							
NH02	S01	Nurse	4 years	6 years	Black	28	Female
NH02	S02	Senior carer	15 years	12 years	White (British)	36	Female
NH03	S03	Senior carer	6 years	3 years	White (British)	30	Female
NH01	S04	Carer	1 year	1 year	Asian	24	Female
Phase 2 – interview guide 2							
NH01	S05	Nurse	1 year	1 year	White (European)	28	Female
NH01	S06	Care assistant	2 years	2 years	Black	31	Female
NH01	S07	Care assistant	3 years	3 years	Black	39	Female
NH03	S08	Activities Coordinator	25 years	12 years	White (British)	61	Female
NH02	S09	Care assistant	2 years	2 years	White (British)	20	Female
NH02	S10	Kitchen assistant	14 years	14 years	White (British)	52	Female
NH03	S11	Senior carer	10 years	4 years	White (British)	34	Female

NH02	S12	Care assistant	27 years	8 months	White (British)	45	Female
Theoretical sampling to include nursing home managers and activities coordinators							
NH04	S13	Nursing home manager	22 years	14 years	White (British)	46	Female
NH05	S14	Activities coordinator	24 years	20 years	White (British)	55	Female
NH05	S15	Activities coordinator	16 years	12 years	White (British)	51	Male
Phase 3 – interview guide 3							
NH06	S16	Care assistant	6 years	2 years	White (British)	26	Female
NH06	S17	Care assistant	10 years	4 years	White (European)	41	Female
NH06	S18	Care assistant	14 years	14 years	White (European)	48	Female
Phase 4 – interview guide 4. Theoretical sampling to include those in supervisory position							
NH07	S19	Nursing Home manager	12 years	12 years	White (British)	43	Female
NH07	S20	Nurse	15 years	15 years	White (British)	38	Female
NH04	S21	Nurse	24 years	4 years	White (British)	48	Female

Table 9 details the demographics of relatives. Five relatives were recruited in total. Two were the husbands of female residents living with advanced dementia, two were daughters of parents living with advanced dementia and one was the wife of a male resident living with advanced dementia. I initially recruited four participants, one nurse, two senior care assistants and one relative at NH01.

Table 9 Demographics of relatives of people with advanced dementia

Home ID	Participant ID	Role	Experience working with older people	Years in home	Ethnicity	Age	Gender
NH01	R01	Daughter	8 years	3 years	White (British)	69	Female
NH02	R02	Daughter	4 years	12 months	White (British)	59	Female
NH04	R03	Husband	12 years	2 years	White (British)	78	Male
NH04	R04	Wife	7 years	6 years	White (British)	80	Female
NH06	R05	Husband	7 years	2 years	White (British)	81	Male

5.3 Open coding

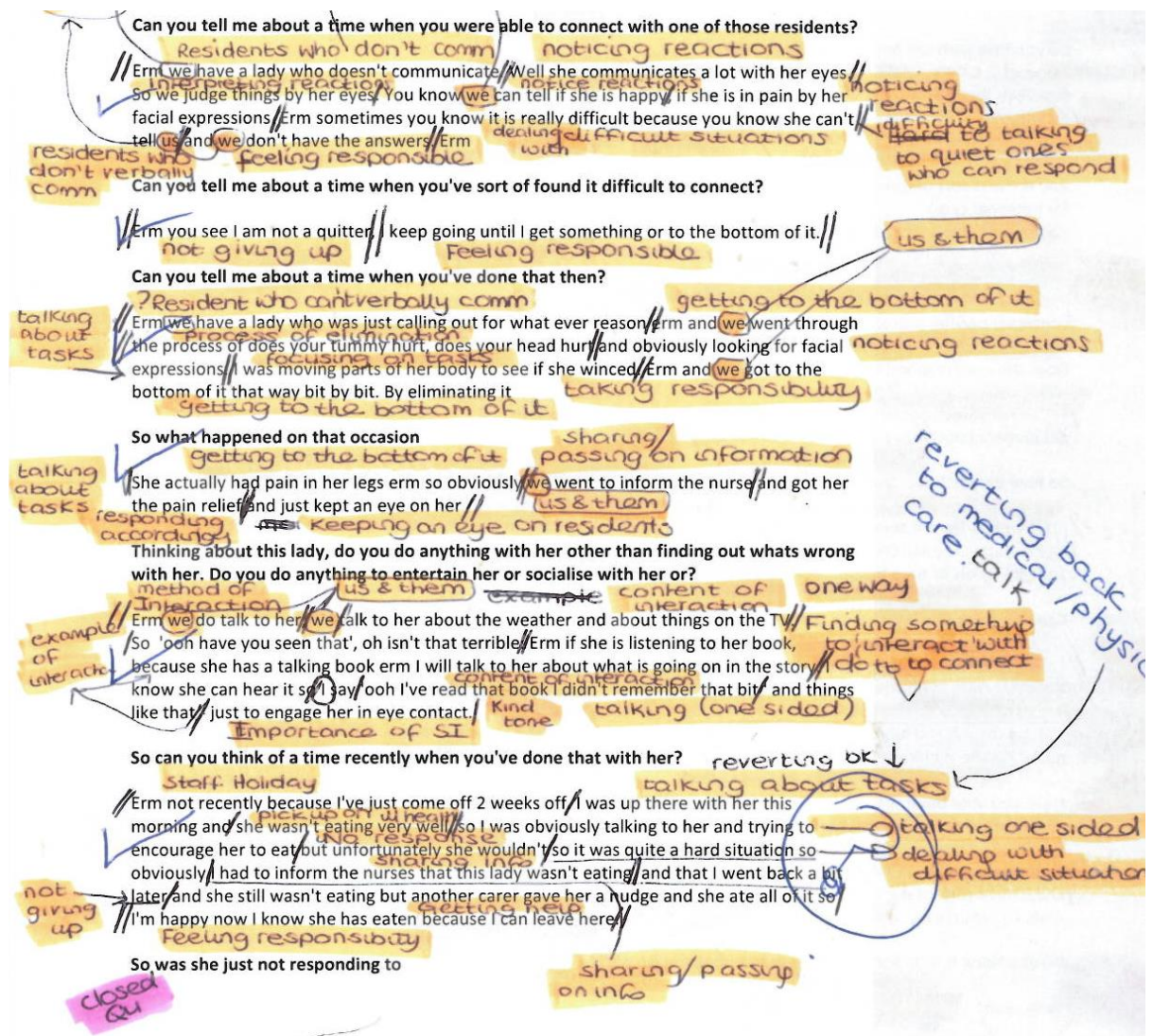
In this section I describe the process of open coding, giving an account of the process and then reflections of Phases 1-4. By the end of open coding, I arrived at 31 major categories. They are shown in Table 11: The properties and dimensions of open coding. Arriving at these 31 categories was a complex and iterative process which I will now describe.

5.3.1 Phase 1: process and reflections from data collection and analysis

5.3.1.1 Process

I initially coded the first four participant interviews. First I created open codes by segmenting data into meaningful expressions or short sequences of words. Figure 6 is a transcript which shows how I did this.

Figure 6 An example of open coding.



To give an example, 'passing on/sharing information' was an open code that summarised the following segment of data:

"She actually had pain in her legs erm, so obviously we went to inform the nurse and got her the pain relief and just kept an eye on her" S12
Care assistant.

Some open codes applied to more than one segment of data. For example The open code 'noticing reactions' was used to encompass a number of segments of data including: *"she communicates a lot with her eyes"*, *"we can tell if she is happy or if she is in pain by her facial expressions"*, *"and obviously looking for her facial expressions to engage her in eye contact"*.

The same was done for the open code of *'feeling responsible'* which was used to encompass: *"it's really difficult....we don't have the answers"*, *"I keep going until I get to the bottom of it"*, *"I am happy now I know she has eaten"*

I followed this process for each of the four transcripts.

5.3.1.2 Reflections

Reflections following the initial analysis made me realise that as I began open coding, I had assumed staff would use psychosocial interventions to connect with residents with advanced dementia e.g. music, connecting through the senses, physical objects or imitation. I think this was due to my exposure to the literature review, where evidence to date has largely tested the effectiveness of psychosocial interventions to connect with residents with advanced dementia.

After reading and re-reading early interviews however, staff suggested connections with residents with advanced dementia were not as a result of psychosocial interventions, but took place during routine care and relied on a number of factors that centred on interactions between the staff member, the resident and their wider environment.

Reflecting on my own experiences of visiting and working in nursing homes. I recalled that the use of psychosocial interventions was usually planned in advance by activities coordinators or external staff. My grandmother and many others with advanced dementia were not often involved in these sessions without support. I realised there were probably times where psychosocial interventions were used to connect with residents with advanced dementia, the interviews thus far however, suggested that this was not the 'go to' strategy, particularly for care assistants.

I was never present for personal care so I had no insight in to what went on during these private and intimate times. Taking an abductive approach, I briefly consulted the literature to validate the idea of connecting during personal care. I found studies which suggested personal care was a good time to interact. Edvardsson et al (2014) found that brief intimate interactions

between nursing home residents and staff promoted personhood. Similarly care assistants (n=13) in a qualitative study, identifying perceptions and experiences of providing Person Centred Care in practice, suggested it was important to create a bond during routine interactions (Colomer and de Vries, 2016).

The analysis of the first four interviews (See Appendix 10: Phase 1 Interview Guide 1) raised a number of questions for me. Given that connections were not dependent on psychosocial interventions (as I initially thought), I was interested to know more about what staff did during times of personal care.

5.3.2 Phase 2: process and reflections from data collection/analysis

The next set of interviews (participants 5-12) remained open and was guided by the participants, I asked more focused questions including:

1. When did staff connect?
2. Where did they connect?
3. What did they do to connect?
4. How did they connect?
5. Why they connected?
6. What was the best time to connect?
7. What helped them?

This provided more structure to allow me to explore if connections did occur in personal care and if so what helped without leading participants (See Appendix 11: Interview Guide Two). To ensure I did not introduce bias from my exposure to the literature, I was very careful to remain open and let participants guide the interviews. I also reviewed and scrutinised my interview style with my supervisors using the transcripts after each interview

5.3.2.1 Process

Phase 2 involved interviewing participants 5-12. I coded each transcript as I did in Figure 6. Open codes with similar meanings were grouped together to form categories', with the open codes retained as the 'properties' of the category. At the end of phase 2 I had a set of categories that summarised the content of transcripts 1-12. Table 10 shows the results of how I did this.

Table 10 An example of open coding

Category	Open code	Example Quote
Caring values	<p>"Putting self in their shoes",</p> <p>"showing empathy",</p> <p>"feeling responsible,</p> <p>"big softy"</p> <p>"being caring"</p>	<p>"I try and act how I would like people to act with me" S06 Care assistant</p> <p>"I think it is important to try regardless of what you get back, I wouldn't like to go a whole day without someone speaking to me so I think because I am that type of person it makes it easier" S06 Care assistant</p> <p>"I relate it to when I did mobile care. They don't want you to go in do your work and leave, they want you to sit with them for ten minutes as you might be the only person they see that day. Although it is different here, I still class it like that because some people don't get visitors all day. It must be awful" S07 Care assistant</p> <p>"I'd like to think when my time comes someone will talk to me or read me a book, talk to me about the news" S12' Care assistant</p> <p>"I am a big softy, I don't know really, I mean my gran, well my great gran, she had dementia when I was little. She died when I was ten so I can't really remember, but everyone says I could communicate with her and she would do things for me" S08 Activities coordinator</p> <p>"It is all about caring. You have just got to give it your best. That's what it is all about like you are delivering it to your grandparents or your mother or brother" S03 care assistant.</p>

According to Strauss and Corbin (1998) once categories are identified through open coding, the researcher should develop them in terms of their specific properties and dimensions. For example for the category non-verbal communication, I grouped: “moving closer to the person”, “using touch”, “smiling”, “using kind facial expressions and “eye contact” together. I did this because I identified them as actions that shared a common characteristic - they did not require the spoken language. By doing this each category was given specificity through its definition of common characteristics (properties).

The next step was to understand how these properties varied along their dimensional ranges for example the extent, frequency, intensity and duration (Strauss and Corbin, 1998). I did this for each category, some worked better than others. Table 11 illustrates the properties and dimensions that emerged through open coding

Table 11 The properties and dimensions of open coding.

Categories	Properties (i.e. open codes)	Dimensions (extent, frequency, intensity, duration)
Caring attitudes	<p>Showing empathy, being caring, being kind, showing compassion, helping others, being reliable, being patient, being respectful.</p> <p>“A heart full of kindness”, “Putting yourself in their shoes” “Empathy”, “Passionate”, “I am that type of person”, “I am a big softy”, “it is all about caring”, “if it was me I would want people to be</p>	<p>Individually expressed to residents and to staff, extent, frequency and duration is variable depending on personality, pressures of job. Those with caring attitudes strive to express caring attributes at each interaction (with residents or peers) for the duration of the interaction and for the purposes of helping others</p>
Using strategies	<p>Laughing, making jokes, being playful, being silly, trying anything, doing the little things, finding something the resident is interested in, pester power</p>	<p>Frequent visits to up to four times per day. Extra visits where possible. Purpose of strategies: cooperation during personal care and meal times, to cheer people up, create pleasure, a sense of responsibility towards residents</p> <p>Prolonged visits where possible. One on one intimate visits meant staff built close relationships.</p> <p>Over a long period of time, it can take months to learn. Communication patterns, build up trust.</p>
Understanding advanced dementia	<p>Knowing what to do, everybody is different, everybody experiences dementia differently, at different times, on different days, ability to respond, attitude towards dementia</p>	<p>Informal learning i.e. learning on the job, learning from peers (daily), weekly supervision, during interactions with residents (every 4 hours minimum), reflecting on own experience (daily), regular informal chats (daily), regular meetings (team meeting once per week), handovers (at every shift) – less emphasis on than formal training (few examples).</p>

Categories	Properties (i.e. open codes)	Dimensions (extent, frequency, intensity, duration)
Having positive attitude towards dementia	Care staffs attitudes thoughts about dementia and people living with dementia- "I don't have bad experiences, only good experiences" versus "there is not a person to connect with"	At all times, during times of interaction with residents and colleagues. Particularly important in guiding informing the frequency, extent and duration of connections. Continuum of believing there is a person to connect with versus thinking there is not a person to connect with
Using advanced communication skills	Using non-verbal techniques to connect with residents attention to facial expressions, posture, eye contact, reading reactions	During interactions with residents, usually during personal care. More readily described during less pressurised environment, when there is more staff, when staff have more support from superiors and experienced colleagues Frequent visits to up to four times per day. Extra and prolonged visits where possible. One on one intimate visits meant staff built close relationships. For the purposes of cooperation during personal care and meal times, to cheer people up, create pleasure, a sense of responsibility towards residents Learned on the job, usually from experienced colleagues
Interpreting reactions	Learning communication patterns, understanding communication attempts "For me it's about keeping an eye on facial expressions, their posture & them stiffening up on you – if they are not relaxed and not enjoying what you're doing, you can tell"	During interactions with residents, usually during personal care, every four hours for the length of personal care Learned on the job, usually from experienced colleagues, over a long period of time. It can take months to learn. Extra and prolonged visits where possible. One on one intimate visits meant staff built close relationships.

Categories	Properties (i.e. open codes)	Dimensions (extent, frequency, intensity, duration)
Getting to know residents	Knowing residents as people, their likes/dislikes, background, communication repertoire help to facilitate connections	During personal care (four opportunities per day at least) for the duration of personal care. Extra visits where possible, one on one visits interactions. One on one intimate visits meant staff built close relationships.
Being able to problem solve	Adapting, trial and error, finding a way around it “Sometimes you have to take a step back and say well this isn’t working”, “I mean you get negative responses, you have to work round it”	As required. The frequency, extent, duration and intensity varied across staff and across situations. Some staff were more skilled than others, staff learned how to problem solve on the job, over time, through trial and error and asking experienced colleagues.
Sharing ideas	Staff from all positions in the organisations sharing knowledge and ideas bringing ideas together, learning from each other	In teams formally an informally (daily), supervision (weekly), on the care home floor (daily). Intensity varies according to the ideas. Is on-going.
Taking responsibility	Feeling responsible for the residents well-being can facilitate connections “as long as I leave the room and she is bright eyed and looking happy	Individual, the extent, frequency and duration is variable depending on the staff member’s personality and pressures of job. Those who take responsibility often express caring attributes at each interaction (with residents or peers) for the duration of the interaction and for the purposes of helping others
Being hands on	Working with residents directly for a sustained length of time facilitated connections	Daily interactions with the resident during personal care (four opportunities per day), for the duration of personal care. During interactions with the resident in their room. At team meetings, one to ones, supervisions, on the nursing home floor in real time.

Categories	Properties (i.e. open codes)	Dimensions (extent, frequency, intensity, duration)
Fostering relationships	Process of building relationships with residents, family and staff of all levels which leads to connections, intimate, reciprocal	Individual, the extent, frequency and duration is variable depending on the staff member's personality and pressures of job. Those with close relationships. often express caring attributes at each interaction (with residents or peers) for the duration of the interaction and for the purposes of helping others
Pushing boundaries	Being creative to connect with residents with advanced dementia	Individual, the extent, frequency and duration is variable depending on the staff member's skills and knowledge. Time pressure can impact the extent, frequency and duration and intensity of pushing boundaries as can the resident's response. Usually during personal care, but for social purposes as well.
Using positive approaches to residents	Behaviours of staff, how they approach residents. Communication, telling resident what you are doing, calm, gentle touch, caring, kindness, observe their reactions "They might not understand what you say but it is the tone and the way you approach them. If you are happy and jovial, they will be happy and jovial back"	On the job in real time. During personal and other interactions (opportunity at least four times per day), extra where possible, depends on staff member. Intensity depends on staff member and their skills and motivation. Duration depends on time pressures, other tasks, and resident's response.
Playing it by ear	Dealing with issues as and when they arose could facilitate connections	On the job in real time, usually during personal care for the purposes of a task, but also for social purpose. The frequency, extent, duration, intensity is variable depending on staff members individual ability, support from others, capacity to learn from others and resident response. It can also be affected by competing priorities, under pressure, to meet deadlines, during disagreements.

Categories	Properties (i.e. open codes)	Dimensions (extent, frequency, intensity, duration)
Experiencing reciprocation	Getting a response from a resident/team member - cooperation	During interactions with residents, on the nursing home floor with staff, during personal care (residents room) social situations, informal chats, formal team meetings. The frequency, extent, duration, intensity of reciprocation is variable on resident's moods. It can also be affected by staffs ability to connect, skills, time, competing priorities.
Experiencing outcomes of connections	The product of connecting with a resident during reciprocal interactions facilitated connections with other residents	During interactions with residents, on the nursing home floor with staff, during personal care (residents room) social situations, informal chats, formal team meetings. The frequency, extent, duration, intensity of reciprocation is variable on resident's moods. It can also be affected by staffs ability to connect, skills, time, competing priorities
Working in home for longer/ shorter periods of time	Staff became skilled at connecting with residents over time, with experience	More frequent in nursing homes with caring cultures.
Having experienced staff	Experienced staff work as role models, share knowledge, ideas and support.	More frequent in nursing homes with caring cultures and effective leaders. Frequency, extent, duration and intensity is variable depending on the attributes of the experienced staff member.
Being part of a stable workforce	A constant, steady workforce (low staff turnover) can facilitate connections	More frequent in nursing homes with caring cultures with effective leadership, supported by experienced staff.
Having enough staff	Higher levels of staffing facilitated connections	Higher staff levels more frequent in caring cultures with effective leadership. The extent depends on societal factors, pay, opportunity etc.

Categories	Properties (i.e. open codes)	Dimensions (extent, frequency, intensity, duration)
Experiencing effective leadership	Inspiring change in team members can facilitate connections. Gives role clarity, the right attitudes and behaviour, encourages communication, team spirit, impart knowledge, build a skilful competent team, kerb bad habits, bonding	Frequency, extent, duration and intensity is variable depending on the attributes of the leader, and the teams capacity to learn and be taught.
Having role clarity	Know what your role is, knowing it is part of your job to connect with residents with advanced dementia can facilitate connections.	During daily interactions with residents (personal care x 4 opportunities). At induction supervision, mentoring, one to ones. Effective leadership and experienced staff can increase the frequency, extent, duration and intensity of this. Can be prevented during times of high workload, lack of collaboration, disagreements within team, ineffective leadership
Being able to manage time	“You have little moments with them, it is how you use that time”, “just giving him that extra little bit of time to respond”, “one of the saddest things about this job is that you don’t have the time” Managing competing priorities	The frequency, extent, duration and intensity varies depending on the individual staff member’s ability and capability. Can be impacted by time pressures, competing priorities, workload, leadership, and support from other staff.
Having a quiet environment	When it’s noisy she doesn’t respond to me” – a quiet environment facilitates connections.	More frequency during personal care, intimate times, less frequent in social areas. Depends on other residents, other staff, residents mood at the time, workload, time pressures.

Categories	Properties (i.e. open codes)	Dimensions (extent, frequency, intensity, duration)
Being in a dementia focused environment	Residents are at the heart of care, regardless of the level of their cognitive impairment. Manager sets the tone. There is clear mission statement, staff are clear about roles and responsibilities	Dependent on the culture in the home, more frequent in caring cultures, with effective leaders, in supportive teams.
Friendly atmosphere	The tone of environment in which people work. Manager sets the tone, the organisation makes employees feel valued. Teamwork	Dependent on the culture in the home, more frequent in caring cultures, with effective leaders, in supportive teams.
Having family engagement	Family were able to facilitate connections between staff and residents Helping staff get to know resident, sharing knowledge, ideas, tips and pointers	The frequency, extent, duration and intensity varies depending on the family member. It is also influenced by the staff and teams ability to be open and listen. Can be dependent on the culture in the home. More frequent in caring cultures, with effective leaders, in supportive teams.
Being in a learning environment	Staff members are able to learn on the job are more likely to connect	Dependent on the culture in the home, more frequent in caring cultures, with effective leaders, in supportive teams.
Knowing professional self	Dealing with issues as and when they arose could facilitate connections	Dependent on the culture in the home, more frequent in caring cultures, with effective leaders, in supportive teams. More frequent when staff have role clarity. More intense when staff are supervised, formally and informally, at team meetings etc.
Learning on the job	Trial and error, getting to know residents learning patterns of communication, recognising communication attempts, getting to know staff, asking for help	Dependent on the culture in the home, more frequent in caring cultures, with effective leaders, in supportive teams.

5.3.2.2 Reflections

This more detailed open coding step of trying to understand the properties and dimensions of the categories was tricky. As Strauss and Corbin (1998) suggested, some were easier than others. I was helped by using analytical tools such as: memo writing and constant comparison. Using these tools enabled me to break apart the data to dig beneath the surface. This is an example of the abductive logic described in Chapter 3.

In practice this meant reading the transcripts through again and reflecting on the 'voices' of participants, asking myself what the participants were 'getting at' (Blair, 2016). It meant writing memos about what I thought was going on. This reflective process allowed me to open up the text. I also went back to ask participants both open and focused questions to clarify codes and subsequently expand or eliminate categories. This interpretivist approach allowed me to look for the best explanations, those that had the most explanatory power. An early memo illustrates how I did this.

MEMO

Interviewer: how were you able to connect?

Participant: *'I think it was just using pester power. I just kept going in to her room and getting nothing. Then one day I went in, picked her hand up and said 'I am going to do your nails' and she just looked at me and smiled and I was like 'ooh great' but it took months and months for me to get that'* S08 Care Assistant.

MEMO: the word pester power strikes me as an odd word, taken at face value it could mean the care assistant visited the residents frequently. Addition of the word 'using' however, implies it is a technique or strategy rather than just frequent visits. Thus it might have other meanings i.e. using pester power as a strategy to create familiarity, to make the resident feel comfortable, to learn the residents' communication pattern, to build a relationship, to create control. The word 'using' therefore broadens the interpretation of the term 'pester power' – it might mean more than just visiting a person frequently, it might be a strategy.

There are times and places where it might or might not be used (i.e. if the resident is poorly). This is not yet evident, it is important to pay attention to meanings of sentences.

Writing memos allowed me to compare data to my own experiences, which helped guide me through analysis.

MEMO

Reflecting on my own experience, I've seen nursing home staff use humour to connect with residents. If I think about the circumstances in which I've seen humour i.e. I have seen humour used to make a task easier, to get a reaction, to cheer people up, for cooperation during meal times. I've also seen it for social purposes, to create pleasure. Other times it seems staff have feelings of responsibility towards residents. There are different types of humour i.e. silly, sarcastic, anecdotal, dry, situational etc. Some staff who use humour as a regular strategy, others use it for specific residents who they know will respond. Some staff are natural jokers, others have to try that bit harder. What this tells me is the term 'humour' has certain properties such as: frequency, duration, degree, type, purpose, ways of using, place of using. Each staff member sits somewhere on the spectrum of each of these properties. For example the following quotes indicates to me that this care assistant uses humour frequently, she uses a specific type of humour (being silly), she is quite intense with it, it is used for the purpose of connecting:

'I have a habit of getting one of her little toys & I dance with it at the end of the bed. I am a bit mad and it makes her laugh' S07.Care assistant

'I tend to pick on the other carer when I am with her. I will say 'ooh she is crazy that one, she is mad isn't she' and she will laugh with us' S07 Care assistant.

When I analyse the rest of the interviews I will pay attention to: how often, how long, how much, for what purpose, where, when and what staff do to connect. In this way I can begin to get some idea of how connections vary across care staff and to see whether any patterns of connections emerge.

I used tools such as memo writing and constant comparison to do this throughout the data analysis process. I initially did this for each of the first twelve interviews before moving on to axial coding.

5.3.3 Phase 3: process and reflection from data collection/analysis

In Phase 3, I conducted interviews with participants 13 to 15 and returned to conduct second interviews with three of my Phase 1 participants. I continued

to carry out open coding, grouping conceptually similar ideas as open codes and clustering open codes with open meanings in to categories

Whilst personal care was considered a prime time to connect with residents with advanced dementia, I wanted to minimise bias and ensure I explored all avenues. As such, I collected some data from those not involved in personal care. I theoretically sampled activities coordinators and nursing home managers, interviewing them with interview guide 2 (see Appendix 11: Phase 2 Interview Guide). During interviews with participants 13 to 15, I began to notice that many staff referred to the use of 'time'. The nursing home manager (S13) in particular, was explicit in highlighting that a number of her staff were worried about having enough time to interact. She spoke about her role in giving them permission to interact, which facilitated connections. She gave many examples of how she created time for her staff. Following this interview, I used constant comparison and looked at the memos I had written to see if this was apparent in other interviews. I found phrases such as "I just don't have time", "I'm always so busy", and "I'm always juggling time" as key quotes from participants. For participants it was clear "use of time" was required to make connections. This also fitted with why care assistants had said personal time was their prime time to connect – because they did not have the time to spend with residents elsewhere. I kept this in mind.

At this point I conducted follow up interviews with three participants I had previously interviewed (participants 2, 3 and 4) in order to explore the use of 'time' further.

Once I had clarified 'time' as important, I integrated it in to my interview guides, to form interview guide three, which was used with participants 15 onwards. In these interviews, as well as asking the previous questions (in interview guide 2), I tried to find out, in depth, about the driving force behind how and when staff connected and what helped them. Taking an abductive approach, I also consulted a nursing home resident and relative participation group to allow me to further sense check and look for ideas that might help me clarify this further. My preliminary findings resonated with those in the group who had relatives living with advanced dementia. They also suggested there was much more to the story however. In particular they spoke about

the personalities of staff and how that influenced a staff member's motivation to connect. They also talked about the managers and how important they were.

In an effort to try and understand this further, I naively moved on to axial coding. In the next section I will describe how I moved to axial coding, before reverting back to open coding.

5.4 Axial coding

In axial coding the aim is to expand categories to elucidate a process. Whilst axial coding is different to open coding, these are not sequential steps, researchers may move back and forth across coding steps. Axial coding may therefore begin during open coding before data collection has finished.

It is unclear when the best time to begin axial coding is. However, a number of categories are required, and thus a significant amount of interviews have to be performed. Ultimately it is up to the researcher to decide. I therefore had to make a decision about when to move to axial coding from open coding. I began to do this after the first twelve interviews.

Whilst Strauss and Corbin (1990, 1998) gave some guidance, I found it difficult to grasp. I assembled chunks of data from the transcripts to try and understand the: what, where, why, when and how surrounding categories but this did not enable me to explore the categories in sufficient depth. I felt confused about codes, categories and sub categories. I had an initial hunch that time was important and that caring attributes were an important motivator of connections, but I realised I had little data about contextual factors. From this, I realised there were gaps in the data from the perspective of those in management roles

I therefore sought to collect more data about these aspects before continuing axial coding. I reverted back to open coding to analyse this new data

5.5 Revert back to open coding

5.5.1 Phase 4: data process and reflection from collection/analysis

I realised that there were gaps in the data about the influence of the organisation on staff's ability to form connections. It was the retroductive process, particularly speaking with the residents and relative participation group that led me to this realisation. I became aware that I was only considering the data at the superficial level. I realised I needed to pay attention to the interactive messages conveyed during time spent with the participant, and look for connections between variables. To address this I needed to make more inferences about issues that were indirectly or implicitly present in staff interviews. Constant comparison highlighted that whilst participants did not directly talk about contextual influences, they did talk about these indirectly. I paid attention to where they had done this. I also amended the interview guide to include more probing questions about contextual influences (See Appendix 13 Phase 4 Interview Guide).

Date: 12.4.17 Theoretical memo

I have a hunch from indirect interferences, that staff connect with residents because they 'learn on the job' rather than receiving formal training. From the data I've got, I found that staff might be encouraged to connect, but receive no specific training on how to do it. Some staff know connecting is important (some think there is no point – do they lack empathy?). What else influences how they connect? Are there other contextual things? Staff told me they get to know the person on the job, by reading care plans, they learn to read the person by getting to know them, they know the signs to look for etc. they ask other staff, use knowledge from other settings. As a result they build up strategies as they go along and become experienced carers. What do these experienced carers then do? Learning on the job is just an assumption at this stage. Also what is the manager's role? Are staff helped to 'learn on the job' by their manager? Does leadership play a part? I have only one nursing home manager's perspective so far so I need to find out from their perspective how they think staff connect with residents. Is learning on the job really the subtheme I want to use. Further exploration is needed. Potential questions to ask managers:

- How do they think staff know how to connect?
- How do staff know what to do?
- What influences the time they spend during personal care?
- What instructions are staff given about connecting with residents with advanced dementia?
- What motivates staff to want to connect?
- Are staff given training?
- Do connections happen regularly?

What support are they provided with?

For the final interviews I theoretically sampled those in a supervisory and management position and conducted follow up interviews with two care assistants (participants 6 and 11) to allow me to obtain different perspectives about contextual factors. This highlighted the importance of relying on other more experienced staff to help them learn on the job.

Memo 10.6.2017

Managers indicated they played a role in facilitating staff to form connections. They talked about giving permission to interact (do they creating a caring culture?). It seems they give the go ahead. Managers in the last few interviews implied however, that the way teams worked together was of equal if not more importance. Managers oversaw things, but staff learned what to do from each other. Perhaps it is experienced staff that help newer staff learn on the job? I need to re-read the transcripts to try and understand this a bit more.

After revisiting my data I was able to see how the manager played a supporting role in terms of giving staff permission to 'make the most of time' during personal care. Managers also suggested staff learned how to make the most of time, on the job over time, with the help of more experienced staff. However, it was still unclear on how the relationship played out. I therefore conducted follow up interviews with two more participants.

Follow up interviews with participants validated my findings i.e. care assistants largely learned what to do from experienced staff, rather than through formal education or training. However, they raised the issue that experienced staff did not always help less experienced staff and that

sometimes they could be obstructive or uncooperative. When I asked how they got round this they said things like:

“Well the manager sorts it or if she is not there then the next person in charge, it’s the way it is here” S12 Care Assistant

“Our manager, she makes it a nice place to work for us, we can count on her” S07 Care Assistant

After re-reading some earlier transcripts I spotted a relative had made reference to the issues:

“To be fair, if they (staff) don’t fit in with Marys (managers) thingy then they’ve got to go. I mean they can be good at what they do, but if they don’t fit in the overall thing of this place, then they don’t stay. We had a nurse here, she knew her stuff, but she didn’t interact. She didn’t seem to care, so didn’t stay long, they had to get rid”. R03 Husband

At this stage of interviewing and analysis, I found there were no new data that added depth or dimensions to the categories that had already been developed. I therefore made the decision to cease data collection as I felt I had achieved theoretical saturation. However, I remained open to the idea of returning to data collection should the need have arisen.

5.6 Revert back to Axial coding

I returned to axial coding. To assist in the process, I made use of a tool developed by Scott and Howell (2008). This process, enabled me to identify the sub categories of the categories, making them multi-dimensional, rather than one dimensional. The tool facilitated this by encouraging me to ask questions of my data including the questions:

- When did each category occur?
- Where did it occur?
- Why did it occur?
- How did it occurred?
- With what consequences did it occur?.

Appendix 14 Conditional Relationship Guide, gives the results of conducting axial coding using the conditional relationship guide. Elucidating the process surrounding each category was an iterative process for which I used a combination of inductive and deductive thinking. The categories were revised multiple times. I often moved back and forth across open and axial coding, using theoretical sampling to improve or reject underdeveloped codes. Taking an abductive approach I also looked for clues in the literature, and sense checked with participants throughout.

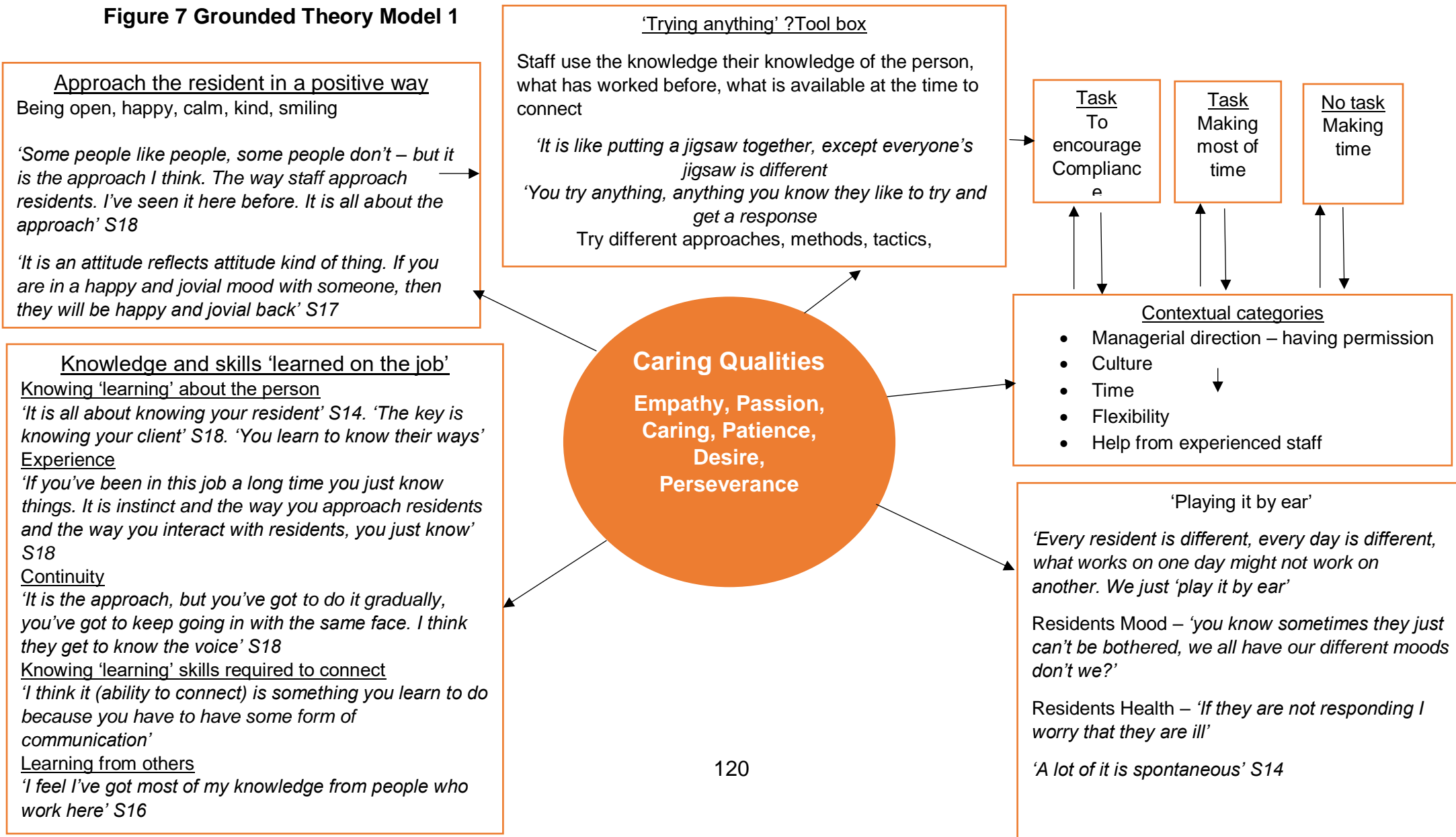
5.7 Selective coding

I then moved on to selective coding. The aim of selective coding is to develop a story line that logically explains the many patterns discovered during axial coding. A core category is first identified. The core category is the central phenomenon considered to be at the heart of the overall social process. Once a core category is identified the researcher should reflect on how/where all of the other major categories (in this case n=30) fit in the overall story line. The central purpose of a Grounded Theory is the development of a process, its sub components, the relationship among them and the influencing conditions (Strauss and Corbin, 1990)

I had a hunch that caring qualities was the motivator that facilitated nursing home staff to connect with residents with advanced dementia. I therefore devised an initial model of what I thought was the social process.

Figure 7 Model 1 shows the first iteration of the core category.

Figure 7 Grounded Theory Model 1



Although Model 1 was an arrangement of categories that seemed important for connections, reflections from constant comparison, looking for clues in the literature and memo writing, led me to the conclusion that whilst caring qualities were certainly a contributing factor to whether staff connected with residents, they did not explain much of the variation in the data. Thus while caring qualities described what motivated staff to make connections, it did not account for how staff had to adapt to integrate and incorporate contextual issues. It was the issues raised in my literature review and sense checking with residents and relatives in particular, that alerted me to the fact that such contextual issues were important.

The following memo gives an illustration of how the focus shifted from 'caring qualities to 'using time'.

Date: 5.7.16 MEMO following Interview five

Time was a major issue for this nurse. She said she knew it was her job to interact but she was busy and had a lot of other residents to see. She said having more staff would help increase the time she had for social interactions. This would mean staff did not have to rush interactions. Staff could then take their time. She indicated tasks are a priority and that social interactions occurred when staff finished their work, if they had time.

Date: 23.11.16 MEMO following Interview nine

S09 talked about time being an issue but suggested she made time where she could. S09 made the 'most of the time' with residents by interacting during personal care. The nurse (S05) didn't seem too. The nurse said she didn't know what to do and that it would not make a difference anyway.

To validate this idea I looked within and across all of the transcripts. The following excerpts show how 'using time' increasingly emerged as I re-analysed the data using constant comparison, complemented with memo writing.

Date 8.1.17. MEMO following interview twelve

This member of staff indicates she makes the most of time. She connects during personal care and she connects after work.

'I make time to interact'.

'My job doesn't finish at 2.30pm, I don't walk out at 2.30pm, I walk around and I make that time to interact, because that's me'

Care assistants have told me that most of how they connect is during personal care. Perhaps making the most of time is a key component. Some staff do it and some don't, the ones that make the most of time perhaps connect more?

Interview Sixteen

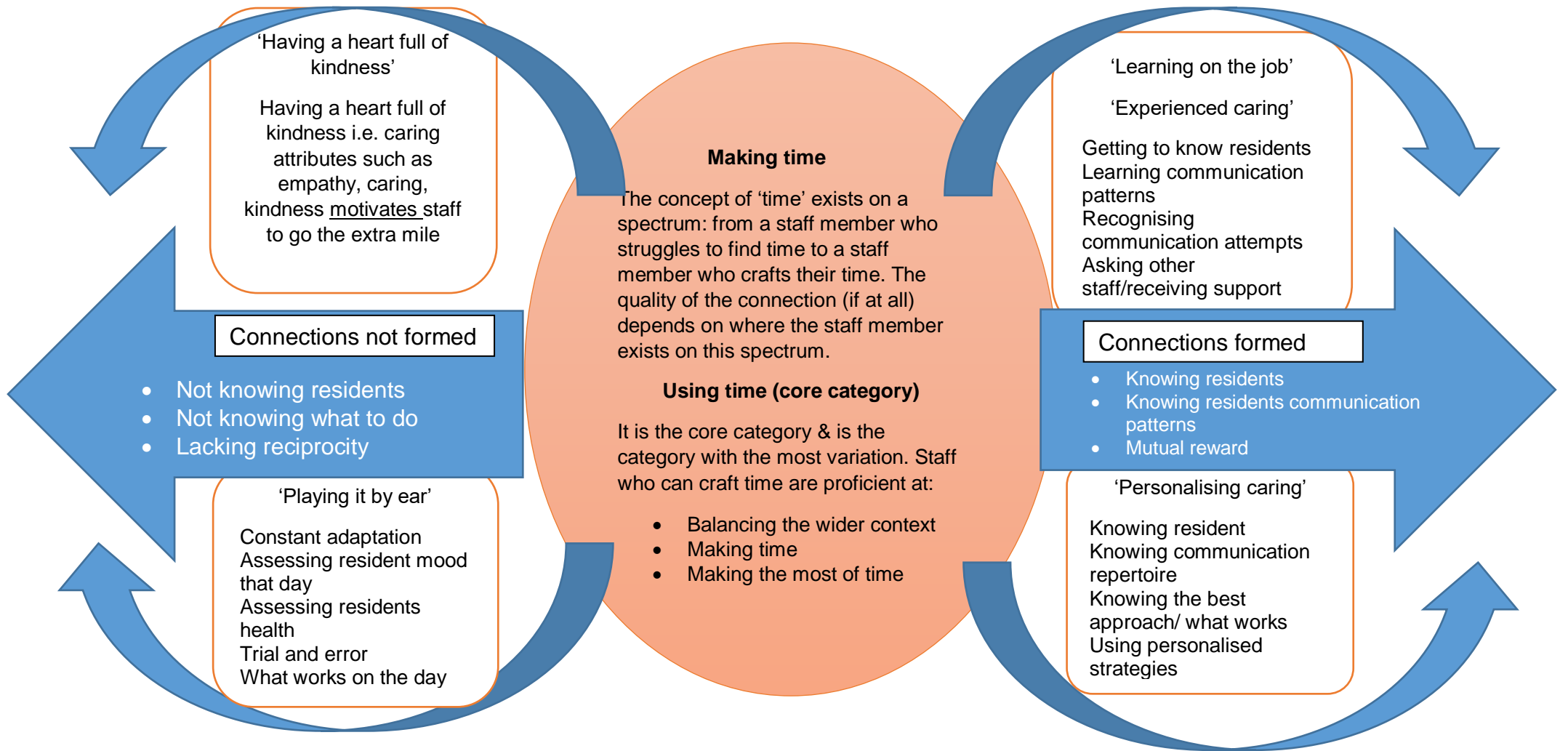
Quote	Memo
<p><i>It was just a little moment and that's what it is all about, little moments like that. Involving them in a conversation or doing something silly.</i></p> <p><i>So many little things happen over the day, It's hard to think and I feel like I'm repeating myself. I guess it's just about taking the time for those little moments.</i></p>	<p>It is clear to me now that 'time' is important and explains more of the variation. It is unclear what influences time.</p>

Interview Thirteen

Quote	Memo
<p><i>It was not that I was just putting food in her to keep her nutritionally balanced, but I am engaging with her as I do it.</i></p>	<p>She is making the most of the time, interacting while doing a task. It is in these intimate one to one situations where staff connect</p>

In reconceptualising the proposed core category from caring qualities to 'using time', the category of 'caring qualities' was not discarded, but rather it was later encompassed within the core category of 'using time'. This assisted in explaining that staff who were motivated to make connections, resolved their main concern of struggling to find time, by making the most of time. In this way the Grounded Theory Model 2 was developed. For a depiction of Model 2 see Figure 8

Figure 8 Grounded Theory Model 2.



The theoretical memo below explains that while time was identified as an important issue, the process was still not clear.

Theoretical memo 3/3/17

Model 2: now shows 'time' as the core category. However, I do not think it emphasises the essential role contextual factors play. This model focuses more on individual staff level factors. Earlier analysis highlighted the importance experienced staff played, and the role of the manager for creating a caring culture. One of the limitations of existing research is not considering such factors. I need to re-consider the model, I need to first systematically ensure time is the core category and secondly find a way to pay attention to the part played by contextual factors.

Whilst I had a hunch that the core category was 'time' and that contextual factors played a more prominent role, I needed a way to systematically confirm it. Scott and Howell (2008) developed a second tool to assist with the transition from axial coding to selective coding. The aim of the reflective coding matrix is to develop a story line of the many patterns discovered during axial coding. Once a core category is identified, the reflective coding matrix encourages the reader to reflect about how/where all of the other major categories (n=30) fit in the overall story line. Some of the categories relate to contextual factors, some refer to individual factors others add depth to the story by illustrating properties and dimensions. It was this way I was able to tease out the contextual factors that were missing from previous models.

Table 12 shows how each major category was mapped on to the reflective coding matrix. This stage was complex. It was unclear where some categories sat, thus I placed them to one side and tried to pick the ones that made the most sense first. I went through multiple iterations of the process and stopped when I felt the data were placed in a way that best explained them (Figure 9, Model 3). Going through this process was similar to putting a jigsaw together, trying different combinations.

6/31 major categories: physical environment, caring culture, leadership, experienced staff, specialised dementia units and family engagement were considered to be the contextual necessary to trigger individual factors, that

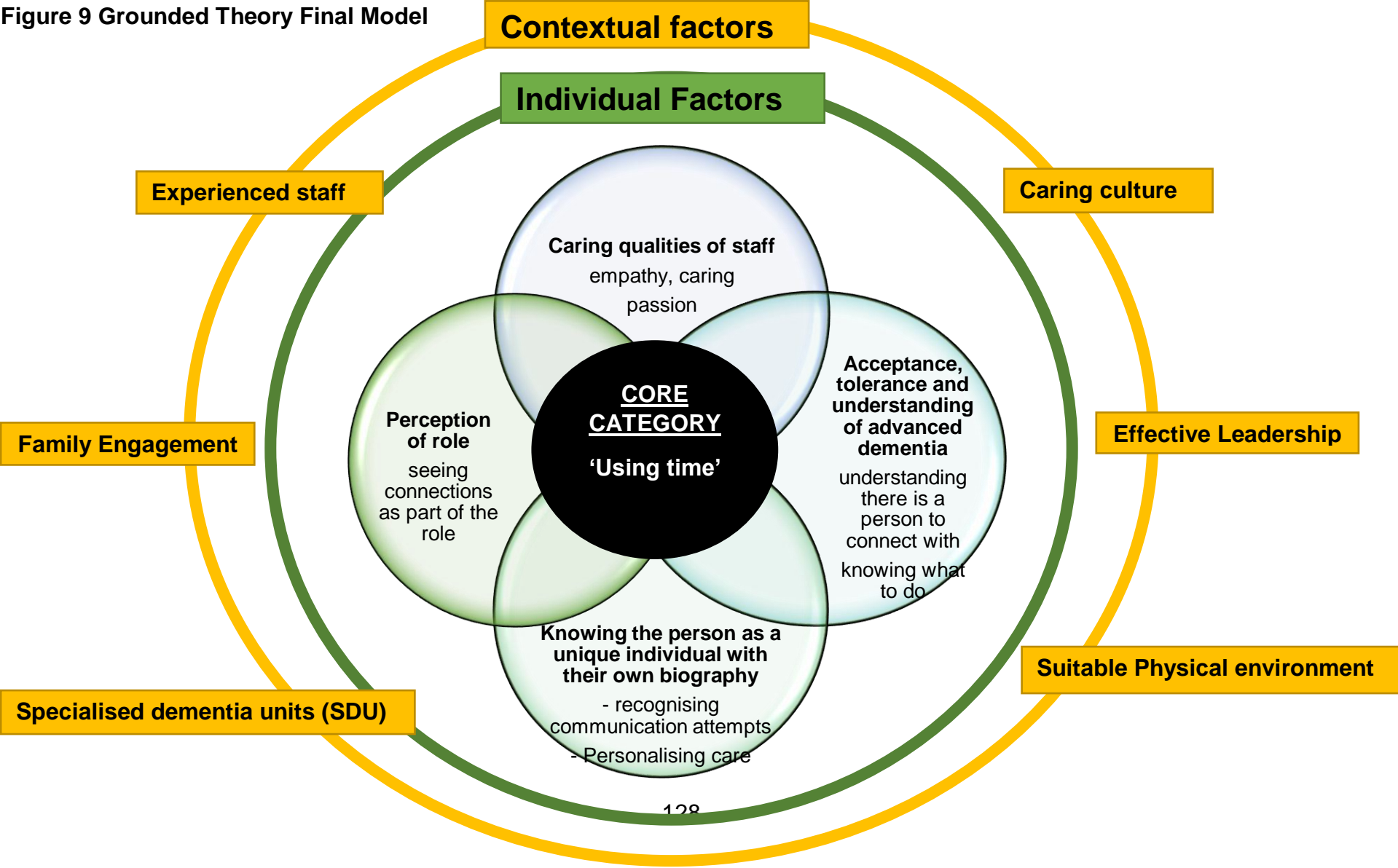
enabled staff to 'make the most of time'. 4/31 major categories considered as individual factors were: accepting, tolerating, understanding dementia, perceiving it's your role (to connect), getting to know the person and caring qualities. The remaining major categories were considered to be properties or dimensions that added depth to the story line.

The final reflective coding matrix (Table 12) was the pattern that I felt told the story about how staff connect with residents with advanced dementia best.

Table 12 Reflective coding matrix findings.

Core Category	Using time			
Individual factors	Accepting, tolerating, understanding dementia	Perceiving it's your role (to connect)	Getting to know the person	Caring qualities
Properties (characteristics of the process)	Confidence, competence and awareness within role Playing it by ear	Ownership	Understanding individual variance (everybody is different)	Values and respects the person living with advanced dementia.
Dimensions (property location on continuum)	Length of service in home Level of experience in dementia care. Problem solving Ability to learn on the job	Taking responsibility Team work Recognising limitations	Knowing like/dislikes Sharing ideas Learning from others Relationships Sharing self Family engagement	Approach to resident Atmosphere Setting the tone
Contexts	Specialised dementia units, Experienced staff	Effective leadership, Experienced staff	Experienced staff, Quiet environment vs stimulating environment Family engagement	Caring culture
Modes for understanding consequences (process outcome).	Positive attitude towards dementia Outcomes of connections (motivate staff to use time)	Role clarity	Shared language, understanding with resident	Reciprocation Motivation

Figure 9 Grounded Theory Final Model



The story is as follows:

According to participants in this study their main opportunity to connect with residents with advanced dementia was during personal care. Staff who were able to make the most of their time were most able to connect. Staff learned how to do this over time 'on the job'. A number of contextual factors such as: effective leadership, specialised dementia units, a caring culture, specialised dementia units and family engagements triggered individual factors such as: understanding, accepting and tolerating dementia, perceiving it is your role, knowing the person and possessing caring qualities which facilitated staff to make the most of time.

Further description of the story and its complexity will be discussed in Chapters 6, 7 and 8

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5.8. Conclusion

In this chapter I have described the simultaneous process of data collection and analysis, and the emerging findings of the project. I explained the procedures I followed during coding, resulting in successive refinement of my Grounded Theory through two detailed iterations before arriving at a third model which I felt explained the social process of how nursing home staff connected best. Throughout each section I have woven in when and what data collection occurred, along with key decisions and changes I made along the way. The emerging theory is described fully in the next chapters.

6 Chapter 6: Contextual factors that facilitated nursing home staff to connect with residents with advanced dementia

6.1 Introduction

My first research question was 'What contextual factors facilitate connections?' Given the identification of the core category of 'using time', this question becomes: 'what contextual factors facilitated nursing home staff to use their time effectively to connect with residents with advanced dementia?' and it is this which I address in this chapter. These included: effective leadership, specialised dementia units, a caring culture, experienced staff and family engagement, which I included in the Grounded Theory model as shown in Figure 9, p 128. These were also briefly described in Table 12 which illustrates the properties of each of these contextual factors. Here each is described in more depth and illustrated with quotes from the data. I highlight where there was interdependence between contexts, addressing research question four. I also present examples of where contexts did not lead to staff using their time effectively. I end the chapter by summarising the contextual factors.

6.1.1 Effective leadership

Leadership emerged as a contextual factor that influenced whether nursing home staff made the most of their time to connect with residents with advanced dementia. In this section I will suggest that staff working in different positions within nursing home organisations demonstrated effective leadership. I suggest that formal leaders such as managers and/or nurses gave nursing home staff encouragement, confidence and permission to connect. I highlight how effective formal leaders engineered effective leadership throughout their nursing homes by empowering experienced staff working in different positions to act as role models, teaching their skills, and sharing their knowledge and ideas. This in turn enabled less experienced staff to learn how to connect on the job.

According to one nursing home manager, her role was to give members of her team the confidence and permission to take the time to connect:

It is that confidence thing again. It is alright for me being the boss and I've been doing it for years – no one is going to say that I'm wrong. It is going back to that permission. Staff need to know that they can do that [interact] and have the confidence and the experience to interact, so I need to let the team know that it is a good thing to do and that is how we work here and that is how we touch base with people. It is how we interact because it is bad habits and a lack of confidence or experience in their ability or asking 'is it the right thing to do?' And again not knowing the person. If you don't take the time to get to know the person, then you're not going to have that bond, so you probably wouldn't speak to them anyway would you. S13 Nursing home manager.

In a later comment she reiterated this:

I found that a lot, with people who have come from care backgrounds but haven't perhaps being caring for people with dementia, or perhaps worked in homes that are very task orientated that people (staff) almost need permission. They need permission from me, from the organisation, from their line manager that that is important. That it is what we do here. That it is part of your job. You know you're not sitting on a resident bed chatting because you're skiving, you are doing it because it is an amazingly important part of caring for that person. I do that a lot, I make sure that even our house keeping team do. S13 Nursing home manager

Another manager echoed this:

I think some of them (staff) might be a bit shyer than others, or less experienced. Confidence is key to finding a way in and it is my job to ensure the team gives it to them. S19 Nursing home manager.

A number of relatives talked about the manager as overseeing. In this example, the relative of the mother of interviewed lived in a small nursing

home was clearly familiar with the senior staff and their key roles. She talked about the manager overseeing and the team work with her deputy:

Madge is fantastic, she was McMillan before, now she is doing the area managers job as well. She oversees everything.... then she has got Andrea who does the hands on stuff. They work together great.
R04 Wife.

In the next quote a relative implies that the manager played a key role in nurturing the leadership of others and that this had a beneficial impact on the quality of care:

You see Mary [manager] all the time showing the girls what to do, nothing is too much trouble, she shows them, not tells them you see
R03 Husband

Another nursing home manager echoed this point. She indicated that her own attitudes impacted on her staff's attitudes and interactions with residents. She implied that she empowered experienced staff to act as role models:

Older staff lead by example, because I am not always around, we have four units. I try and make sure they have the confidence and the experience to do that, so I need to let the team know that it is a good thing to do. S13 Nursing home manager

She spoke on a number of occasions about how she endeavoured to ensure experienced staff knew it was their role to teach and impart knowledge:

Well I buddy people up who I think will work well and learn from each other. Some of the older ones have heaps of tips and pointers. S13
Nursing home manager

She indicated she did this by acting as a role model:

There isn't a day that goes by that I don't talk to staff about it [interacting]. Yeah every day. I want them [staff] to be happy. I see my role as the manager as having a competent, skilled, well-trained but happy team. If I can have staff here that are all those things, but who

come to work enjoying their job as well, then I think they are going to be better at care, because they want to be here. They understand what they are doing and if something happens or they feel stressed or rushed, they can come and get me and tell me and I will help, but so will the others too, we all muck in. S13 Nursing home manager.

Experienced carers were described to play an informal leadership role. They were suggested to provide the hands on support which enabled staff to learn how to make the most of time to connect on the job.

For example care assistants told me that when they felt supported, they were more likely to connect with residents with advanced dementia. In the following quote a care assistant talked about her ability to make the lives of people with advanced dementia as full as possible because she was supported by an effective leader who encouraged team work:

It's about making their life as full as possible, it is not about their dementia or putting them in that bubble. You've got to remember they are a human being and it's their life. You've got to have something, you've got to have a life not an existence, so I think it is very important to do whatever you can. S06 Care assistant.

When asked how she was able to do this she responded:

We do it every day, we have reports every morning and every afternoon so if there is something wrong, we will write it up and if we are really concerned then we will go and speak to the nurse and the nurse will talk it through with us. They give us the time, even if it is really busy and they are run off their feet too they will stop to help, we all muck in, it makes the job easier, you know what I mean? S06 Care assistant.

Another care assistant talked about how a nurse gave her the knowledge she needed to make the most of time to connect with a resident with advanced dementia during personal care. In this case the care assistant gave an example where she sang to a resident. When asked how she knew what to do, she said:

One of the nurses taught me. We have a handover every morning and every afternoon and obviously listening to other staff. I find out what they have discovered and what they have noticed about certain things and obviously the nurses know stuff. S08 Care assistant

In the next comment, a care assistant talked about the first time she had connected with one particular resident who was living with advanced dementia:

She had spoken to me before but it was only ever a couple of words. The night nurse said 'Ooh she loves it when you sing' so I said 'Ooh have you heard my singing? Then that night, the nurse started to sing and I joined in. She (the resident) was absolutely beaming and laughing with a smile and for me that was everything. S12 Care assistant.

Both of the care assistants in these examples were clear they were able to connect with the resident with advanced dementia because of the support they received from their colleagues.

Nurses also talked in their interviews about the role they played as leaders in imparting knowledge which helped staff to make the most of time to connect with residents with advanced dementia:

It is reassurance for the staff half of the time, because they are frightened that if they are not getting a response, that they're not doing it right and it's not that they're not, it is just that the person is that far advanced that they have lost that skill. It is difficult, it is a difficult field to work in. S21 Nurse

Experienced care assistants were also described to encourage team work, which enabled staff to learn on the job:

I used to really struggle with Bob, I had a buddy, but we both struggled. It's awful but we'd tried to avoid it. You could just tell he wasn't happy, he used to scream when we touched him. It was Terry-Ann that helped us in the end she said 'He can answer you, look do

this' and she showed us what to do to make him calm. S16 Care assistant

It was the experience and willingness to teach the two newer care assistants what to do and how to connect, that they were able to make the most of time thereafter. This demonstrates interdependence between effective leadership and experienced staff.

6.1.2 Experienced staff

Experienced staff were described as an important contextual factor that helped less experienced staff make the most of time. They acted as role models for new, inexperienced staff who were described as not being able to foster the same connections as those who had worked in the nursing home for a long period of time.

A nursing home manager highlighted the importance of experience in enabling staff to be confident to make the most of time with residents:

It takes confidence in your ability to be able to sit and do that and juggle other things and that comes with experience. S13 Nursing home manager

In a later comment she reiterated the importance of experience again, in relation to the need for persistence:

If you're not very experienced or newer I think you often give up, especially with people with advanced dementia. It is easier to give up because you aren't getting that immediate response. S13 Nursing home manager

Staff working in different positions i.e. nurses, managers, activities coordinators and care assistants all had similar views on this issue,

A nurse attributed her ability to make the most of time as being connected with her experience:

I think it comes with experience. I've been doing this for 22 years now.

S21 Nurse

Such experienced staff were integral to helping new and inexperienced staff to form connections:

Those who have worked here many years. When you are new they tell you what to do and what works for who. Some people have worked here for 20 years, 7 years, 16 years. S02 Care assistant.

We ask for help from colleagues, they've worked here a long long time, I've only worked here one year, yes so they help us I guess, I don't know what I'd do without Nancy, she is my oracle, she's everyone's. She's part of the furniture. S04 Care assistant

Some of the experienced staff were described as the effective leaders described in the previous category of 'leadership':

Well I usually just ask to Rose to help, if it wasn't for her I wouldn't have a clue. It's like, well sometimes you don't want to disturb the nurses, or feel stupid if I ask a question that I should know if you know what I mean, but Rose has been here forever, she is like our mother, she tells us, its nowt I ain't heard before ha ha. Well, we all ask her what to do bless her. S06 Care assistant

Well from asking the others, you know some of them have been here forever, they help us, I've only been here a little bit, so that's how we do it. They know everything and help us all. S16 Care assistant

Whilst experienced staff were facilitative, there were also examples of where experienced staff were not perceived to assist newer or less experienced staff to make the most of time to connect:

Sometimes it's hard, and there is no one to ask, no one to help us so we just do what we think is right. S09 Care assistant

When asked who would know how to help she said:

I don't know, I aren't in the cliques. You know, some of them have worked here for years but they all just socialise together. S09 Care assistant

Another example included:

Well we're all busy, we just have to get on with it. I can't be asking people every five minutes, they have their own jobs. I mean don't get me wrong, if I asked they would help me, but I do just try and figure it out myself. S02 Care assistant

In some interviews staff who had worked in the nursing home a long time, were described to be complacent or 'palming work off':

' I mean I've only worked here eight months, you get paired up with a senior when you start so they can show you the ropes. Sometimes I feel her (senior carer) isn't that bothered, it's like her heart isn't in it anymore....she's always desperate to get off or swap shifts. For me my job doesn't finish dead on the dot, hers does though, she'll go at home time but i'll finish everything.....I mean I don't mind, its just what I've always done. She is really nice don't get me wrong. S17 Care assistant.

A relative also suggested experienced staff did not always make the most of time to foster connections:

She'd been here years, never spoke to Kaz once. In fact you barely saw her. She didn't seem overly bothered – she was like a corporal, hard on the staff, making sure they'd done what they were supposed to. R03 Husband

Two care assistants in different nursing homes of a similar size, with different ratings of quality, suggested that the manager played a role in preventing complacency. For example when they were asked how nursing home staff dealt with such situations the care assistants said:

Well the manager sorts it or if she is not there then the next person in charge, it's the way it is here S12 Care assistant (CQC rating good)

Our manager, she makes it a nice place to work for us, we can count on her S07 Care assistant (CQC rating requires improvement).

A relative said:

To be fair, if they [staff] don't fit in with Marys [managers] thingy then they've got to go. I mean they can be good at what they do, but if they don't fit in the overall thing of this place, then they don't stay. We had a nurse here, she knew her stuff, but she didn't interact. She didn't seem to care, so didn't stay long, they had to get rid". R03 Husband (CQC rating good).

This re-emphasises the importance of the manager for setting the tone in the nursing home. A manager in an nursing home considered by the CQC to be of outstanding quality, suggested whilst she set the tone in her home she did not do it alone and relied on the relationship she had with her team:

I don't do it alone. I rely on my staff to help set the tone. Some have been here for years. They've stayed with me starting as care assistants, some are now seniors, others have gone off to be nurses. S13 Nursing home manager

6.1.3 Caring culture

Promoting a supportive, caring culture where residents and nursing home staff lived and worked symbiotically facilitated connections. A nursing home manager indicated she promoted a caring culture for residents when she spoke about not creating an 'us and them' environment:

I mean what we would like to achieve here is not an 'them and us' culture. If someone asked me if there was something wrong I would say 'You're right it is not a great day' rather than creating a gap between you. You can bring yourselves closer by sharing a little bit of yourself. I think that does provoke a nice interaction and nice engagement. S13 Nursing home manager.

She spoke again later in the interview about creating a caring culture for staff:

It is not easy because I think people have a lot of assumptions, like I said earlier, when people have worked in other establishments before here, especially if they have worked there for a long time, it is almost inbred in them, that negative culture of care that is very task orientated. We have the uniforms on, you are the residents and we are the staff – big divide. So I think that we're fighting against an older culture. So we are bringing people in to do that. Sometimes it is easier to have new carers or carers that are new to dementia care because they are not going to bring with them negative attitudes that other people have. I think that is what stops people as they have just got used to doing it another way, but I also think that some people just lack confidence. S13 Nursing home manager

When asked how she got around such negative attitudes she said:

Well its my job to make sure I have a good team around me that knows and more importantly cares. S13 Nursing home manager

When asked about what facilitated nursing home staff to connect with residents with advanced dementia, a nurse in a small nursing home considered to be of 'good' quality by the CQC, highlighted the importance of the manager in creating a caring culture:

Yeah well a good manager is the main thing for us, they referee. There are some people who get on better than others. When people are on who don't like each other it can cause problems. Our current manager doesn't take any of it though. She makes sure there is none of that, which is just as well because I don't have the stomach for it. S01 Nurse

Relatives spoke a lot about the culture and ethos in nursing homes suggesting a caring culture facilitated connections with their loved ones and also made them feel connected and part of something:

They are all excellent carers, they are good at their job, they enjoy their job and they like the environment they work in. I think that's the key. I just love the atmosphere in here. It's all laughter, chatter. I walk through the door and I want to come here. My daughter in law works here now, Kaz picks up on it, if there is something negative going on she will just withdraw. R03 Husband

In a later comment the same relative said:

You walk through the door and it's like walking through the door of my own home. It's not Mrs Hancock, it's not even Karen, its Kaz, cos she is Kaz. R03 Husband

Another relative described a caring culture in which staff took as much time as was needed to assist residents:

I'd say you get contact here from early morning till maybe 4pm every 45 minutes. Someone is going in for something and when they are feeding, it can take ages. It doesn't matter how long it takes, they will sit and feed them. R04 Wife

This category of 'caring culture' connected with 'leadership' as when asked what she thought led to such a culture, the relative said:

Oh its Mary (manager), definitely Mary. She runs it well. R04 Wife

When asked what made the environment she worked 'friendly and welcoming', a care assistant in a different home also suggested the manager was responsible for creating caring culture:

It's definitely because of Connie, we had a manager before and it wasn't like this, I could tell you some stories, but now it is so much better and I swear its cos of Connie. S12 Care Assistant

A caring culture was suggested as important to ensuring staff perceived it was their role to connect, as describe in the following quote:

I tell all my staff it is the getting to know residents that is important. I try to make it clear so we are all on the same page. We are not task focused here on [unit]. S13 Nursing home manager.

Staff suggested that caring cultures meant staff knew it was their role to connect:

You know, you see people here, staff, just sitting and holding someone's hand and you know it's very simple, it's very easy but you can tell that it's all that person wants. Even if it's only for a minute or two, they just want somebody sitting next to them to literally hold hands and it might be that they are not saying anything, they are not doing anything, they are just looking around like they do, but the person is getting some human contact and the staff member has made the time, in their day to do it. It is just lovely, it is a lovely thing.
S20 Nurse

A nursing home manager was clear she felt a caring culture was essential to ensure connections were attempted:

To get the best life and care for the residents. It is almost like staff need to be given permission to know that caring for people with dementia is about interacting. It is about spending time talking, sharing information, sitting, holding hands, being with the person. Knowing that doing that is just as important as getting somebody ready for bed, getting someone up and dressed on a morning. S13
Nursing home manager

Later she gave an example of how a caring culture allowed care assistants to express their caring qualities:

I can think of someone in particular [staff] who was sat with someone [resident] who was again further along in their journey and more advanced and she was sitting with the lady and brushing her hair, I walked past and she said 'hello' to me, she wasn't startled and didn't stop what she was doing because she knew it was okay to stop for a minute to do something with the resident. S13 Nursing home manager

In most cases managers themselves attributed their caring culture to their team:

It's a team effort, its not me, we all play a role. S19 Nursing home manager

There were examples of where despite having a caring culture, staff did not make the most of time. A manager indicated that in these cases staff did not stay employed in the nursing home for very long:

You know, it doesn't always work. In the past I've tried many times to create a lovely environment where staff can thrive, but sometimes it is just not there in them. I will keep telling them and then they must get sick of it because they leave. S13 Nursing home manager

A care assistant reiterated this:

She won't do it, I don't like working with her too much. She doesn't talk to the residents or even try, it's in and out, and that's not what we're about here. I've tried to tell her, the others have tried to tell her. If she won't listen to our manager though, then she won't listen to us. She won't last long, they never do, Sarah [manager] won't have it.

S11 Care assistant

The findings thus far highlight interdependence between contextual categories. The manager appears key to creating a caring culture where keen and experienced staff can thrive as role models, but one which also addresses those experienced staff who are complacent and do not want to share their wealth of experience. This indicates interdependence between effective leadership from the manager to nurture effective leadership in experienced staff.

6.1.4 Specialised dementia units (SDU)

Findings from this study suggested that specialised dementia units facilitated staff to make the most of their time to connect with residents with advanced dementia.

A nursing home manager was clear that she thought the skills her staff acquired through working in a specialised dementia unit, enabled them to

connect with residents with advanced dementia. When talking about the specialised skills of her staff she said:

One of our sister homes has a gentleman who they are not managing very well. He can't speak and he gets frustrated easily. They [staff in the home] find it as a challenging behaviour, whereas it's not, it is he just can't communicate and they can't communicate with him. They are a residential home and are not used to an EMI [Elderly Mental Infirmary] setting so they struggle. When I have spoken to other care staff who don't work here they say 'I couldn't do that' and it makes you realise how skilled your staff are, and it is because they do it day in day out. S19 Nursing home manager

When asked if she thought the 'acquired skills' from working in a specialised dementia unit were used with residents with advanced dementia she said:

Oh definitely, they do it day in and day out. When you are working with people who struggle to communicate all the time you find ways round it, you have to. S19 Nursing home manager

The ability of staff working in specialised dementia units to adapt and problem solve was highlighted on a number of occasions:

We have another lady who struggles to communicate with us, but again she smiles. I went to give her breakfast today and she turned away. After thinking about it, this lady likes you to be face on when you are assisting her. At first I was stood out of her eye line so she probably wondered what was going on. So I carried on but this time facing her and she ate her breakfast. S15 Activities coordinator

I would say don't get disheartened if she doesn't show you any facial expressions. Keep trying and talk to her the whole time, tell her everything you are doing. Make sure you involve her, keep going. Do not give up, but do not annoy her either. Well that always works for me anyway. S14 Activities coordinator.

A nurse talked about having a higher staff-resident ratio as a consequence of being a specialised dementia unit which gave her more time to connect.

We are quite lucky here since we have become a specialised unit as now we have extra staff on. We don't always need five carers, but we will run on five to make sure we have extra time. Our manager really recognises it. If we drop the ball then someone could have an accident and it's not worth it. S20 Nurse

Only three of the seven nursing homes were specialised dementia units. There were many examples from the remaining four nursing homes of where staff had made the most of time to connect. Thus findings should be interpreted with that in mind. Further consideration of this is given in the discussion section.

6.1.5 Suitable physical environment

Many staff talked about the physical environment as being something that helped or hindered connections. The following collection of quotes illustrate this.

A care assistant in a large nursing home, considered to be of 'good quality', discussed the impact a busy physical environment had compared with a quiet environment on how residents responded to her:

So if people are shouting or anything like that then I find there are a couple of people who don't tend to eat that well and if you compare it to another time when it is really quiet then they eat really well. So it is definitely about the environment as well as your approach to them.

S16 Care assistant

When asked for a specific example she said:

We were literally just sat in the lounge with everybody and it was a relatively calm evening and everything was good and everything was done. And it was nice and quiet in the lounge. I think everyone was watching a film or something? So it was just a nice peaceful atmosphere which helps. S16 Care assistant.

A nursing home manager who ran a large home of 'outstanding' quality expanded on this. She talked in detail about a calm and peaceful physical environment as important for facilitating connections. When talking about a particular resident with advanced dementia, she suggested the resident's room was optimal for staff to connect because of this calm and peaceful atmosphere:

It was quiet and it was calm. It is important. I think this is something on Cherry [unit for advanced dementia] that we've found makes a huge difference, because you really need to concentrate on the person you're with and you can't do that if there are all sorts of other things going on. We do have special hoists and chairs and some people do go through to the lounge, but we have found that it is not necessarily the ideal place to link in with somebody or to interact with somebody because there is too much going on. S13 Nursing home manager.

When asked to expand, she said:

You will find the television is on. There might be one or two other residents in there. This one lady talks constantly and she will repeat certain sentences again and again and again and you know that's what she does. So that can be distracting for the resident, but for the staff too. If they are trying to say something or do something with that person and there is a lot of noise and other things going on, it can be distracting. So in her room is optimal. We don't purposely keep people in their room, but this particular day she had been poorly anyway I think. I must say I have helped her to have breakfast before in the lounge, but yesterday it was particularly noticeable about how relaxing it was. There was her music in the background and just her and I really. S13 Nursing home manager.

A relative of a resident residing in the nursing home of 'outstanding' quality agreed. He suggested his wife was able to engage more when she was in her room because of the peaceful environment, but also because of the personalised décor and familiarity of her room:

She likes her room, we've done it all up for her. Poppies are her favourite so we have done it out in poppies. Now she is bed ridden you know, she'll wake up and she will look around her bedroom and she will smile to herself and she will look at me and say 'ahhh'. If she goes out to the lounge, in her wheel chair, you know to have her hair cut and things, she can't wait to get back in her bedroom. Her face lights up when she goes in her room R03 Husband

Another relative in the same nursing home as above, reiterated the importance of a calm and pleasant physical environment to facilitate connections:

Some of the places I looked at were these old houses that have been converted. So you will have Mrs so and so around the corner who never sees a living soul, or you'll have no garden. Sometimes there is no outside space for them to sit and maybe listen to the birds. They have bird feeders here. There is no point in having high windows that they [residents] can't see out of. This place is almost purpose built, Arthur can look out on to the green there. I think the environment is definitely up there with care. I think no matter how bad the dementia, they can still see can't they? So I will say to Arthur, can you see the sky and the trees and the tree over there has a wonderful blossom on it in the spring and I'll say 'look, look at that, isn't it beautiful'? and he will turn and look, he will look. You know but if you're looking at a brick wall its not great. So I think the environment is so important. All of them have got a view out of every window. R04 Wife

Whilst connections were perceived by nursing home staff and relatives as more likely to occur in a quiet, calm and personalised environments, alternative environments were also described to be facilitative. In this situation music and a party atmosphere altered the context in a way that facilitated connections:

It is like the party we had on Tuesday, the Xmas party. We've got certain ones who loved it, they were dancing and they were singing. I will show you a video of a lady, I am not sure if she is with us now, but

she had no movement or communication whatsoever, and we brought her down and we've actually got it on video as it actually happened and her foot started tapping. It was amazing, she wasn't communicating before that at all, then she just started tapping and you could see she was getting some enjoyment out of it. S15 Activities coordinator

Another example of where a connection occurred despite a noisy environment was given later in the interview:

On Tuesday we had a musician and I couldn't get hold of you [S15 activities coordinator] because I wanted the camera but I couldn't find you anywhere, you were doing something else – but we have a gentleman, he has got advanced dementia, he is very rigid and he wasn't talking – it is what I call frozen. We had him up on Tuesday. Now usually when we've had him up before we've put music on and had no response, but on Tuesday, there was a carer and it was Diane. She was just stood behind him and she had hold of his hand and she was just rocking it and she let go and he was doing it himself and he was smiling and I was looking for [S15 activities coordinator] to say 'quick get the camera' but I couldn't, we missed the opportunity, but he was actually doing it to the music. S14 Activities coordinator

When asked what they thought had led to these connections they said:

I don't know, I don't know, I think it was because of the atmosphere. S15 Activities coordinator

Yeah a party atmosphere. We had nice music playing, you know like a sing along, but a lot of people who you didn't think would respond, responded. I mean some of them came in and had to leave because it was too much noise. But it varies on every single day. S14 Activities coordinator

The physical environment appeared to be an essential context that helped or hindered staff from using their time effectively. An appropriate physical environment, coupled with a caring culture where an effective manager

encourages experienced staff to promote leadership through team work, has thus far been described to facilitate nursing home staff to connect with residents with advanced dementia.

6.1.6 Family engagement

Nursing home staff and relatives suggested that family were able to provide knowledge about residents with advanced dementia. A care assistant illustrated this:

We get to know as much as we possibly can and we do background on people, especially if they've got family, because they will come in and they will tell you: 'Oh they used to do this' or 'They used to like that'. If they don't have any family then we try and go to their closest friend. S06 Care assistant

Other care assistants had a similar view:

I don't think so, really. I mean if I struggle, I usually talk to the family. The family are usually good at giving you clues as to what they like and don't like. S07 Care assistant

As did a nursing home manager:

I think it can be hard if you've got a resident who has come in, who is unable to talk or doesn't give you anything back, it can be hard to get to know them. It is a lot slower process compared to someone coming in who is full of chatter and more of a character. It takes more time and more patience to get to know them and you have to rely on care plans and family for clues, it takes that bit more effort to get that connection and I think that's where the personality of the staff comes in, some staff go that extra mile to do that. S19 Nursing home manager

An activities coordinator also suggested family helped them to get to know residents better, which allowed them to make the most of time to form connections:

I don't think she likes a lot of people and from talking to her family she has never been a very sociable person. She is sociable when she has to be, but she has basically kept herself to herself. But this is part of your job – you have got to learn what your resident is about and what their past is. S14 Activities coordinator.

Relatives who participated in this study also felt family played a key role in helping staff to connect:

You've got to be able to focus on something that they have really really enjoyed in their past life. Obviously if there are relatives involved it is going to be a big help because if you get somebody going into a nursing home and there are no living relatives that can tell you anything, it can be so frustrating because when I used to go up to the day centre, they played bingo and it's not something mum ever did, you know they think all older people play bingo. R05 Wife

Nursing home staff spoke about the challenges of connecting when a resident with advanced dementia did not have family to draw information from:

Most of the residents have already been with us for a long time and have deteriorated, so it's been a case of we know them. The staff who've worked here have worked here years. We have had a little lady who came in recently on end of life and she hardly responded, she didn't have family so they (staff) really found that a challenge. One of the girls Annie, she was taking in different foods, trying to find out what she liked and things like that but we didn't have that time to get to know her. S19 Nursing home manager

An activities coordinator reiterated this point:

You have got to know your client, you have to learn their ways. I mean it is hard. We have a lady in now and she just came in yesterday, now until she has been with us for a few weeks, we don't know what she likes. She doesn't have family, so it is like a learning curve. S14 Activities coordinator.

Whilst family were considered to be helpful in assisting getting to know residents, it was not always the case and family could be perceived by staff to be a hindrance:

It doesn't always pan out, I mean I've had people with advanced dementia whose family think they should be doing certain things, but they are really not interested and it's not what the person wants so that's a difficult situation. I try most things family suggest and if I am not sure I will go and ask the nurse. Sometimes families argue with each other and you're stuck in the middle. I am quite good at resolving arguments, I have six kids, but not everyone is, so it can be hard at times. S07 Activities coordinator

Relatives of residents with advanced dementia also experienced difficulties with other relatives:

I used to go in and I used to give him drinks because Antony was a scooter man. I am a motorbike man and I used to talk to him about his scooters and we used to get a sort of conversation going. She [Antony's wife] said 'no no, there is no point as he can't understand you, he doesn't talk to anyone anymore', but me and Antony got a conversation going, not talking as such, but pointing and smiling you know what I mean. I used to go and give him a yoghurt, when Kaz was getting washed or bathed or something and I thought he liked it, but she stopped it all. She doesn't believe me when I say I've spoken to him.
R03 Husband

Thus while family can be considered an important contextual factor giving valuable information about the resident to enable staff to use time wisely, they can also prevent staff from using time wisely. This indicates family engagement is an enhancing, but not essential contextual factor that facilitates staff to use their time effectively.

6.2 Conclusion

Six contextual factors: effective leadership, experienced staff, a caring culture, specialised dementia units, physical environment and family engagement were important contexts that facilitated nursing home staff to make the most of time to connect with residents with advanced dementia. The findings revealed that there was interdependence between some of the contexts (effective leadership, a caring culture and experienced staff) which will be discussed further in Chapter 9. In Chapter 7 I will now describe individual factors that facilitated staff to make the most of time

7 Chapter 7: Individual staff factors that facilitated nursing home staff to connect with residents with advanced dementia.

7.1 Introduction

My second research question was 'What individual staff factors facilitate connections?' Given the identification of the core category of 'using time', this question becomes: 'what individual staff factors facilitated nursing home staff to use their time effectively to connect with residents with advanced dementia?' and it is this which I address in this chapter. I present the four individual factors: accepting, tolerating and understanding advanced dementia, perception of role, caring qualities and knowing the person, which I included in the Grounded Theory model as shown in Figure 9, p 140. These were also briefly described in Table 12 which showed all the categories derived from the data. Here each is described in more depth and illustrated with quotes from the data. I go on to acknowledge that the process of 'using time' to connect with residents with advanced dementia is not linear. I end the chapter by considering interdependence between contexts and mechanisms, thereby addressing research question 4.

7.1.1 Acceptance, tolerance and understanding of advanced dementia

Nursing home staff indicated that connections with residents living with advanced dementia were more likely if they understood, accepted and tolerated the impact advanced dementia had on residents. This became increasingly evident throughout the interviews. For example, such staff knew there was a person to connect with, they understood connections took time, reactions were subtle and despite best efforts there was not always a reaction. When staff knew this they 'played it by ear'. Table 13 shows these five aspects giving a quote that illustrates each of them

Table 13 Accepting, tolerating and understanding the impact of advanced dementia.

Theme	Supporting quote
Believing there is a person to connect with	<i>I have a tendency of going to this ladies room and I always say 'hello it is Natalie'. It is something I encourage the other members of staff to do ('hi it is.....'). They might not know one of us from the other, but at least if you've said a name then that's good. I mean we don't know an awful lot about dementia do we? They could remember our names, they might not, but as long as you tell that person who you are, they might suddenly think 'Ooh I recognise that voice. S12 Care assistant.</i>
Understanding connections take time	<i>I would say don't get disheartened if she doesn't show you any facial expressions. Keep trying, and talk to her the whole time. Tell her everything you are doing. Make sure you involve her, keep going, do not give up. S12 Care assistant.</i>
Accepting there is not always a reaction	<i>Some people do not respond to you, but I wouldn't stop talking. Some people will not actually respond to you at times. You can talk to them and give them a full lunch and they won't even open their eyes. They will literally just eat with their eyes closed and not react whatsoever. S11 Care assistant</i>
Understanding reactions are subtle	<p><i>Sometimes they will only move their eyes towards the window, but you know that they've recognised what you're saying on some level. S20 Nurse</i></p> <p><i>A lot of it is body language and facial expressions. They might pull a pained face, a happy face, a go away I am going to scream at you face. You can tell a lot by just looking at someone's expression. S17 Care assistant.</i></p> <p><i>Oh she knows Kaz to a tee, she talks with her eyes you see, blink twice for yes, once for no. R03 Husband</i></p>
Accepting it is not always the right time for the resident:	<p><i>It might be because of their dementia, it might just be too hard or they might just not be bothered that day. We all have different moods don't we and get in different frames of mind. They might just not want to that day. S06 Care assistant</i></p> <p><i>Annette is his favourite, she always gets a smile or a giggle, but he was just too ill to eat, I mean that weekend I thought it was the end, pauses, sorry. Annette, she was just lovely, she didn't give up and said 'no its not, he's just under the weather, I will come back later' and she did and he ate. R04 Wife</i></p>

Understanding advanced dementia and its impact on residents helped staff resolve their main concern of struggling to find time by allowing them to 'play it by ear'. Such staff understood that every person was different, every day was different and every context was different. They understood the process of connecting with residents was subject to continuous adaptation. Staff who were able to play it by ear, were able to take each moment as it came, balance the wider influences and make the most of their time. They took the person as they were in that moment, were able to seize opportunities to connect when they arose, but also moved on and came back later when they were not getting a response. This required effective time management ('making the most of time').

In the following quote a manager talks about how residents' moods could change frequently and as a result staff had to 'play it by ear', adapting and interacting whenever they could:

That joy when something works, but obviously wanting to work hard to improve when something doesn't work, because it doesn't always work. I think that is the thing sometimes with dementia. Sometimes with people living with dementia you struggle on and you struggle on. You try hard to engage, to get that person to smile or be calm if somebody is heightened. It is wonderful when it does work, but you also have to understand that the very nature of their illness means that sometimes it won't and that doesn't necessarily mean we've failed, but at that time maybe we didn't have the right approach or maybe they just needed us to go back another time or something else, but it can be hard especially for new people I think. It is about that ability to adapt and take the person as they are on the day and actually wanting to go back to try again. We make sure everyone knows that in our team, I rely on them (team) to help convey that. S13
Nursing home manager.

Not understanding advanced dementia and the impact it had on residents often led staff to assume there was no longer a person to connect with. In the

following quotes a staff member indicated this by saying she tried to connect by laughing and joking but felt the resident was 'vacant':

Oh yeah there are people in their beds, they don't always understand you. I say hello, but there is nowt else you can really do. I just wave at them. S10 Kitchen assistant

When asked for a specific example:

Today when I've walked down with the tea trolley. I just waved and said hello, but a lot of them just look at you. With Meg, I went in put the TV on and opened a window. I tried to joke with her but she is just like vacant. S10 Kitchen assistant.

A nurse who held a similar view thought her time was better spent elsewhere:

Sometimes I do not interact, not because of her, I think it is more because I'm busy and I try to do my job and I know that it is part of my job to interact with them, but, I found that in the morning when I am giving her, her tablets and I will go and I will ask how she is, like usual, she doesn't really respond and I am thinking well, I have to go because I've got another ten people to attend to and then I have to do something else and this is what stops me. S05 Nurse

7.1.2 Perception of role

The way staff viewed their role was another important factor that influenced whether connections were routinely attempted with residents with advanced dementia. It became evident that staff either saw connections as part of their role, or they saw it as going above and beyond their core role. In the following quote a care assistant illustrates this. She talks about some staff not seeing interaction as part of their role:

No they [staff] wouldn't see the point. I think you've got carers that can do that sort of thing and you've got your carers that just do the care work as a job and I don't think they go above and beyond. They'd say

'I just do this' and that would be it. So I just think it depends on what type of carer you are, as to how much you interact and how much you see or don't see the point in doing something. S06 Care assistant.

Another carer reiterated this point implying she did not see connecting as part of her role. In the following quote she did not appear concerned if a resident did not interact. As long as the resident was clean and had eaten, her job had been done:

It's not really alarming to us. As long as he is eating and drinking okay then that's fine. We will not worry too much if he doesn't do anything else as long as that's done we have done our jobs. S04 Care assistant.

A kitchen assistant also spoke about not seeing interacting with residents with advanced dementia as part of her role:

Like we go round with a menu and things, but it's like I say I am in the kitchen all the time, so it's a different side. I mean the only time I see them is when I go to their rooms or down in to the lounge. So really I don't interact with them much. S10 Kitchen assistant

In a later comment she said:

I mean we still walk past their rooms and say hello sort of thing and wave, but as for anything else that is the carer's side of it. S10 Kitchen assistant

When staff did not see interaction as part of their role connections were not routinely attempted. In comparison staff members who did see interaction as part of their role made the most of time and were more likely to form connections:

Yes you do have little moments with them. It is how you use that time you have with them. S17 Care assistant

I always try to use meal times to interact as you may not get many other opportunities during your shift as you're always dashing around from one thing to the next. S13 Nursing home manager.

We do go in to peoples rooms, even if they are in their rooms all the time, we do make sure we go in and spend some time with them. I do it as much as I can whilst I am assisting them. Whether they respond or not we still talk to them. They have got music and some people have got sensory things that they can enjoy. They might not be able to communicate (verbally) but we give them these little knitted things with buttons on. So we just sort of sit and give them those things to give them a bit of stimulation. But again that is Person Centred so it is about them and what they like. S16 Care assistant.

7.1.3 Knowing the person as a unique individual with their own biography

Nursing home staff suggested connections were more likely to occur if staff knew the resident. Staff therefore learned each person's likes, dislikes and background, they learned their communication repertoire and learned how to recognise communication attempts. This was done over time, by being hands on, and by receiving support from colleagues, managers and relatives.

In this section I will explore how staff made the most of their time by reading care plans, speaking to staff, spending time with residents to pick up patterns of reaction, and asking others for help – all of which contributed to them getting to know the person as a unique individual. According to staff, getting to know each resident individually was of utmost importance when connecting with residents with advanced dementia and allowed staff to make valuable use of the time available. If staff did not know residents, they struggled with the time they had.

The following quotes illustrate the time taken to get to know residents as individuals and how important this was acknowledged to be:

I tell my whole team it is the knowing somebody really well that gets those moments for us all. It's knowing that man and knowing what he can do and what he can't now do, but knowing what we need to do to get that reaction and it is a lovely feeling. S13 Nursing home manager

You need to get to know the person obviously. Figure out how they like to communicate with you and what you need to do to bring out the best in them. It takes time, time and patience. S18 Care assistant.

Basically unless you know the clients right, you would probably say there is no response, but because we have known them for a long time, especially the ones who have been here a long time, you do see little glimmers, little signs in their face and because like Ron he can't communicate back, but we are convinced he can hear and understand because of the way he reacts. Now everyone wouldn't know that, but we know the small changes, but you have got to actually know your resident to say 'oh that went down well' or 'that didn't go down well.

S14 Activities coordinator

Relatives of residents with advanced dementia talked in detail about the importance of nursing home staff getting to know their loved ones and how they could help:

They know everything about Karen, so you know, it works, it works here. I mean even right down to the cleaning staff. They don't just come in and clean, they come in and they talk to Karen while they are cleaning, they know what to talk to her about, and otherwise they wouldn't get anything back from her. R03 Husband

Yeah she loved that, but now she's no longer watching the TV, so now I am playing CD's to her. I sit and sing to her and she responds to that. She will put her hand up and she'll touch my face so yeah, staff who can do that can get a response, Alya can, she is mums favourite. I think you've got to find something that they've enjoyed in the past really haven't you and work with that and we can help by filling in the gaps. R01 Daughter

Not knowing residents well enough hindered the ability of nursing home staff to form connections. This meant they were not able to utilise their time well.

There was a perception that staff who did not take the time to get to know residents did not connect:

And again not knowing the person. If you don't take the time to get to know the person, then you're not going to have that bond so you probably wouldn't speak to them anyway would you. S13 Nursing home manager.

New staff acknowledged they needed time to get to know people before they could then get a sense of connection with them:

I can't honestly say I have [connected] with her yet. I mean I've only actually worked in this home for eight months so you know obviously for me I am still getting used to everything and everybody, it takes time, erm so no I don't think I have actually. S12 Care assistant

Relatives also spoke about the limitations of nursing home staff not knowing their loved ones:

She used to have an excellent home care team who took care of her, who she knew very well. She had a rigid, well not rigid, but set routine. They knew what she wanted when she wanted it, so she didn't have to ask all that much. You know they sort of spoiled her [resident] in that she'd put out her hand if she wanted her hanker chief or a drink or something and they'd put it in her hand, but now of course if she does that nobody knows what she wants. R02 Daughter

Getting to know residents took time and patience. Each nursing home staff member had to learn each resident's unique communication repertoire in order to build their own relationship so they could connect. The following quotes highlight how staff learned the communication repertoire of residents through close observation and interpretation:

Yeah there is one resident who doesn't speak at all. You just do whatever it is you want to do and her facial expressions will show you. She will laugh, she will smile, she might raise an eye brow at you or roll her eyes. So that way you know if you go in and sort of say 'good

morning are you alright?’ she will either tut and roll her eyes or sometimes she will laugh and sort of say yes but nothing verbally so you don’t get any sort of conversation. S11 Care assistant

She responds with eye contact, not verbally. She occasionally makes little noises and when the noises get louder I know ‘okay you’ve had enough now’ so I will go. S12 Care assistant

When asked to expand on the little noises she said:

It is just by the different sounds she makes. Like a child would babble at you and when they’ve had enough they will start to get grumpy and start to cry. Her level gets louder and louder and I think ‘Ooh its time to leave. S12 Care assistant

An activity coordinator spoke about observing residents as a way of getting to know them:

His face seemed to light up. You can see, but it is more of a visual thing than speech. S15 Activities coordinator.

Staff indicated learning these techniques were possible because they were hands on with residents. According to staff ‘doing it every day’ was important:

When I have spoken to other care staff who don’t work here they say ‘I couldn’t do that’ and it makes you realise how skilled your staff are, and it is because they do it day in day out. S19 Nursing home manager.

Yeah like for me I work four to five days in the week...this one [resident] she doesn’t talk. Then suddenly out of nowhere when I was doing her personal care one day, she just said ‘give up’. She was not aggressive or anything, but from that time I heard her voice, then I thought ‘ahh I know she can talk’ so now I can ask her things and so step by step I did different things. I made her smile and I made her raise her arms. I think this lady had a history of assault so that was why she was really scared. Like when you did something she wouldn’t

let go of your hand, she wouldn't raise her arms or roll on her side, so what I did that time, I was calm - I sort of touched her like this [shows me - by gently stroking my arm] so when I observed that she was calm, I observed she could raise her arm by holding her hand. So she raised it and when I confirmed it with the other staff who worked up there on alternative days, they said they noticed it too, so simple things like raising her arms, even if she doesn't talk. S04 Care assistant.

When asked how she was able to do this, the nursing home staff member said:

For me it is because I observe, I assess them, I am hands on, I also ask those who know them really well, you know the staff who have had that interaction with them in the past. S04 Care assistant

From listening to other staff, because they have been here a lot longer than I have. They know her better and have discovered more since she has been here. They have noticed certain things and obviously the nurses know the most. S12 Care assistant

I personally have got a lot of my knowledge from the people who have worked here a long time. S16 Care assistant.

Getting to know residents, learning their communication repertoire and asking experienced staff for tips enabled staff to develop their own unique approach to communication with each resident. Staff found time to connect with residents with advanced dementia within their day despite other priorities because they knew the resident, they knew what to talk about, they quickly realised if someone was not happy and they were able to respond in a way they knew the person liked. They were able to ask relatives and staff for pointers and tips which led to them developing their own unique approaches. This was a process which developed over time with staff learning 'on the job'.

7.1.4 Caring qualities of staff

The category 'caring qualities' directly emerged from the data as something that facilitated connections between nursing home staff and residents with advanced dementia:

I think the key to interaction is the right personality, no doubt. You need to have a heart full of kindness. If you are a kind person you can achieve all sorts of things in dementia care. S13 Nursing home manager.

Many nursing home staff talked about caring qualities such as: having empathy, being kind, feeling passionate and having a caring nature as being key facilitators for forming connections. In the next quote, a care assistant is putting herself in the shoes of the resident explaining what she would expect if she was a resident with advanced dementia:

For a lot of this job you need empathy. If you can't think 'how would I feel' or 'what would that do to me' then it's no good. If somebody came in, got me washed, got me dressed, put me in a chair, fed me, got me out of a chair, took me to the toilet, put me back in a chair. Then somebody else came in and put me to bed or somebody might play a game with me, let me watch – but never spoke to me, what kind of a life would that be? So I think it is very important even if you are sick of hearing your own voice, just to try. S06 Care assistant.

When asked how she was able to connect, an activities coordinator talked about empathy:

I am a big softy, I don't know really, I mean my gran, well my great gran, she had dementia when I was little. She died when I was ten so I can't really remember, but everyone says I could communicate with her and she would do things for me. My family would say 'aww come on do it for Debbie' or 'Debbie is coming to do this, so whether it is something from my childhood I don't know? I just think if it was me, I would want people to be nice, to put themselves in my position. S08 Activities Coordinator.

When asked about what helped her to connect with residents with advanced dementia, a care assistant suggested caring values were essential:

It is all about caring. You have just got to give it your best. That's what it is all about, like you are delivering it to your grandparents or your mother or brother' S03 Care assistant.

Relatives reiterated the importance of caring qualities:

She will sort of talk to him in a nice loving manner. You know he relates to that definitely. Even if it is only a few words or something like that and you know sometimes they will give him a kiss on the cheek and he'll go like this [looks up in an affectionate way]. It is about love for Arthur. R04 Wife

Even if they just touch him, or put their arm around him. It is vital for me because Bob can't converse with me 99.9% of the time, but he can when I touch him. R05 Wife

They care, they care, even though the money is dreadful, which is not right. Caring is everything, it is absolutely everything. R03 Husband

According to nursing home managers, caring qualities, gave staff the motivation to go that 'extra mile' to connect with residents with advanced dementia who were unable to verbally communicate:

I think it is just their personality and I've seen some of them go in and they are quite jovial and have a laugh and a joke, then there are other staff who are excellent at the care side, but are a bit more reserved and just sort of do what they physically need to do. I think it is within them. Everyone is different aren't they, some staff go that extra mile because it's within them, they spend that little bit more time trying. S19 Nursing home manager

You've got to want to do it in the first place. You've got to want to be here and want to take care of that person to get the right reaction. S13 Nursing home manager

Nursing home staff who possessed caring qualities resolved their main concern of 'struggling to find' time by referring to the importance of having an intrinsic motivation or an underlying desire to want to connect with residents with advanced dementia. In the following quotes staff directly talk about this:

There was a lady who I was very close to, who I'd known for many years. She was in the later stages of dementia. Well I was upset that day, I came to work upset. It was something to do with my father. I tried to keep it to myself, but she (the resident) knew. She absolutely knew without me saying anything at all. She wasn't able to verbalise that she knew, but I knew she knew because she was patting my leg. She was patting me on my leg and she was looking at me and I knew, I absolutely knew, that she knew I wasn't myself. I said to her 'oh you know this has happened' and I sat and talked to her about it. It wasn't against the rules and I know I made that lady feel useful. To share like that can be a positive thing. S13 Nursing home manager

Relatives said similar things:

Kaz loves the girls [staff] and the girls love her. They [staff] treat her as a friend as well, you know they discuss their problems with her, they say 'Kaz if you could ever talk again we'd be in real trouble. R03 Husband.

Nursing home staff who possessed caring qualities resolved their main concern of 'struggling to find' time by having 'something inside' them, an underlying desire to want to connect with residents with advanced dementia. In the following quotes staff directly talk about this underlying desire:

I think it is something inside you. You can give people the knowledge and experiences but you've got to want to connect in the first place. S21 Nurse.

They (nursing home staff) talked about making the most of their limited time:

I think when you're doing personal care and you're talking and you're involving her, even though she is not with us, well she is with us but you know what I mean. She might not understand or follow the

conversation but she is still a part of it. So we were talking and she laughed. She was laughing at us. I said to the other person 'Ooh look, she is laughing.' So I said 'Are you laughing?' and her facial expressions said yes. S18 Care assistant.

Other staff spoke about making time after their shifts to show to residents that they cared, as in the case of this care assistant:

I still make time. My job doesn't finish at 2.30pm. I don't walk out of here at 2.30pm. I walk round before I go home. I make that time to interact. I pop in to every single bedroom and say I am off home now, but I will see you tomorrow. S12 Care assistant.

Relatives said the same:

They work their socks off, they don't leave on time, very rarely. Well some do, but not Andrea, I've seen her sat reading a magazine to Kaz, I say to her 'Haven't you got a home to go to?'. R03 Husband

Possessing caring qualities often led nursing home staff to behave in caring ways that facilitated connections. Staff who approached residents in a gentle and caring way were more likely to connect with residents with advanced dementia. The way nursing home staff approached residents was therefore of utmost importance. The following care assistant illustrates this point. She talks about how her approach to residents with advanced dementia set the tone of interactions:

I think if you don't appear to be annoyed and you try to smile no matter what, that tends to break the ice. Sometimes your facial expressions make them think they are doing something wrong. If your facial expression shows somethings not quite right, that can change their whole mood. S11 Care assistant.

Another care assistant reiterated this point. She suggested if nursing home staff were not kind or friendly, or they did not tell the resident why they were there or what they were doing, they might become frightened, which would prevent a connection from being formed:

Well yeah because whenever we are going in to assist somebody, no matter what it is we're doing, we will always say 'oh we're just going to do this' so they know exactly what we are doing. You know they are expecting it and know what is coming. You get a good response that way. Whereas if we go in and don't tell them what we're doing, then we find that they aren't compliant. They don't work with you and get scared. So like I say communication is a massive thing. S16 Care assistant.

When asked if she thought her approach made a difference to whether she was able to connect with residents with advanced dementia she said:

Oh yes absolutely, definitely. If someone just came at me I'd be scared, I'd be terrified. You have to talk to people. You can't just go in and do something to someone, you have to talk to them, especially if they can't talk to you. You've got to go spend time with that person and look for a sign that they are happy for me to do it. If they aren't then they will pull away or they will grab if they didn't like it. So with this lady if she didn't want me to do her nails, then she'd grab or she would pull her arm away – but she didn't. She just sat there and let me do it and she was nearly asleep. S16 Care assistant.

Relatives also talked about the importance of approaching their loved one in the right way. When asked for an example, the daughter of a resident with advanced dementia said:

Yeah I remember one time she [staff] came in and said something like 'good morning Doreen, it's Sally, I've brought you a cup of tea' and she got fairly close to mum and stooped down for mum to be able to see something of her face, she then said 'do you remember me?'. She then said something like 'I'm the one with the little boy who fell over yesterday', which mum then sort of flickered and responded in her way. They don't all seem to do that though, I remember one time in another nursing home, the nurse came, grabbed her arm and wondered why she screamed out and became aggressive, it's not rocket science is it? R01 Daughter.

Whilst many nursing home staff were described to have an approach to care that led to connections being formed, staff talked about other approaches to care such as 'text book caring'. Staff who approached care in a text book way were described as doing all the right things, in the right order, at the right time, however, they did not have the same caring approach. Text book caring was described by staff to be task focused. Staff were rarely motivated to connect with residents with advanced dementia:

I think some people are 'text book carers' and they do all the right things, in the right order, but then other carers have just got that little bit more empathy and put themselves in their position. I used to do mobile care so that's probably where I have got it from. They don't want you to go in and Hoover the house if they're just living on their own. They want you to make a cup of tea and sit with them for ten minutes as you're the only person they see all day and although it is different here, I still class it like that because some of them don't get visitors or they are out of the way because they are in one of the end rooms so you just think, you know, it must be awful if you are in one of the rooms like the lady down there, she's just there all day. They don't even put the TV on in the morning for her. I always put the TV on or the radio on, just so there is background noise. You don't want to be laid in silence, when you know there aren't people walking past. Well I wouldn't want to. S08 Care assistant.

I think it's something inside you. I have known a lot of carers that aren't as caring and can't understand dementia. I think it depends on the type of person you are, because, a lot of the time we do the talking and we try to jolly people along. It depends on who you are and if you want to do it. S06 Care assistant

Nursing home staff with a text book approach were described, at times, to lack the empathy and motivation required to connect with residents with advanced dementia:

I think because people are usually chatty aren't they and then if you've got somebody that is mute and you're not getting anything back, so

some [staff] just stop speaking to the resident and stop trying to initiate conversation, even though the resident can probably still hear them and interact with them. But because they are not getting anything back they stop trying. I've seen it a lot before. S20 Nurse

Relatives spoke about some nursing home staff lacking empathy, which led to them not acting in a caring manner:

It frightens him if anybody says anything in a bad tone. Any person who can't be kind wouldn't relate to him. R04 Wife

When asked for an example she said:

Well she'd [care assistant] gone in and I'm not sure why, but he'd been aggressive in some way. I'm not sure what happened. Anyway she said to him 'don't you shout at me like that' and apparently that had really upset him. I came in after so didn't hear it, but Betty [another relative] did and told me. He never gets aggressive usually. I think it is a bit like animals really, they relate to the tone in your voice [even if they don't know what you're saying]. You know if somebody turns around and says something very caring to you in a loving manner. You've got to be able to put yourself in their shoes doing the job they do. R04 Wife

Another relative gave an example where empathy and caring behaviours were not demonstrated, along with the consequences:

It was the person's attitude. Very much her [care assistant's] attitude, which is permanent. She did not go in and say to him 'I am going to do this now Bob', she just did it and it scared him. He was making a scared noise like urrrrm arrrghhh, but she just carried on. You always get one. I am not going to tell you who for obvious reasons, but she is always like it and if she comes in and is in a bad mood [because she has great mood swings] she stomps everywhere then you know about it. The day before yesterday she never even spoke. I always know when she has been in before I even look at the record. I just know by

the way he has been done. I know by the actual care and he can be a little bit irritable if I go in straight after. He will be irritable so I know it has upset him. You can sense it can't you. R05 Wife

When asked to expand about the approach of that member of staff, the relative said:

She just doesn't speak to him at all. The only time she speaks to him is when she is feeding him. It's not just Bob. She likes her music on as well, she say's it is the only way she can do her job. She puts her music on in their rooms, preferably radio one. R05 Wife

Staff and relatives suggested text book caring meant staff might give up on interactions too soon, particularly if they were not receiving a response from the resident:

I think we all want to get something out of it, not in a selfish way, but you want to sort of know that you are doing it right more than anything. So if you are doing someone's nails or brushing their hair, you want to know that that person is enjoying it or it is not upsetting them. So if you get no reaction, I can understand that people with less experience might think 'ah perhaps I am wasting my time here. S13 Nursing home manager.

To be fair, if they [staff] don't fit in with Marys [managers] thingy then they've got to go. I mean they can be good at what they do, but if they don't fit in the overall thing of this place, then they don't stay. We had a nurse here, she knew her stuff, but she didn't interact. She didn't seem to care, so didn't stay long, they had to get rid. R03 Husband

7.2 How individual factors interacted with each other.

Interacting factors

Throughout Chapter 7 thus far, the examples I have given have often foregrounded one individual factor leading to staff being able to make the

most of time, but it is clear that some examples have also featured other factors in the model, showing that they operate alongside each other and interact. In this section, I attempt to demonstrate in greater detail how the factors may interact.

7.2.1 A link between: caring qualities of staff, knowing the person as a unique individual with their own biography and using time effectively to connect

Possessing caring qualities and knowing the person often appeared to interact to facilitate nursing home staff to make the most of time. The nursing home staff member talked initially about making time to connect. She then indicated that her ability to 'make the most of this time' was because she was able to put herself in the resident's shoes (demonstrating empathy), and because she was able to find common ground (because she knew the residents). This meant she was able to talk to residents with advanced dementia about the things they liked:

I make time. I make a point of going to talk to people. Torturous to me would be someone leaving the radio on all day or having the TV blaring all day, particularly if it is something they don't even want on. I've walked in before to cartoons and that annoys me, because who actually likes cartoons unless you have kids. It's not hard to get to know someone and find out what they like. I know everyone, I make a point of it. I am a quiet person as well, so I would only like it on for an hour or so, so I go in and ask them 'is that getting on your nerves now' and have a quick chat. I mean, I wouldn't want to be treated that way and they'll either nod or raise an eye brow. It's just making that extra bit of effort and finding that extra bit of time, it's not hard really. We work in their home. S20 Nurse

7.2.2 A link between: caring qualities of staff - knowing the person as a unique individual with their own biography acceptance, tolerance and understanding of advanced dementia

The following quote illustrates how possessing caring qualities, knowing the person and understanding dementia interacted. In this example a care assistant was describing a situation where she had made the most of time to connect with a resident with advanced dementia:

It wasn't that long ago, I got the biggest beaming smile I'd ever seen. She had spoken to me before but it was only ever a couple of words. The night nurse said 'oh she loves it when you sing' so I said 'oh have you heard my singing? Then that night, the nurse started to sing and I joined in. She [the resident] was absolutely beaming and laughing with a smile and for me that was everything' S12 Care assistant

It appeared to me that this care assistant attributed her motivation to connect to her own caring qualities. The care assistant also indicated that she understood and accepted there was a person to connect with. She knew, from her colleague (experienced staff) that the resident liked music and between them the two staff knew the resident well enough to know what type of song to sing.

7.2.3 A link between: acceptance, tolerance and understanding of advanced dementia – perception of role - knowing the person as a unique individual with their own biography

Another link was identified between the way the nursing home staff member understood advanced dementia, the perception of her role and how well she knew the person. This is illustrated in the following quote. The member of staff assumed there was a person to connect with, who would have a view on whether his breakfast was nice or not. She saw communication and connections as part of her role. She had taken time to get to know the person and his communication patterns, really well, including what he liked/disliked, whether there was something wrong or if the person was happy/sad. This allowed her to form connections:

Oh yes I love chatting, it's all part of it, I never shut up, but with this one chap, he only speaks very very rarely, so to find out if his breakfast is sweet enough I touch his lip and he will sort of lick it and he will either clamp his lips shut, but if its sweet enough he opens his mouth. It is just the little ways with them. I've worked here a long time so I know him really well. S20 Nurse

When asked how she knew what to do, the nurse responded:

You just know, I can't really explain it, I guess you get to know them and as their dementia advances you know what was once normal and what's not and you watch for changes. S20 Nurse

7.2.4 A link between: caring qualities of staff– acceptance, tolerance and understanding of advanced dementia – perception of role – knowing the person as a unique individual with their own biography

The final quotes of this chapter illustrate how all the individual factors can interact, influence and affect each other:

I was moving around, I was saying good morning and hello to people and I saw him. His eyes were following me. He can't move a great deal, but I noticed that as I was moving around the room he was sort of watching me, so I went up to him and I said 'Hi Norman, good morning, how are you today?' and he just looked up and looked right at me [he has big eyes] and he just said 'good morning' and it was a lovely big smile. You know his voice was really quite clear and it was just very, very lovely. Just really lovely and I think he really wanted me to go and see him that day because he was following me [with his eyes] everywhere I went and he was watching me like this. And when I went over, he seemed really pleased, so I sat with him for a little while. S13 Nursing home manager

When asked what she spoke about she responded:

I was telling him things about my family and just about what was going on and what was happening outside and in the world and he was truly

listening. That's why I could see the difference this day, because there was nothing much there, but he was truly listening to what I had to say, but the very fact that he smiled and said good morning was a really special thing because it is not very often that he manages to speak like that. S13 Nursing home manager

When I asked how that made her feel she said:

I was really pleased and it was a lovely moment. It sounds a bit cheesy but it makes you feel joyous, it really does. That's why I am doing this job for moments like that and you know I tell my whole team it is the knowing somebody really well that gets those moments for us all. It's knowing that man and knowing what he can do and what he can't now do, but knowing what we need to do to get that reaction and it is a lovely feeling. It is lovely to know that he did, he really did want to engage with me and it's almost like he sought me out with his eyes and luckily I was able to see that. S13 Nursing home manager

This manager implicitly suggested that caring qualities, such as empathy and kindness, motivated her to connect with the resident. Her knowledge about advanced dementia i.e. the fact she knew there was a person to connect with and it was the right time for him, meant she was able to play it by ear. This allowed her to spontaneously connect when she was doing another task. She was able to make the time to capitalise on that moment with that resident, on that occasion. She spoke about knowing the person for a long time, which helped her form this connection. She knew how he communicated and what to look for, which allowed her to recognise that he wanted to engage. She was able to personalise care by talking about things he wanted to hear about. It was a mutually rewarding experience. The example shows how factors operated alongside each other to allow the member of staff to make the most of time to form a connection. The example also showed where contextual factors come in to play, the manager indicates she tells her whole team about the importance to connect, this implies effective leadership and a caring culture.

The final example is a passage from a relative:

What would help tremendously is if the poor staff have more time to do it and that's it in a nutshell. It is not because they don't care, because Arthur has been one of the longest residents here, they love him. I mean sometimes it might take them 30 minutes to do Arthur in the morning, erm because he has eczema, so they have to put cream on all of his body and I am sure he is not the only one and he needs two people, but they really haven't got time to do anything else other than that, they do try bless them, they will joke about while they are doing what they do, but they have to rush off, but its not their fault bless them. R04 Wife

She talked about time as the key issue. She was explicit, in her view that she thought the nursing home staff 'cared' and wanted to connect. She implicitly suggested nursing home staff knew him well enough to connect and by acknowledging their attempts to use humour during personal care, she implied they saw connections as part of their role and made the most of time to do so.

The purpose of these illustrations has been to highlight that when a number of individual factors (and contextual factors) come into play simultaneously, connections with people with advanced dementia are more likely to occur. As already suggested, however, connections relied on a complex interplay of factors centred around: the staff member, the resident with advanced dementia, and their wider environment. In Chapter 6, I suggested contextual factors such as effective leadership, experienced staff, a caring culture, physical environment, specialised dementia units and family engagement were important for enabling the individual factors described in this chapter. I will now summarise Chapters 6 and 7 by theorising how contextual and individual factors interact, thereby addressing research question 4. In Chapter 8, interdependence is described in more depth and illustrated with quotes from the data.

7.3 Interdependence between contextual and individual factors

Findings from Chapters 6 and 7 suggested an effective manager was key to creating effective leadership throughout the home. Effective managers encouraged experienced staff, working in different positions within organisations, to act as role models (or informal leaders) that facilitated staff to learn how to make the most of time to connect on the job. When effective leadership was in place, then staff were more likely to perceive it was their role to make the most of time to connect. Staff practically learned how to do this on the job. Empowered experienced staff (role models) played a central role in teaching staff by sharing knowledge and ideas. Staff were then described as more likely to accept, tolerate and understand dementia, more likely to get to know residents and more able to express their caring values.

Experienced staff however, were described to not always use their influence for good, at times, creating power imbalances. Some experienced staff were described to become complacent or not receptive to change for example. Caring cultures created by a formal leader such as a manager were described to help to alleviate this. The manager was described as important for creating a caring culture in which role models could thrive. This was not always the case however, as a person's caring values, or lack thereof, were described to influence this in practice.

An appropriate physical environment was described by participants as essential for facilitating connections. However, an appropriate physical environment alone was not described to facilitate connections. It was dependent on other contexts being present i.e. effective leadership, a caring culture and experienced staff.

In order to make the most of time to connect, leaders (formal and informal) created a culture that gives nursing home staff permission and support. The physical environment is also essential to support connections. Even if there was an effective leader who created a caring culture whereby experienced staff facilitated connections an inappropriate physical environment could

prevent connections. Whilst the physical environment was essential, the ability of nursing home staff to make the most of time, was also dependent on other contexts (effective leader, caring culture, effective manager) being present and that an appropriate physical environment alone does not facilitate nursing home staff to make the most of time.

Specialised dementia units (SDU's) were highlighted in the findings as an important context that enabled staff to develop expertise about dementia which contributed to staff being able to make the most of time. Family engagement was also an important contextual factor as it facilitated staff to get to know residents. Whilst important however, participants suggested that staff were still able to connect in non-specialised nursing homes and without family engagement. Specialised dementia units and family engagement were therefore enhancing contextual factors rather than essential contextual factors. For example staff in this study suggested they were still able to make the most of time without them, but they provided enhancing features when they were present.

In this section, I have theorised how contextual and individual factors interact, thereby addressing research question 4. In Chapter 8, interdependence is described in more depth and illustrated with quotes from the data.

7.4 Conclusion

Four individual factors: accepting, tolerating and understanding advanced dementia, perception of role, caring qualities and knowing the person facilitated nursing home staff to make the most of time to connect with residents with advanced dementia. The findings revealed these do not operate individually or in a linear fashion, and so I illustrated how they interacted and operated alongside one another. I then went on to consider how contextual and individual factors interacted with each other. In Chapter 8 I will now describe the outcome of using time to connect with residents with advanced dementia.

8 Chapter 8: Outcome 'using time'

8.1 Introduction

My third research question was: 'how and when do staff connect with residents with advanced dementia?' Given the identification of the core category of 'using time', this question becomes: 'how and when do staff use time to connect with residents with advanced dementia?' and it is this which I address in this chapter. Proposing the core category of 'using time', in terms of 'how' connections were made, I suggest that care staff connected through non-verbal interactions during personal care. In terms of 'when' they connected, I suggest that this was when staff made the most of time during personal care. Throughout the chapter interdependence between individual and contextual factors is described in more depth and illustrated with quotes from the data. I end the chapter by suggesting the optimal conditions for effectively using time to connect is for all of the contextual and individual factors to be present.

8.2 How and when nursing home staff connected with residents with advanced dementia

Nursing home staff largely connected with residents through non-verbal communication such as: eye contact, touch and body language. This was often in the context of personal care. Whilst nursing home staff spoke about using many of the approaches described in the literature review (see Chapter 2), for example using music, physical objects, sensory stimulation and massage, the way they made connections was opportunistic, informal and based on their knowledge of the person. Nursing home staff did not place emphasis on using specialised interventions to connect. Instead, by virtue of their role in delivering personal care, connections predominantly occurred during these intimate times.

knowledge, or gets to know the individual resident and has the potential to positively or negatively influence how connections are formed.

Making the most of time' describes an attainable, but not always possible ideal process. Staff continually shifted on the continuum of 'using time' between positions where they were 'struggling for time' and those where they were 'making the most of time'. The following quotes highlight this process which fluctuated, giving peaks and troughs within and across days. They are from the same member of staff who talked on a number of occasions about how 'time' impacted the connections she made:

I always try and make time. Obviously though we have to make sure everyone is okay throughout the day, but whenever I do get time I sort of sit with people where I can. Yesterday was a nightmare though as we were short staffed. We'd had a death so it was all hands on deck.
S16 Care assistant.

In the next quote the care assistant talked about making the most of her time in spite of such contextual challenges:

I have this particular lady and I gave her a hand massage and she was just so relaxed and I painted her nails. She was almost asleep. I do different things like that, things that I know she would like because this person doesn't talk at all. She does come out of her room, but she doesn't communicate. I know that she likes hand massages you see and she likes having her nails painted and things like that, so it is just doing stuff that is specific to them. S16 Care assistant

When asked how she was able to fit that in to her daily routine she said:

Well our manager is really flexible so as long as we've done everything we wants she doesn't mind...it's just experience to be honest, I was at a point where I had finished everything, so I thought: 'oh I've got a spare half an hour before we have to start going round all over again, so I am going to sit and spend some time with that person. So I went over and said 'Shall we do your nails' and she can sort of nod for yes, so I took her hand put it in mine and did what I was

doing and she literally laid back in the chair and her eyes were closed, there was no grabbing or pulling, she was so relaxed S16
Care assistant

The same care assistant talked about a time when she did not have a spare half an hour, but resolved her main concern of struggling for time, by making the most of the time she had, creating little moments:

There was a resident, I think it was this morning, we were just in there and we were talking about, well we were finding a towel or something like that and erm it is just general chit chat between ourselves [staff], then I said to the resident 'oh look it's over there' [because I'd already pulled all the bedding out and the covers back looking for it], so I was like 'Ooh look there it is and tutted haha. I said 'I wouldn't be able to find my head if it wasn't screwed on haha' and she started laughing - so it is just like little bits like that. I just involve them in my conversations no matter what it is about – you know just to get that reaction. S16 Care assistant

Other staff also talked about making the most of the time they had with residents with advanced dementia during personal care. It became clear that despite not being able to verbally communicate, people living with advanced dementia could be very active in interacting during personal care. From the examples given to me by staff, it seemed that many of the connections occurred when staff were creative and made the most of their time during personal care:

Yes you do have little moments with them. It is how you use that time you have with them you know to chat with them, keep them happy and I think on the whole I don't have bad experiences, I only have good ones. You know I have had bad ones but that's not their fault and it is just if they are in the mood. S17 Care assistant.

Other more experienced staff made time during their day:

Yes with the first lady we were talking about before, there was something on the television. I can't remember what it was but she was

watching it and I happened to say something about it and her eyes just lit up and she gave me a little tiny grin and I went 'Ooh okay' and I carried on talking about whatever it was and that to me was everything, because I thought 'Ooh I've got through' I've made that little bit of a difference, you know she is interested in whatever this particular item on the TV was. I mean I don't bring it up all the time because its not always on the TV. I try to sort of do day to day things when I am talking to her depending on what is going on at the time, but that particular item she was sort of like engaging and to me that was really good because I thought we are on a winning line here and I did talk to her about it for a good few minutes and then she just closed her eyes and went to sleep. S12 Care assistant.

I could give you lots of examples because I think one of the things that I find up on Cherry, is that actually meal times are a really good time to interact and engage with someone. I always try to use that time to interact as you may not get too many other opportunities during your shift as you're always dashing around from one thing to the next. S13 Nursing home manager.

While it was clear that residents could be active during personal care, it was important for staff to be 'in sync' time wise with residents' wish to spend time in connection (or not). Staff who were able to adapt by understanding it was not always the right time to connect, were able to resolve their main concern of 'struggling to make time':

I mean you get negative responses of course you do, you get them all the time. Sometimes you have the time to sit with residents and you're doing your absolute best to try and interact, you know to talk about things that interest them, going at a slow pace, using props to help you and they will still look at you blankly – so yeah there is no perfect way' S17 Care assistant

Staff who understood this knew to come back later in order to gain an outcome of connecting with the resident. Some staff talked about making the

most of time with residents at end of life describing how connections with residents with advanced dementia continued until the end:

Later when he was in bed all the time he couldn't really come out or do anything, you know he was at end of life. I will always go and say hello and rub their hand though still and I'll say 'hello its June, I've just come to see you. S07 Activities coordinator

I once sat with a lady who was dying, but yeah, its just something you've got to do isn't it? I think it is. S10 Kitchen assistant

I look after people from admission right up until they pass away. I will sit with them and stroke their hand and they might not know who I am I still talk to them about their family or the weather you know, they can't acknowledge that I am there, but I think they can hear me and they'll know. S20 Nurse

Relatives also talked about nursing home staff making the most of time:

I hear them talking to him. One girl goes in and says 'Arfur Arfur Arfur' and she can make him giggle sometimes by doing that. R04 Wife

They don't just come in and clean, they come in and they talk to Karen while they are cleaning R03 Husband

The following relative referred to the core category of 'using time' describing how care assistants either made the most of time (or not). In her account she talked about two very different types of personal care situations. The first was regarding a care team in the previous nursing home, the second from her current nursing home:

The care team she had when she was at Blossom Hill nursing home, well they used to laugh and giggle and jolly her along. She used to hate been hoisted, it's not a comfortable thing, and she is a large lady and so she absolutely loathed that, but the care team she had at that home used to have a big old laugh and kind of joke and tell her stories, while they were doing it, so it made it a much better experience. From what, well I am not around to observe the hoisting (in this nursing home) they ask me to leave the room, but from what I

have picked up its more of a 'right do this, do that, up down, goodbye'
R02 Daughter

8.3.2 The influence of contextual factors on 'using time'.

Despite nursing home staff's willingness to use time effectively i.e. make the most of time, contextual factors did not always allow for this. The following quote illustrates how context impacted staff as they attempted to resolve their main concern of 'struggling to make time' to give dedicated attention to residents:

I know this lady quite well and I know she likes to eat. She opens her eyes and still understands when I am coming at her with a spoon, you know when I am sort of hovering there. She knows to open her mouth. If she wants it she will open her mouth. It's nice, you know it's not a struggle. I don't have to persuade her, but I've noticed in the lounge that distraction element and it might be something like, erm, I am thinking of an instance where we were trying to have that one on one and that lovely smiley situation but then someone else is trying to talk to me, you know like a carer says, 'Ooh is resident X up yet?' so I answered 'No she is still in bed'. The television was on in the background, it wasn't too noisy but it was speaking. I think it was BBC news 24 or something and a few seats down there was another lady who if she sees you wants your attention. So she was shouting 'hey lady, lady' to me so I was breaking off saying 'I will be with you in a moment'. 'I will come and see you in a moment' sort of thing. Basically I wasn't giving this lady my full attention because there were other things pulling me away like the TV or other staff, there were other people walking around and I actually noticed if I was leaving it too long for example if I was having to turn away she was almost dropping off to sleep' S13 Nursing home manager.

In another quote a care assistant indicates how contextual and individual factors interact to allow staff to 'use time' effectively i.e. make the most of

time to connect. In this particular example, experienced staff in a caring culture helped the care assistant to accept tolerate and understand dementia to get to know a resident with advanced dementia:

You know I really did struggle with him for a long time, I'd go in countless times and just get nothing back. I thought it was me, that he just didn't like me. It was Amy that helped me in the end, she knew him, and told me things about him and things that he liked so I was like able to get on his wave length. S12 Care assistant

When asked to remember the first time she connected she said:

Oh well it was when I knew to talk about golf, I put it on and from then on he smiled and was brighter. So now if I struggle, I'll mention golf or put a DVD on. His wife brought some in, so I do that just to get that little bit of response back when I am taking care of him, lightens the mood, you know. S12 Care assistant

When asked how 'Amy' had helped her she said:

Oh well I work with her the most so it was easy, but any of the seniors will help, I get on with her best but have no qualms about asking the others. S12 Care assistant

8.3.3 Struggling to find time

Finding time to connect with residents with advanced dementia was the main concern of staff working in nursing homes. While many staff wanted to form connections, they were constantly constrained by having other tasks to do and having other people to attend to. This left them with little time and flexibility within their role to form connections with residents with advanced dementia.

Many nursing home staff, care assistants in particular, revealed that personal care was their main opportunity to spend time with residents, and therefore a key component of their ability to connect:

When we go in it is for personal care, so we wash them, change their pad, give them some breakfast, I always talk to them where I can, but it's tricky when they are always in their rooms, someone goes in every hour for something, so they get that at least. S03 Care assistant.

Despite personal care being an optimal time to connect, the perception of having little time to do anything other than the task involved in personal care was highlighted on a number of occasions:

We don't get time to do anything else other than personal care. S18 Care assistant

The only thing that stops me is the lack of time. I'd quite happily sit and read a book or draw pictures or do whatever they like to do, just to see their reaction, but I don't have time. S16 Care assistant

Some staff suggested they worked in a culture that prioritised physical needs over social needs, this impacted their individual behaviours:

If staff finish everything on time they will go and draw for residents or spend time talking to them. S01 Care assistant

I think it is a necessarily evil that we tend to concentrate on the medical needs of someone rather than the emotional needs of someone. Sometimes keeping someone washed, clean, fed and dry is more of a priority, it is all about time, time and money. S17 Care assistant

While many staff told me connecting was both important and rewarding for them, it was not the priority:

Sometimes I do not interact, not because of her, I think it is more because I'm busy and I try to do my job and I know that it is part of my job to interact with them, but, I found that in the morning when I am giving her her tablets and I will go and I will ask how she is, like usual, she doesn't really respond and I am thinking well, I have to go

because I've got another ten people to attend to and this is what stops me. S05 Nurse

Relatives of residents living with dementia reiterated this:

*With all the will in the world, in the best nursing home in the world, they can't give them the time that they need really, I don't think. R01
Relative*

*I don't know how they manage in nursing homes, to try and do as much as they can with them [residents] with so little time. R05
Relative*

For many staff it was a daily struggle to meet the physical care needs of residents, for example through personal care and assisting with meals:

Unfortunately with the pressures of the job you don't even get time to do what you need to do, let alone spend time with individual people and that's what you need to do with people who can't communicate. Time, it is so rewarding when you get a positive reaction but the more rushed you are, the more intimidating you're being by being in a hurry S17 Care assistant.

You just don't have enough time, there is not enough staff, it is not enough for what they need. We don't get quality time with the residents. Yeah if we had the time to just go sit with them for half an hour or an hour that would help. It would help a lot but we just haven't got the time or the staff to allow that. S18 Care assistant

When describing their experiences of visiting their loved ones, relatives suggested that they felt like they had to help at times. For example the daughter of a resident living with advanced dementia assisted with meals and personal care:

*I found Riverdale were really good cos they've got open visiting and they're more than happy to have you there doing medication and feeding them, you know if they haven't got time, we muck in. R01
Daughter*

When asked to clarify she said:

I try and help because I'd go in and I'd give her her dinner and cos like they say I know her better and it makes their life a bit easier and I think it takes a lot of strain off the staff. R01 Daughter

Another relative said they helped the staff out by getting involved in social activities. The daughter of a resident living with advanced dementia for example guided her mum through an exercise class:

There is a little exercise class with an outside lady who comes in and there is hand stretching and toe tapping and that kind of thing and I've taken mum to it, but I've had to guide her through it by sitting with her. You know, it's okay for the lady to ask her to stretch her fingers but, if she is sat there on her own she just sits there and has no idea what is going on. R02 Daughter

When asked what prevented them from making the most of time, a care assistant indicated leadership and culture prevented them from getting to know residents:

We just have to do what we're told to do, if we want to sit and chat and get to know someone then it puts us back and we have to do it in our own time, which is fine by me, but it's not fine with the senior or the manager. They'll get on our case. S12 Care assistant.

Even in nursing homes where staff felt well supported and trained in a culture that supported connections, the constantly changing nature of a nursing home environment often meant staff were pulled away from any quality time they had with residents:

I wasn't giving my full attention to this lady because there were other things pulling me away – like the TV or other staff. S13 Nursing home manager

It really is a challenge to get that one on one engagement sometimes, mealtimes especially because it is the busiest time. We see it as a time for one to one interaction, but I have to be honest it doesn't

always work like that, but that is what we are trying to get to. S13
Nursing home manager

You know they let them wander around and do their own thing because I suppose they are always busy aren't they in nursing homes. I think they try their best, but sometimes I think they don't always have enough staff to sort of spend the time with them. With Bob, he can't get out of bed, sometimes they will be in and out because alarms are going off so they are getting distracted. You know most people with dementia benefit from one to one. R05 Wife

Indeed the dependency of residents living with advanced dementia meant that meeting their physical needs demanded a lot of time. Staff often got caught up in the very basics of care. Many staff also suggested the majority of their time was taken up by residents with distressed reactions:

This one lady, she usually participates. She is really confused but with regards to music, she likes it, so on exercise day they had music and she usually participates but that day she was very weepy, very weepy so I just pulled her out from the group because she was putting her hands on her ears like she didn't want to listen. So I pulled her to one side and tried to comfort her. I just sat with her until she felt better.
S04 Care assistant

He has dementia, he is always confused and you see he doesn't understand it and he is always aggressive. It took a long time to calm him down and I had to leave him and go and come back, go and come back because he was wet and you can't leave him if he is wet. You have to change him, so you have to struggle to change him and sometimes it takes two, three, four, people before you can change him. S02 Care assistant

No, he doesn't sit down, this one man, he doesn't sit down, he will be walking around, he will never eat, he doesn't understand anything, even if the pad is wet and you want to change it, he will never sit down. Even if he sees the daughters he will say 'who are these

people' 'where are you coming from' he will be screaming and yeah, it's very sad, very very sad, it takes a lot of our time, even though he has one on one care. S03 Care assistant

Every day in a nursing home was described to be different. Planning a specific time to connect with residents with advanced dementia on any given day, even for those staff whose job it was to meet the social needs of residents, was challenging. To add further pressure, even where staff had made the time to connect, being unable to predict the mood, health and interest in social interaction of each individual that day, meant staff could not always connect despite their best efforts. Fostering connections with residents with advanced dementia was described by staff to be spontaneous and unstructured. Staff were clear that there was not a one size fits all approach to connecting with residents with advanced dementia:

Obviously it depends on the individual. I was telling a joke yesterday while I was pottering about attending to people and there were a couple of residents sat at the table with me and I was having a joke with somebody that was sat with us and another resident just started laughing which was great because he usually struggles and doesn't respond to me, so that day he was just in the mood I guess, so I went over and sat with him. It is random. S16 Care assistant.

The core category of 'using time' reflects the temporal nature of forming connections with residents with advanced dementia. There are many things that impacted on the way staff 'used their time' including how they resolved their core concern of 'struggling to make the most of time' The quotations show that when staff could use time effectively they 'made the most of time', both staff and residents benefitted from the quality connections that were established.

Table 14 illustrates a summary of contextual factors, individual factors and the outcome of using time. However, as suggested in the findings chapters the relationship is not linear and there is interdependence between individual and contextual factors.

Table 14 An overview findings

	Description		Description		OUTCOME
Chapter 6: Contextual factors that facilitated connections	Effective Leadership: if there was an effective leader, staff felt more supported and encouraged to communicate and connect. They felt they had permission to use their time to sit with residents & do social things with them. Effective leaders empowered staff	Chapter 7: Individual factors that facilitated connections	Acceptance, tolerance and understanding of advanced dementia: staff understood that every person was different, every day was different and every context was different. They understood the process of connecting was subject to continuous adaptation.	Chapter 8: Outcome 'Using time'	Making the most of time Connections formed between staff and residents with Advanced dementia vs not forming connections
	Caring culture: staff felt supported to form connections, there was a reduction of an 'us and them' culture, and less formal environments. Team work was encouraged and empowered staff		Perception of role: staff who perceived connections to be a part of their role were more likely to use their time wisely.		
	Experienced staff: acted as role models to other staff. Experienced staff knew the residents well and knew ways, based on their previous experience to connect, they knew how to manage time to efficiently (if they wished) to form connections.		Caring qualities: staff who possessed caring qualities such as empathy and kindness made extra time during tasks, at the end of their shift, and successfully balanced competing influences. Staff were motivated and persevered. They made the most of the time by going the extra mile to read care plans, spoke to staff, spent time with residents to pick up patterns and asked others for help.		
	Specialised dementia unit: if the nursing home had a specialised unit staff had more exposure, experience and training to care for residents with advanced dementia. SDU's had higher levels of staff.		Knowing the person: staff who learned about the resident, their background, communications repertoire and recognised communication attempts were more likely to form connections. This was done over time, by being hands on, and by receiving support from peers and managers		
	Physical Environment: staff suggested a quiet, calm and peaceful environment was optimal. Noisy, busy environments were confusing and scary				
	Family engagement: staff had access to unique and invaluable knowledge about each residents				

8.4 Conclusion

Most of nursing homes staffs' opportunity to connect with residents with advanced dementia was during personal care. In Chapter 8 I have described in detail the core category of 'using time'. I have suggested that, in terms of how care staff make connections, care staff connected through non-verbal interactions during personal care. I suggested in terms of when these connections are made, that staff who were able to make the most of time during personal care were most able to connect. Throughout the chapter I have aimed to illustrate how contextual factors and mechanisms led to staff making the most of time (or struggling to make the most of time). I have ended the chapter by suggesting if all the elements were present, this gave the optimal conditions to facilitate staff to make the most of time. In Chapter 9 I offer an interpretation of the findings.

9 Chapter 9: Discussion

9.1 Introduction

In this chapter I begin by summarising the Grounded Theory I proposed to explain what facilitates nursing home staff to 'make the most of time' to connect with residents with advanced dementia. I spend most of this chapter considering my findings in relation to the broader literature. I go on to argue that this thesis makes an original contribution by considering both contextual and individual factors and how they interact to influence staff making meaningful connections with residents with advanced dementia. I discuss the implications of the results for policy, practice and research, before considering the strengths and limitations of this thesis.

9.2 Summary of Grounded Theory

The central argument of this Grounded Theory is that staff who are able to use time effectively i.e. 'make the most of time' are most able to connect with residents with dementia. 'Making the most of time' comes out of the core category of 'using time' and has an effect through a chain of events beginning at the contextual level whereby effective leaders (managers) create a caring culture in which informal leaders (experienced staff) are nurtured. It is then possible for motivated and experienced staff (not all experienced staff, as acknowledged in the findings), to act as role models which trigger individual factors to come into play including: understanding, accepting and tolerating dementia, knowing connections are part of their role, getting to know residents and expressing caring values. In the right physical environment this then enables staff to make the most of time during personal care. The increased training and education from specialised dementia units and experiential knowledge from family engagement then supplement such contexts.

9.3 Links to the wider literature

In this section I consider the findings of my thesis in relation to the wider literature. I begin by exploring personal care as an optimal time to connect, acknowledging the potential barriers of doing so. Next, I consider interdependent individual and contextual factors, in relation to the wider literature.

9.3.1 Making the most of time

'Making the most of time' during personal care was the facilitative element of the core category 'using time'. Consequently, staff who 'used their time effectively' i.e. were able to make the most of their time with residents with advanced dementia, were able to make meaningful connections. Care assistants in particular, but also activities co-ordinators, nurses and nursing home managers, indicated that most of their opportunity to interact with residents with advanced dementia was during times of personal care including intimate care and meal-times.

In this section I will cite other studies that suggest personal care is a good time to connect, thereby supporting the findings from my research. I then go on to cite evidence that suggests personal care is not always the optimal time to connect, which refutes my findings. In consideration of this counter evidence, my argument is that, with the right contextual support, staff can be facilitated to 'make the most of time' to connect during personal care. In other words, whether personal care provides opportunities to connect may crucially depend on the context.

A number of recent studies support the findings from my research by suggesting personal care is a good time to connect (Colomer and de Vries, 2016; Rapaport et al., 2017; Edvardsson et al., 2014; Watson, 2019). In an ethnography, exploring relationship centred care in a medium size nursing home, personal care was cited as an important time to interact (Watson, 2019). Indeed personal care was suggested to be one of the main points of contact between staff and residents and, therefore, a key component of their

relationship. Many care staff, for example saw personal care as an opportunity to connect with the person and foster a sense of belonging. Paying attention to what residents were communicating in embodied ways was an important element of building relationships during personal care (Watson, 2019).

This echoed findings from an anthropological study exploring the promotion of Person Centred Dementia Care. Edvardsson et al (2014) found that brief intimate interactions between nursing home residents and staff promoted personhood. Similarly, a qualitative study exploring care assistants' (n=13) perceptions and experiences of providing Person Centred Dementia Care, suggested it was important to create a bond during routine interactions (Colomer and de Vries, 2016).

In a recent systematic review of studies about approaches that enabled staff to interact with residents in nursing homes (Rapaport et al. 2017), staff in numerous studies indicated that initiating meaningful conversation during personal care was beneficial. This was particularly the case when staff were able to emotionally connect with residents through touch, physical contact and eye contact. Giving residents the time and space to respond was also considered central. Staff suggested spending time talking to residents about their likes, dislikes, showing them photos, singing or helping residents to put on their jewellery did not entail much more time and often made personal care more enjoyable all round. These benefits were more apparent when staff had the time to spend and they did not feel as though they were rushing.

Meal times have also been cited as a good time to connect with residents in nursing homes. Indeed, the nursing homes who participated in this thesis readily gave examples of connections that happened with residents with advanced dementia during meal times. In a qualitative study asking residents (n=11) for their experience of meal times, Watkins et al (2017) suggested meal times increased familiarity between staff and residents and provided routine (Watkins et al., 2017).

Whilst identified as an optimal time to connect, there is also some evidence to suggest it might not be possible or indeed desired by staff to connect during personal care, refuting my finding that personal care is the optimal time to connect.

In Rapaport et al.'s (2017) systematic review of the barriers to, and facilitators of, using psychosocial interventions, staff indicated their feelings towards personal care made it difficult for them to connect. Staff across studies described the negative impact on themselves and their feelings about their work of providing personal care to people living with dementia. Resistance from residents was a particular barrier to interacting during personal care. Staff in many studies suggested this made them reluctant to engage in interactions. In other studies staff were reluctant to engage in interactions because of a fear they might become too attached to residents. Others expressed doubts about their own ability to interact (Rapaport et al., 2017).

In consideration of this evidence that personal care may not be the best time to connect, my counter argument is that staff in these studies may not perceive personal care as the best time to connect, because they do not have adequate support. For example, the barriers, including staff's doubts about their own ability to interact, dealing with residents' distressed reactions and fear of becoming too attached, could be addressed by some of the contextual factors identified by my study including effective leaders creating a caring culture whereby experienced staff support inexperienced staff. Indeed, my study suggests that with adequate support, staff can be facilitated to make the most of time to connect during personal care. The interdependent contextual and individual factors I found in my study will now be discussed in relation to the broader literature.

9.3.2 Interdependent contextual and individual factors

In this section I consider interdependent contextual and individual factors in relation to the wider literature

9.3.2.1 Effective Leadership

The formal leaders in the nursing homes are the managers or nurses. It was clear in my study findings that if formal leaders provided guidance and support and encouraged experienced staff to act as role models (or informal leaders), this facilitated nursing home staff to make the most of time.

A qualitative study exploring the role of leadership in nursing homes supports this finding. More specifically, Rokstad et al (2015) suggested that managers who played a central role in care practice, who created structural empowerment and delegated authority were more likely to succeed in the implementation of Person Centred Dementia Care (Rokstad et al., 2015). The importance of having leaders' who were adept at identifying motivated, enthusiastic and capable members of staff who could develop a clear vision is also highlighted in the Person Centred Dementia Care implementation literature (Chenoweth et al., 2015; Chenoweth et al., 2019; Fossey et al., 2019). In two qualitative studies, effective leadership from managers and senior figures in the organisation was deemed important for the implementation of Person Centred Dementia Care. Effective leaders were described as encouraging, mentoring and supporting staff (Chenoweth et al., 2015; Fossey et al., 2019). Strong leadership facilitated care staffs' ability to put Person Centred Dementia Care training into practice. When managers provided effective leadership, such staff (role models) were actively supported by their managers, and their role and status were clearly communicated to the other staff (Chenoweth et al., 2015)

In my study encouraging experienced staff to act as role models and informal leaders had a number of valuable functions for staff. Empowered experienced staff, supported by a manager, ensured staff perceived it was their role to make the most of time to connect with residents. Experienced staff also shared their knowledge and skills, which led to staff accepting, tolerating and understanding dementia. They also used their knowledge and experience to help staff to get to know residents. These functions will now each be discussed in further detail.

Perception of role

In my study effective leadership from managers and empowered, experienced role models were important for determining whether care assistants saw connections as part of their role or not. In some cases, nursing home staff told me that tasks were their priority and connections came second, whereas others told me that their manager was clear that connections were an integral part of their role. In their qualitative study exploring the sustainability of a Person Centred Dementia Care Psychosocial intervention, Chenoweth et al (2015) provide support for this finding. For example, managers in their study suggested it was important staff knew how to relinquish a task-focused approach to care. Such managers used 'champions' (or empowered experienced staff) to help them achieve this. This occurred through mentoring programs and regular supervision (Chenoweth et al., 2015).

A qualitative study exploring the role of relationships in nursing home echoed the important role leaders play in whether staff perceive it is their role to connect (Jones and Moyle, 2016). A number of staff in their study said they were told by their superior not to get too familiar with residents or form attachments or relationships. Participants in their study (n=39) were clear that, as a result, some staff did not see connecting with residents as part of their role. When this happened staff were not perceived to be providing Person Centred Dementia Care (Jones and Moyle, 2016).

Fossey et al (2019) suggested that it was important for staff to recognise Person Centred Dementia Care as an integral part of their role in order to support its on-going use in practice. This meant staff had to recognise the value of using such approaches. This finding resonates with my findings. Similarly, studies exploring the implementation of Person Centred Dementia Care also required nursing home staff to be open to learning and to be motivated (Fossey et al., 2019). For example, staff who were capable, energetic, supportive, and willing to learn were reported to translate their

Person Centred Dementia learning into improvements in care quality and resident well-being. (Chenoweth et al., 2019).

Accepting, tolerating and understanding dementia

For participants in my study, accepting, tolerating and understanding dementia and getting to know residents was 'learned on the job', rather than taught in any formal way. It became evident that nursing home staff were using advanced communication skills to connect with residents with advanced dementia but they had never had formal training in such skills. Instead staff implied they learned how to connect on the job, over time, through experience and by learning about the resident. Nursing home staff in my study attributed this to learning from experienced staff. A qualitative study exploring the perspectives of care assistants (n=13) about the use of Person Centred Dementia Care in their nursing home adds merit to this finding (Colomer and de Vries, 2016). For example most participants said they had not received any formal training or education in Person Centred Dementia Care. Quotes from the study indicated their knowledge had come from learning from other, more experienced staff (Colomer and de Vries, 2016). This emphasises the importance of experienced staff for imparting their knowledge and skills.

A qualitative study seeking the experiences of mental health staff (n=70) on delivering Person Centred Dementia Care reported a similar finding. Smythe et al (2015) revealed that staff found it difficult to define the process of what they did. Staff suggested they learned from experience 'on the job' usually relying on more experienced staff to teach them. It was apparent in my thesis and the aforementioned studies that in an environment where few care staff get formal training, they learn through modelling of more experienced colleagues (Smythe et al., 2015).

In studies by Chenoweth and Fossey, knowledge of dementia, gained through education and training, was cited as important for the

implementation of Person Centred Dementia Care (Chenoweth et al., 2015; Chenoweth et al., 2019; Fossey et al., 2019). Taken together with role modelling and peer support, these were described as leading to a strong sense of agency and made it easier for staff to sustain providing Person Centred Dementia Care. (Chenoweth et al., 2019; Fossey et al., 2019). By contrast, Staff in my study placed greater emphasis on role modelling and team support than formal education for enabling them to gain knowledge about dementia.

Getting to know residents

In my study, nursing home staff said they relied on experienced staff to help them get to know residents. There were countless examples where staff said they had learned how to get to know residents by asking for help and sharing ideas and successes. The value of experienced staff for helping other staff get to know residents has also been cited in the wider literature (Smythe et al., 2015; Colomer and de Vries, 2016; Rapaport et al., 2017).

In their qualitative study seeking the experiences of mental health staff on using Person Centred Dementia Care, Smythe et al. (2015), revealed that staff believed they learned about individual residents' needs over time, from those who were more experienced. Colomer et al (2016) reported a similar finding in their qualitative study. They highlighted the important role that experienced staff played in guiding junior staff to implement their Person Centred Dementia Care training. In their systematic review, exploring the effective components of psychosocial interventions, a key facilitator for many studies was the scope of the intervention to allow staff to get to know the person. Having the opportunity to reflect both formally with managers and informally during routine care with experienced colleagues was cited as a key facilitator to this (Rapaport et al., 2017).

Whilst providing a valuable function, there is the possibility there may be unintended consequences of experienced staff acting as role models. For example, such experienced staff could become complacent in their roles or

not want to teach or act as role models. Indeed, staff gave examples of this in my study. It is also demonstrated in an ethnographic study exploring nursing home staff interactions. There was evidence of complacency, which impacted on the quality of care delivered:

The taken-for-granted attitude among some staff combined with little or no writing or reading, made it even harder for the staff in need of information about the new resident. There were serious consequences for the new resident (Eika et al., 2015, p 6).

Power imbalances also impacted individual staff perceptions of their role:

Some, more experienced, assistants seemed to have more authority than others....."As unlicensed staff it is very difficult – eh. It often happens that you are trapped between two who have strong opinions about how to care for the new resident, right? Eh, sometimes one feels like a chameleon - that one goes into the roles of those one works with at any given time (interview assistant) (Eika et al., 2015, p 4).

Thus experienced staff were not always facilitative. Findings from my study indicated that complacency and power imbalances could be prevented by effective leadership and a caring culture. There is evidence to support this argument. In their longitudinal study, Laschinger and Fida (2014) found a significant inverse correlation between leadership and bullying over time. Conversely in their cross-sectional study of nursing home assistants (n=5311), Tong et al (2017) found power imbalances and bullying were more likely to occur when there was ineffective leadership and a negative culture (Tong et al., 2017; Laschinger and Grau, 2012). An effective leader who created a caring culture could limit such power imbalances, as demonstrated in an ethnography exploring nursing home staff interactions:

The head nurse (HN) attempted to support each staff's self-confidence and self-reliance in their interaction with the residents, "to make them aware how much each one of them matters" (interview

HN), and she kept her door open when she was in her office (Eika et al., 2015, p 5).

The influence of effective leadership in creating caring cultures whereby experienced staff were empowered, rather than complacent will now be considered in further detail.

9.3.2.2 Caring Cultures, Effective Leadership and Experienced staff

Experienced staff in my study indicated that their ability to lead (either formally or informally) was dependent on the culture they were working in. The manager was key to this. Managers were integral to encouraging experienced staff, working in different positions within organisations, to act as role models (or informal leaders). When this happened it enabled staff to learn how to connect on the job. Nursing home managers either created a culture where experienced staff could act as role models or not.

This is evident in existing literature (Smythe et al., 2017; Handley et al., 2017; Sjögren et al., 2017). Where there was a dementia-friendly culture, staff had positive attitudes towards working with people with dementia. Hierarchical structures hindered implementation, whereas a culture of care that facilitated relationships among teams had a facilitative effect (Chenoweth et al., 2015; Fossey et al., 2019). In a recent systematic review exploring the effects of Person Centred Dementia Care at the organisational level, a caring culture was considered essential for implementation. Chenoweth et al (2019) found that the work culture must align with Person Centred Dementia Care values.

In a cross-sectional study involving residents (n=1460) and care staff (n=1213), a manager who created a philosophy of care where nursing home managers and nurses worked together with care assistants, valuing their knowledge and skills was considered to create a caring culture. In their realist review, Handley et al (2017) concluded that a Person Centred Environment where leaders provided support and encouragement to the staff

they worked with was an essential context for providing Person Centred Dementia Care. This is supported further in an action research study which aimed to evaluate the effect of using the Person Centred Situational Leadership Framework. More specifically, Lynch et al (2018) suggested leaders who connected to their team, who listened, collaborated with, involved, trusted and created a positive team climate, facilitated the implementation of Person Centred Dementia Care (Lynch et al., 2018).

In presenting my argument that an effective leader creates a caring culture whereby experienced staff are nurtured to act as role models, attention should also be paid to opposing findings in the literature. There is a debate as to whether culture can be manipulated by the leader (Bate, 2004; Schneider, 1994; Lynch et al., 2018), or whether culture is created by the actions and reactions of the leader, with the leader in turn being shaped by that culture (Bass and Avolio, 1994). My counter argument is that despite these opposing views, there is still a consensus that leadership and culture are strongly interwoven (Lynch et al., 2018). The lack of consensus about whether leadership influences culture or culture influences leadership is likely to be fuelled by ill-defined constructs in the literature. For example, the parameters around culture and leadership and how they can be operationalised is limited. This is a limitation of the literature.

Reflecting on my own experiences of working in nursing homes, I have often recalled walking into a nursing home and getting an almost instant sense of what the quality might be like. It is a feeling that has been hard to articulate before now. On developing my Grounded Theory, I can see how the culture and effective leadership may characterise this 'feeling'. For example, where staff are rushing around and looking on edge this gives the visitor one feeling, which contrasts with a nursing home with a relaxed and jovial atmosphere where you feel welcomed. It is unclear how effective leadership and a caring culture can be disentangled at this point. Whilst I have sought to explain what I mean by 'a caring culture' and 'effective leadership', it is clear more work needs to be done to develop these constructs to inform practical solutions for nursing homes.

Caring values

In this thesis, where there was effective leadership (from managers and experienced staff) in caring cultures, nursing home staff were more likely to express their underlying caring values such as empathy, kindness and compassion.

As with other findings, this is again reflected in literature. In their qualitative study exploring the sustainability of a Person Centred Dementia Care intervention, Chenoweth et al (2015) found that effective managers instituted mentoring programs which empowered staff who were eager to learn. The quality of leadership was considered to attract staff who were capable, energetic and supportive to others. This was linked to quality of care (Chenoweth et al., 2015). In a qualitative study investigating the role of leadership in the implementation of Person Centred Dementia Care, Rokstad et al (2015) echo this. Staff in their study felt, with an effective leader, they were able to act in the best interests of the residents. This motivated and encouraged them as they were able to spend time with residents and were more focused on nurturing relationships (Rokstad et al., 2015).

Whilst a caring culture may be an optimal context for leaders to enable staff to express their caring values and teach and share knowledge, this may not always occur. Indeed, there are examples of nursing home staff and or experienced staff (as explained earlier), who do not connect despite this. Caring values (or lack thereof) therefore appear important and may hinder facilitative contexts. For example, nursing home staff may know it is their role to connect, they may accept, understand and tolerate dementia and know the person well enough, but may not have the caring values to motivate them to connect.

The phenomenon of possessing caring qualities has been described in other populations, using different terminology, such as caring attributes and personality traits (Teng et al., 2007; Smythe et al., 2015; Mullan and Sullivan, 2016; Kovach et al., 2010). This has demonstrated a link between the

personality traits of nursing home staff and perceived quality of care. A cross-sectional study looking at the relationship between the personality of hospital nurses and quality of care received revealed that 'openness' was positively correlated with patient perceptions of 'responsiveness' and 'empathy' (Teng et al., 2007). A similar finding was reported in nursing home staff. In their sample of certified nursing assistants (n=177), personality traits such as: flexibility, thoughtfulness and likeability were significantly associated with staff who were most likely to perform well in their roles (Kovach et al., 2010). Where caring qualities were absent, nursing home staff were not perceived as motivated. Staff did not make an effort to connect and were comparable to the 'text book' staff described in this thesis i.e. they did tasks in the right order but did not go the extra mile.

This demonstrates that even in a caring culture with effective leaders, connections may not be attempted because of a lack of caring values of the individual staff members.

Attention should also be paid to those staff who do not feel supported by their managers or leaders, who do not work in caring cultures and are unable to rely on experienced staff to assist them. Some staff in these situations strive to make connections anyway, because they possess the caring values described above. This situation challenges the contextual factors of effective leadership, a caring culture and experienced staff posed in this thesis. In consideration of this, my counter argument is that whilst it is commendable that staff strive to connect even when they do not feel supported by their superiors or environments, there is evidence that this is not sustainable.

In a qualitative study exploring the experiences of nursing home staff (n=11) under threat of organisational change, Fläckman et al (2009) demonstrated how barriers like this impacted nursing home staff over time. Findings from this study showed a transition in experiences over 24 months. Staff went from taking pride in their work, having satisfaction and confidence over care, in a calm relaxed environment, to feelings of being abandoned, conflict and low self-esteem. A loss of control, identity and decreasing influence overtime translated in to a lack of commitment (Fläckman et al., 2009). In their

qualitative study exploring the meaning of care assistants (n=11) experiences of working in a nursing home, Carpenter and Thompson (2008) gave many examples of care assistants who worked in their role because they wanted to make a difference to people's lives. They talked about responding to a higher call and expressed a heartfelt passion for what they did. However, there were many examples of how, over time, contextual factors led to them feeling devalued and disempowered in their role. This led to a lack of job satisfaction and a desire to leave their role (Carpenter and Thompson, 2008). This suggests, whilst possible in the short term, individuals need to be supported in the long term to sustain care.

9.3.2.3 Specialised Dementia Units

Specialised dementia units were highlighted in the findings as an important context that enabled staff to develop expertise about dementia which contributed to staff being able to make the most of time.

The wider evidence suggests specialised dementia units are effective. In a longitudinal analysis assessing the role of specialised dementia units on nursing home residents (n=323) with advanced dementia, Cadigan et al (2012) reported greater satisfaction with care, than in non-specialised units (Cadigan et al., 2012). This finding was echoed in another study which compared levels of care in specialised dementia units compared to other nursing home units. The study showed residents in specialised dementia units received a better standard of care. It was suggested that staff working in specialised dementia units had the expertise to attend to the social and emotional needs of residents, as well as their physical and medical needs (Luo et al., 2010). Palm et al (2014) supports this claim. In their cross sectional study of nursing homes (n=51), they explored the characteristics of specialised dementia units. Specialised dementia units were reported to have smaller integrated environments serving home like meals. They were reported to have more registered staff, with specialised skills and more expertise compared with nonspecialised units (Palm et al., 2014).

Whilst the evidence supports the effectiveness of specialised dementia units, findings from this study demonstrated that staff were still able to connect in non-specialised dementia units, though it seemed they were at a disadvantage compared to staff in specialist units. In specialised dementia units staff have more knowledge and expertise. This implies they are more likely to accept, tolerate and understand dementia. Specialised dementia units are also described to have more staff which implies staff are more likely to have the time to get to know residents. However, given that staff in non-specialised dementia units were able to give examples of where they were able to connect, perhaps the ability to connect is related to having experienced staff (in caring cultures) that can teach other staff how to make the most of time to connect.

This indicates specialised dementia units could be an enhancing context due to their focus on caring for people with dementia; one more likely to have an effective leader, a caring culture and experienced staff. This does not suggest specialised dementia units are not effective. Indeed specialised dementia units often have higher staffing levels, with more dementia training. It seems that the cohesiveness of the team, and the creation of a culture where staff can learn from each other is of equal, if not more importance. This finding is supported by two literature reviews looking at how staff influence quality in nursing homes which found higher staff numbers, with more education and training alone did not automatically lead to quality (Backhaus et al., 2014; Spilsbury et al., 2011).

9.3.2.4 Family Engagement

Family engagement was also highlighted as an important context that enabled staff to get to know residents. However, findings demonstrated that staff were still able to connect without family engagement or if family were not helpful. For example, nursing home staff in this thesis spoke about family members either enabling or preventing connections with residents with advanced dementia. When perceived by staff to be positively involved, family members were described to provide invaluable information about the

residents, including their likes/dislikes, which helped staff to make the most of their time to connect. However, at times, nursing home staff viewed family involvement as a hindrance, particularly when conflict arose due to differing expectations about what the resident was capable of. This could prevent nursing home staff from forming connections with residents with advanced dementia.

The role family play, particularly their involvement in individualised care and the importance of forming positive relationships with staff has been well established within the existing literature (Irving, 2015; Bauer et al., 2014; Colomer and de Vries, 2016; Tjia et al., 2017). There is also evidence that nursing home staff viewed some family members to become too involved and demanding, which at times hindered their day to day routines (Bauer et al., 2014).

In this thesis I suggested that family engagement triggered the individual factor whereby nursing home staff got to know residents. However, perhaps this is also related to having experienced staff (in caring cultures) that could help staff get to know residents. This indicates family engagement is an enhancing context, but is only effective when there is also an effective leader, a caring culture and experienced staff. Family may be able to help nursing home staff to get to know things about residents, but they are unable to provide the skills, knowledge, environment and culture needed for staff to thrive. Family engagement therefore represents only part of the picture.

9.3.2.5 An appropriate physical environment

Having an appropriate physical environment was also essential for connections to occur, physical environment alone does not facilitate connections and is dependent on other contexts being present (effective leadership, a caring culture and experienced staff). However, even if there was an effective leader who created a caring culture whereby experienced staff facilitated connections an inappropriate physical environment could prevent connections.

This argument is supported by existing literature which suggests the physical environment is important. In their cross sectional survey, Nordin et al (2017a) identified an association between the physical environment and the well-being of residents. Chaotic, medically-focused institutions were suggested to have a negative impact on residents' well-being (Nordin et al., 2017a). In a comparative case study design exploring older people's activity in comparison to their physical environment Nordin et al., (2017b) identified a number of environmental barriers that prevented social activities from occurring. Those particularly relevant to this thesis included: closed doors, long corridors or activities where mobility was essential. Large noisy rooms were also cited as environmental barriers (Nordin et al., 2017b). A qualitative study involving members of staff (n=15) in two nursing homes reported that a calm and homelike environment positively contributed to the quality of life of both staff and residents (Lee et al., 2016). Staff suggested that a comfortable and quiet atmosphere was not only pleasant for the residents, but also allowed staff to connect with and care for residents. An unorganised and chaotic environment had the opposite effect (Lee et al., 2016).

9.3.3 Summary

The central argument of this Grounded Theory is that staff who use time effectively i.e. 'make the most of time' are most able to connect with residents with dementia. 'Making the most of time' comes out of the core category of 'using time' and has an effect through a chain of events beginning at the contextual level whereby effective leaders (managers) create a caring culture in which informal leaders (experienced staff) are nurtured. It is then possible for motivated and experienced staff (not all experienced staff, as acknowledged earlier), to act as role models which trigger individual factors including: understanding, accepting and tolerating dementia, knowing connections are part of their role, getting to know residents and expressing their caring values. In the right physical environment this then enables staff to make the most of time during personal

care. The increased training and education from SDUs and experiential knowledge from family engagement then supplement such contexts.

9.4 Original contribution of this thesis

This study makes an original contribution to the literature. It proposes a theory, from a nursing home staff perspective, of how to 'use time' to connect with residents with advanced dementia. The Grounded Theory 'Making the most of time' provides insight into the complexity of an under-researched area. By the nature of care they provide, nursing home staff are in powerful positions to connect with residents with advanced dementia, yet few studies to date have sought to understand, from staff's own perspective, what enables them to do this on a daily basis.

Much of the research literature about ways of connecting with residents with advanced dementia presents evidence on the effectiveness of specialised interventions. These interventions are often require prior training and carried out in dedicated activity sessions by professionals with specialist knowledge, rather than by the staff who have the most contact with the residents. Few of the studies consider what contextual and individual factors influence the use of such interventions in practice or how they might interact. This study, by contrast, explored individual staff perspectives on their day-to-day connections with residents with advanced dementia, paying particular attention to contextual and individual factors and how these interacted.

I found that most of the opportunities to connect were during personal care. Interdependent individual and contextual factors were identified which helped staff to make the most of time. Whilst many of these individual and contextual factors have been identified in other studies, this study adds to knowledge by generating a Grounded Theory to (1) identify and (2) highlight interdependence between such contextual and individual factors. In summary, this study provides an example of how Interpretive Grounded Theory methodology can uncover and explain social processes in nursing homes.

9.5 Links to policy

In this section I will explore the similarities, differences and use of the Grounded Theory 'Making the most of time' in relation to policy.

Much Government policy (Department of Health, 2009; Department of Health, 2014; Department of Health, 2015; Health Education England, 2018; National Institute for Health and Clinical Excellence, 2018; Department of Health and Social Care, 2017; Care Quality Commission, 2017) advocates the implementation of Person Centred Dementia Care. The theory of 'making the most of time' offers a conceptual understanding of how contextual factors can trigger the individual factors which facilitates staff to deliver Person Centred Dementia Care for residents with advanced dementia from a staff perspective. The identification of interdependent contextual and individual factors and how they interact, offers policy makers a way of operational planning which links to their policy aspirations of bridging the gap between policy and practice.

The theory 'making the most of time' is also relevant to the Dementia Training Standards Framework (Health Education England, 2018). In the current end of life dementia care section, the document is focused on advance care planning for symptoms and pain relief and ensuring all people with dementia and their carers receive "co-ordinated and compassionate Person Centred Dementia Care". The theory 'making the most of time' could provide guidance on how to connect with the most vulnerable residents to ensure they receive Person Centred Dementia Care.

Current guidelines seek to develop practice in dementia care through the use of psychosocial interventions (National Institute for Health and Clinical Excellence, 2018). Such guidance suggests change should occur through psychosocial intervention availability, staff training and education (National Institute for Health and Clinical Excellence, 2018). However, whilst training and education are important, my study suggests more attention should be paid to how effective leaders can create cultures that empower experienced staff to act as role models to facilitate nursing home staff to make the most of

time to connect, whether it is using psychosocial interventions or by interacting during personal care or both.

The recent 'Quality Matters' document, commissioned by the Care Quality Commission, sets out a shared vision for what quality care should look like for residents living in nursing homes. In the document they recognise the duty of the organisation for implementing Person Centred Dementia Care. Their comprehensive shared view of quality suggests nursing homes should be safe, effective, responsive, caring and well-led (Department of Health and Social Care, 2017). A theoretical perspective that explains how individual and contextual factors interact to facilitate staff to connect with residents with advanced dementia in nursing homes may add value to this policy. Furthermore, the focus on connecting with residents with advanced dementia specifically ensures quality is experienced by everyone in the service to ensure people living with advanced dementia do not become isolated.

When considering the potential relevance of this Grounded Theory to policy, it is worth reflecting on McCormack and McCance's (2010) work on culture in dementia care. They raise points which should concern policy makers including the importance of upholding nursing home staff's personhood, if they are expected to provide Person Centred Dementia Care. Staff must therefore feel valued by society as well as their organisation if they are going to change practice. Research and policy show that dementia care is not only influenced by the nursing home context, but is also influenced by broader societal influences (Alzheimer's Society, 2013; Wu et al., 2016; Alzheimer's Society International, 2012). As a result, policy has called for changes in dementia care at both the individual level and the societal level (National Institute for Health and Clinical Excellence, 2018).

This has implications for the theory of 'making the most of time'. For example, external influences such as funding, stigma and value placed on care staff may inhibit the ability of individual nursing homes to implement change. For example, a lack of funding may limit the recruitment and/or retention of staff. Stigma and low value may influence individual attitudes i.e. it may be difficult to motivate and empower staff to become informal leaders. Thus, the policies that promote change in Person Centred Dementia Care

will not become a reality unless a number of conditions at societal level are addressed. Dementia-friendly communities have been a good start in addressing how society perceives people living with dementia (Henwood and Downs, 2014). However, there has been little breakthrough in the way staff working in nursing homes are perceived, which in turns influences how they perceive themselves. The theory of 'making the most of time' explains the process by which contextual factors such as effective leadership, a caring culture and experienced staff help nurture staff's personhood. This then allows them to engage in behaviours such as accepting, understanding and tolerating dementia, perceiving it is their role to connect and getting to know residents. This in turn allows them to make the most of time.

Through its consideration of both individual and contextual influences and how they interact to influence connections with residents with advanced dementia, this Grounded Theory offers policy makers a means of achieving social inclusion for a client group at risk of social isolation.

9.6 Implications for practice

In this section I will focus on the key findings and their implication for areas of practice.

The finding that most of the opportunities to connect with residents with advanced dementia occur during personal care has considerable implications for practice. Small changes in staffs' everyday routine can be implemented immediately in nursing homes at relatively little cost and disruption to the nursing home. For example, emphasising to staff the importance of getting to know residents, learning their communication patterns, and how they like to connect are small changes that could improve the frequency and meaningfulness of connections. Ensuring nursing home staff understand dementia and know it is their role to connect with residents with advanced dementia is an important first step. Namaste could be a useful tool to facilitate this. As described in Chapter 2, Namaste was developed for nursing home residents with advanced dementia who can no longer engage

in conventional group activities. It combines compassionate care with meaningful activity in dedicated sessions. Namaste challenges routine care and provides an alternative structure of care that delivers repeated opportunities for interaction and connection. In my study most of staff's time to spend with residents was during personal care. Namaste provides dedicated time for staff to connect with residents thus creating time outside personal care to connect also. This provides staff with a legitimate reason to do things that promote engagement, rather than for the purpose of function i.e. for personal hygiene. The structured approach of the intervention supports staff to meet the social, emotional, physical and spiritual needs of residents. This has been suggested to reshape nursing home staff's routine towards a more Person Centred Care approach, with staff developing increased respect and dignity towards residents, seeing them as people. Indeed Namaste was described to change the way staff felt about their work. Perception of role was an important factor in whether staff attempted to connect in my study, thus an intervention like Namaste would provide a tool to ensure staff perceived it was their role to connect (Stacpoole et al., 2015; Stacpoole et al., 2017) Additionally adapting the structured approach of the Namaste, to be used during personal care could also potentially support staff to meet the social, emotional, physical and spiritual need of residents with advanced dementia.

Participants in my study talked about looking for permission and relying on experienced staff and appropriate physical environments to connect. Changes therefore, require managerial insight to create a culture where the emphasis is on 'how' care is delivered as opposed to 'what' care is delivered, placing attention on the communication that takes place during personal care rather than the tasks of personal care. Managers are key to ensuring this occurs, as highlighted by Stacpoole et al (2015, 2017), who reported instances of where Namaste failed when poor leadership was in place.

Given the importance of effective leaders, to create a caring culture in which experienced staff are nurtured to become informal leaders, an implication for practice to focus on is how to develop effective leaders. A potential way to do this could be to enact the theory 'making the most of time' within a Person

Centred Care Situational Leadership Framework (Lynch et al., 2018). The Person Centred Situational Leadership Framework (PCSLF) focuses on a leader's ability to diagnose the performance, competence and commitment of each member of staff. The manager takes a flexible approach, modifying their style of leadership to align it with the developmental level of the staff member. For example, the leader and the staff member agree on a diagnosis on the staff's developmental level. This ranges from D1 (enthusiastic beginner), through to D4 (self-reliant achiever). Using a Person Centred Approach, the leader adopts a leadership style, ranging from S1 (directive) through to S4 (delegating) and aligns it to sit with the staff members developmental level. By combining high and low supporting behaviours with high and low directing behaviours, the situational leader supports and empowers staff members. This would fit with the social process of 'making the most of time' to connect with residents with advanced dementia. It was clear from the participants in this study that staff had different abilities, some were able to connect easily, whereas others needed more help.

There has been little work on situational leadership in the nursing home context. Reflecting on my own experiences of working in a nursing home I can see how this might work in theory, but feel it would depend a lot on the manager's ability to recognise and adapt to individual staff needs. This might be difficult in practice without significant training or for managers who take a task focused approach to care (Rokstad et al., 2015). In their qualitative study exploring the barriers and facilitators to implementing Dementia Care Mapping in care homes, Griffiths et al (2019) highlight how a manager who is unable or unwilling to engage in change create barriers to Person Centred Dementia Care. The attributes of the manager seem important in their ability and motivation to take a situational leadership approach.

Contextual barriers may represent a problem for managers to implement a situational leadership approach. For example processes in large or chain owned organisations may be streamlined, which means managers may have to adhere to rules and regulations that limit their ability to be flexible. In their qualitative study exploring leadership behaviours in relation to implementing

culture change for Person Centred Dementia Care, rules and policies were reported to directly conflict with strategies to improve care (Corazzini et al., 2015). Equally, the influence of the funding system could mean managers have to be more focused on outcomes and bureaucracy. Rokstad et al (2015) demonstrate this in their qualitative study exploring the role of leadership in the implementation of Person Centred Dementia Care in three different homes. The documentation, which was time consuming and experienced as a burden on the leaders, had to be updated to release funding. This limited the ability of the leader to support staff. Furthermore the rigid and structured plans gave staff only limited opportunity for improvisation and flexibility in their relations with residents. This kind of influence from the funding system would likely cause barriers to taking a situational leadership approach (Rokstad et al., 2015). It is clear that further work is required to understand the individual and contextual barriers to situational leadership before it can be recommended.

To enact the theory 'making the most of time' managers would play a central role by providing different levels of support to their team. Managers, for example could nurture experienced staff by delegating informal authority that enable them to support the manager. This support could then ensure staff learn to accept, understand and tolerate dementia, perceive it is their role to connect, get to know residents and express their caring attributes. In their action research study.

9.7 Implications for research

There are several implications for future research. In this section I will propose further areas for research including the need for greater conceptual clarity of key terms as well as questions which need addressing and will suggest methodological approaches which could be used to address those questions.

The small sample size of this exploratory study represents a foundation to build upon. Future studies could therefore be extended in search of statistical

rather than analytical generalizability. Potential questions to be addressed using larger sample sizes, but based on the Grounded theory on 'Making the most of time' could include:

- 1) The association between contextual factors, individual staff factors and outcomes (connections) over time
- 2) If one of the factors has more of an influence on whether connections are formed than the others?
- 3) If there is an association between staffing models (mix, ratios) and frequency of connections

A longitudinal study looking at how staff's ability, expectation and attitudes change over time could be useful. For example, in my Grounded Theory I have hypothesised that staff make the most of their time if key factors are in place. It would be helpful to know if this changes over time and, if so, what contributes towards that change. Research is required on how staff can manage their time better to focus on communications and connections over tasks. Future research could identify specific components of individual and contextual factors in further detail. Terms such as effective leadership, caring culture, perception of role, could be operationalised. Understanding what specific leadership behaviours and cultural factors are important and how to identify informal leaders is an important next step.

Throughout this thesis I have referred to nursing homes. However, this term is used interchangeably with others such as 'care homes' in the literature. There is a greater need for clarity about whether studies are referring to nursing homes, care homes, residential homes, and long term care facilities. Insights from staff in other roles such as maintenance or cleaning staff could add further evidence to the theory 'making the most of time'; as could insights in to interactions between staff and family, and residents with residents with advanced dementia. An observational approach could also develop the theory further.

9.8 Strengths

There are a number of strengths to my study. They include: access to the field, insights on how the most vulnerable residents are cared for, richness of data gathered and causal links between individual and contextual factors.

Access to the field: my previous experience of conducting research in nursing homes meant I had existing relationships with some of the nursing homes who took part in this research. This helped with access. Furthermore I was able to build on existing, and create new relationships by feeding back my findings. All of the nursing homes welcomed me back and suggested the results resonated with them. This allowed me to give something back to the nursing homes which took part.

Insights on how the most vulnerable residents are cared for: nursing home staff spoke openly and honestly about how they cared for residents with advanced dementia. Many of the examples were during personal care. The nature of care provided, meant staff spoke about what could be perceived as sensitive matters.

Richness of the data gathered: a limitation of many research studies in people living with advanced dementia is that they do not consider the nursing home staff perspective. The Grounded Theory methodology used in this study meant I was able to gather rich data from staff, which was guided by them. I began with open questions and let them guide the discussions according to their own experiences. I asked for specific examples rather than general descriptions to ground their experiences. This created a rich data set from which I was able to develop a theory.

Causal links between individual and contextual factors: a limitation of existing research is that they do not consider the interdependence between contextual and individual factors. The significance of this thesis is that I have been able to explore and theorise about the interdependence between the proposed contextual and individual factors. Exploring this dynamic interaction, has allowed me to identify a causal chain from the organisation to the individual. This has allowed me to identify factors and understand how

factors interact to facilitate staff to make the most of time to connect with residents' with advanced dementia.

9.9 Limitations

There are several limitations to the current study. They include: potential bias, using interviews as the only method of data collection, the focus only on the interaction between staff and residents and omission of some nursing home staff.

Potential bias: while I took steps to minimise bias, for example by being transparent and keeping an audit trail of the research process, my assumptions could have influenced my interpretation of findings. I brought into the study a view on the nature of living in a nursing home, which could increase the risk of bias. However, this understanding also allowed me to notice and identify information that may otherwise have been overlooked. From the beginning I recognised the importance of my own perspective in the research and addressed its influence by being reflexive throughout.

Using interviews as the only method: while interviews generated rich, in-depth descriptions of care, they were reliant on staff self-reports alone. Had I performed observations as well, this would have allowed me to compare what staff told me they did, with what they actually did. My initial intention was to perform observations. However, as most of the interactions occurred in residents' bedrooms during personal care, there were perceived ethical issues and it was deemed not appropriate. Instead I spent a prolonged time in the nursing homes informally chatting to staff. I also tried to talk to staff immediately after they had performed or observed personal care to get examples of the times they had connected. I also conducted the research in seven different nursing homes with staff in different roles. This allowed me to ask a range of staff from different contexts how they connected. This maximised my ability to understand how and when staff connected with residents with advanced dementia and what facilitated them to do so.

The focus only on the interaction between staff and residents: the focus of this study was only on the interactions between staff and residents, examination of relationships between staff-family or resident-resident was beyond the scope. However, it is acknowledged that these types of relationships are critical and require balanced attention. Whilst I did not examine these relationships (staff-family, resident-resident) it meant I was able to focus on the interaction between staff and residents in depth.

Omission of some nursing home staff: I was unable to recruit any cleaning or maintenance staff. Insights from staff in these roles could have added further evidence to the theory 'making the most of time'.

9.10 Conclusion

This thesis contributes to the literature by considering both individual and contextual factors and how they interact to enable staff to make the most of time for meaningful connections with residents with advanced dementia. Through this consideration, this Grounded Theory offers care providers and policy makers' suggestions about how they can enhance social inclusion for people with advanced dementia, who are a client group at risk of social isolation. It also offers researchers a platform to empirically test and further develop the theory 'making the most of time'

10 References

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Appendices

Appendix 1: Literature review quality rating system

The Critical Appraisal Skills Programme (CASP) was used to rate the quality of studies in the literature review in Chapter 2, (Critical Appraisal Skills Programme, 2018).

Table 16 Critical Appraisal Skills Programme (CASP)

Quality Rating	Quality Rating definition
++	All or most of the criteria have been fulfilled. Criteria that have not been fulfilled are very unlikely to impact the quality or overall conclusion
+/-	Some of the criteria have been fulfilled. Criteria not fulfilled or not adequately described are thought to unlikely impact the quality or overall conclusions of the study.
--	Little or none of the criteria have been fulfilled. This is likely to have an impact on the quality or overall conclusions of the study

Appendix 2: Literature Review Data Extraction

Arts based interventions to connecting with residents with advanced dementia										
Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Van-Der-Vleutin et al., 2012	The contribution of intimate live music performances to the quality of life for persons with dementia	To assess the effect of intimate live music performances delivered by professional singers on the quality of life of persons with mild and severe dementia in nursing homes	Quasi-experimental design – no control group	Type: group Length: 45 minutes Duration: one session Facilitated by: professional music group Music chosen by: professional music group based on resident preferences Assessment: observation list during intervention.	54	Quality of life: participation (human contact, care relationship, communication). Mental wellbeing (positive emotions, negative emotions, communication). German Observational tool.	Significant increase in participation $P=<0.000$ and mental well-being i.e. happier, laughing, reduction in anxiety $P=<0.000$	Intimate live music may improve participation and mental well-being of PWD. Uniqueness of the intervention lies in combination of singing and making authentic contact. As it involves professionals may be difficult to implement. Focused on cause and effect	The observation lists were based on theoretical concepts. The intervention was not.	+/+

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Hammarr et al (2011)	The impact of caregivers' singing on expressions of emotion and resistance during morning care situations in persons with dementia: an intervention in dementia care.	To describe expressions of emotions and restiveness to care among persons with dementia (PWD), during morning care situations without and with music therapeutic caregiving (MTC).	Intervention study pre-post test	Type: individual Length: 10-20 minutes Frequency: every morning Duration: two months Facilitated by: staff working the the care home after attending a course. Music chosen by: hymns & songs that older people might like Assessment: baseline (during ordinary morning care situation), then four times after, once a week, before & after intervention.	10	Emotional expression following the interaction & restiveness to care. OERS emotional rating scale RTCS restiveness to care	Significant decrease in restiveness to care Turning away P=0.013, Pushing away P=0.020 & Grabbing person P=0.037. Significant increase in pleasure P=0.016, alertness P=0.042	MTC can be an effective intervention. It is unique because it can be implemented as part of personal care. However, the study did not consider the views of the staff who would be using it during personal care, nor did they address how to incorporate it in personal care.	No use of theory was detected	+/-

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Gotell et al (2009)	The influence of caregiver singing and background music on vocally expressed emotions and moods in dementia care: A qualitative analysis	To illuminate vocally expressed emotions and moods in the communication between caregivers and persons with severe dementia during morning care sessions	Qualitative	<p>Type: individual during morning care.</p> <p>Length: 6-22 minutes</p> <p>Frequency: varied</p> <p>Duration: average of 13 days</p> <p>Facilitated by: staff working in the care home</p> <p>Music chosen by: researcher based on familiar music (not individualised)</p> <p>Assessment: analysis of video post intervention</p>	9	Emotions and mood, Content analysis	There was a high disjoint between resident & staff in usual care. Staff tried to create a positive atmosphere, was not always met by residents. Care giver singing created mutual vitality, less restiveness. Residents were calmer and more relaxed during caregiver singing.	Care home staff sang during personal care. They did not receive training nor were they required to sing specific songs. The study did not address the barriers associated with staff doing this day to day (i.e. if it would be feasible/ Transferrable). The study did not ask for the perspectives of staff. It focused on cause and effect of the intervention.	No use of theory was detected – alluded to Bower’s theory of emotion in the discussion but the intervention did not appear to be underpinned by any theory	+/-

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Holmes et al (2006)	Keep music live: music and the alleviation of apathy in dementia subjects	To explore whether music, live or pre-recorded, is effective in the treatment of apathy in subjects with moderate to severe dementia	Observational	Type: group Length: 30 minutes of live music, background music and silence Frequency: once Duration: once Facilitated by: external researcher Music chosen by: the facilitator Assessment: every 3 minutes during the 90 minute session.	32	Apathy Dementia Care Mapping observational tool	Live music had a significant effect on positive engagement compared with background music & silence groups $P < 0.05$. Pre-recorded music did not have a significant effect on positive engagement $P > 0.1$	Live interactive music increases positive engagement. Pre-recorded music is less beneficial. The focus was on cause and effect of intervention. Did not involve care home staff or consider their perspective of use in practice. Did not address practical considerations of providing live group music	No use of theory was detected	+/+

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Sherratt et al (2004)	Emotional and behavioural responses to music in people with dementia: an observational study	To examine the impact of social interaction in music listening on behavioural responses of people with moderate-to-severe dementia	Observational	Type: not given Length: not given Frequency: not given Duration: 3 months Facilitated by: external researcher Music chosen: live music VS taped commercial music VS taped musician VS no music Assessment: one hour per music type	24	Social interaction measured by engagement, well-being & behaviour. CTS – continuous time sampling based on DCM codes	Significant increase in levels of engagement $P < 0.01$, interaction $P < 0.01$, extreme well-being $P < 0.05$	Responses were greatest during the live music. Live music increased engagement and well-being. The focus was on cause and effect of intervention. Did not involve care home staff or consider their perspective on use in practice – they did acknowledge it was important to address this.	Kitwood's PCC was proposed as a framework. However, they did not explicitly link results/ discussion with PCC. Use of language also not PCC i.e. challenging behaviours	+/-

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Norberg et al (2003)	Reactions to music, touch and object presentation in the final stage of dementia: an exploratory study	To compare reactions to three kinds of stimulation, music, touch and object presentation	Intervention	<p>Type: individual</p> <p>Length: 90 minutes</p> <p>Frequency: once or twice a day</p> <p>Duration: not given</p> <p>Facilitated by: external researcher</p> <p>Music chosen: according to participants preferences, relatives as proxies</p> <p>Assessment: participants were observed for 15 seconds, then record reactions for 15 seconds and so on.</p>	2	Reactions Observation of Emotional reactions	<p>Significant change in blinking $P < 0.000$ & mouth movements to music than touch $P < 0.000$ or object presentation $P < 0.001$.</p> <p>Significant decrease in verbal reaction with music than touch $P < 0.003$; objects $P < 0.001$.</p> <p>Significant increase in pulse following music $P = 0.035$</p>	Both patients reacted differently to music than to touch and object presentation. The focus was on cause and effect of intervention. Did not involve care home staff or consider their perspective of use in practice. Did not consider music, or object presentation in practice.	No use of theory was detected	+/-

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Gottell et al (2003)	Influence of Caregiver Singing and Background Music on Posture, Movement, and Sensory Awareness in Dementia Care	To illuminate the posture, body movements, and sensory awareness of patients with dementia during three types of morning care sessions with professional caregivers (background VS caregiving VS no music)	Qualitative	<p>Type: individual during morning care</p> <p>Length: 6-22 minutes</p> <p>Frequency: varied</p> <p>Duration: average of 13 days</p> <p>Facilitated by: staff who work in the care home</p> <p>Music chosen by: researcher based on familiar music (not individualised)</p> <p>Assessment: analysis of video post intervention</p>	9	<p>Positive movement & sensory awareness</p> <p>Content analysis</p>	<p>During usual care patients were slumped posture, sluggish, asymmetric motion. During background music & caregiver singing residents had a straightened posture, increased awareness. Residents regained skills. Caregiver singing was better at drawing out these capabilities.</p>	<p>Care home staff sang during personal care. They did not receive training nor were they required to sing specific songs. The study did not address the barriers associated with staff doing this day to day (i.e. if it would be feasible/ Transferrable). The study did not ask for the perspectives of staff. It focused on cause and effect of the intervention.</p>	No use of theory was detected	+/-

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Clair (1996)	The Effect of Singing on Alert Responses in Persons with Late Stage Dementia	To determine the effects of unaccompanied, live singing on alert responses in persons severely regressed with dementia.	Observational	Type: individual, in residents room Length: 30 minutes Frequency: everyday Duration: four sequential days Facilitated by: staff who work in the care home Music: familiar songs	26	Reactions Video analysis – observational scale looking for changes in movement, expression, vocalisations	More alert responses to carer singing compared with reading the newspaper and silence. Responses included: eye/head movements, changes in expressions. No significant difference between singing and reading. Responses increased over time.	People with very late stage dementia responded to both singing and reading. The focus was on cause and effect of intervention however. They did not involve care home staff or consider their perspective of use in practice. Did not consider how to provide music, or reading in practice	No use of theory was detected	+/-

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Kontos et al (2015)	Presence redefined: The reciprocal nature of engagement between elder-clowns and persons with dementia	To examine elder-clown practice and techniques with care home residents with moderate to severe dementia	Qualitative interviews and ethnographic observations	Type: individual in residents' rooms Length: ten minutes Frequency: twice weekly Duration: twelve weeks Facilitated by professional clown Assessment: video recorded reflections, interviews	23	Nature of engagement, Content analysis of video tapes	Residents radiated joy and delight in response to interaction with elder clowns. Resident responded with smiles and strong eye contact which strengthened as the interaction went on. There was a clear state of mutual connectedness.	Elder clowns had a positive effect on residents living with advanced dementia. The focus was cause and effect. There was no focus on how elder clowns could be implemented in care homes more widely nor were there any staff perspectives about elder clowns	No explicit use of theory	+/+

Turn taking to form connections										
Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Astell and Ellis (2006)	The Social Function of Imitation in Severe Dementia	No clear aim	Case study	Type: individual, imitation/mirroring Length: 23mins, 35 mins Frequency: twice Duration: two days Facilitated by: external researcher Assessment: event coding	1	Social function and communication Frequency of communication , event coding	The patient was able to respond. Frequency of verbal/non verbal communication, emotion, eye gaze was significant	Imitation is an effective way to connect. However, is time intensive conducted by professionals, no consideration about use in practice.	If they used theory they are not explicit on how they applied it to this study	+/-

The use of physical objects to facilitate connections in residents with advanced dementia										
Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Joranson et al (2016)	Effects on Symptoms of Agitation and Depression in Persons With Dementia Participating in Robot-Assisted Activity: A Cluster- RCT	To examine effects on symptoms of agitation and depression in nursing home residents with moderate to severe dementia participating in a robot-assisted group activity with the robot seal Paro	Cluster RCT	Type: individual Length: 30 minutes Frequency: twice a week Duration: 12 weeks Facilitated by: staff working in the care home Assessment: quality of life scale assessed by nurses in the care home post intervention and 3 months later	53	Quality of life Quality of life in late stage dementia	Significant improvements from T0 to T2 in depression and agitation when comparing participants in the Paro group activity with the control group. No significant differences were found between the groups from T0 to T1	Paro might be a suitable nonpharmacological intervention. Did not consider effect on staff in this study, but suggested PARO may increase their attention on residents social needs. Did not consider the time or cost implications of this however, or how staff could incorporate in to their day. Little data on how much staff input dolls required.	No use of theory was detected	+/+

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Takayani et al, 2014	Comparison of verbal and emotional responses of elderly people with mild/moderate dementia and those with severe dementia to a seal robot (PARO)	To examine the differences in verbal and emotional responses to a baby seal robot, PARO, of elderly people with dementia residing at an elderly nursing care facility	Cross over Intervention study	<p>Type: individual – paro seal VS stuffed lion</p> <p>Length: not given</p> <p>Frequency: not given</p> <p>Duration: six months</p> <p>Facilitated by: staff working in the care home</p> <p>Assessment: time sampling methods was used. The behaviour of the residents was recorded. Analysis of video's was done post intervention</p>	6	<p>Positive expression</p> <p>Behavioural observation: emotional expression, mood and laughing</p>	Significant increase in: talking to PARO/Lion P<0.05, positive expression P=<0.05. Higher level of neutral expression in lion P=<0.05	Residents with AD had higher frequency of neutral expression to Lion than PARO. This means they were more interested in PARO, not in the Lion. Could act as a vehicle to facilitate connections. Did not consider the time or cost implications of this however, or how staff could incorporate in to their day. Little data on how much staff input dolls required. Little data on how much staff input dolls required	No use of theory was detected	+/+

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Moyle et al (2013)	Exploring the effect of companion robots on emotional expression in older adults with dementia: a pilot RCT	To compare the effect of companion robots (PARO) to participation in an interactive reading group on emotions in people living with moderate to severe dementia in a residential care setting.	Pilot RCT	Type: Paro seal VS interactive reading Length: 45 minutes Frequency: three times a week Duration: five weeks Facilitated by: external therapists Assessment: baseline, mid point & 5 weeks after the first intervention. Three week wash out period then the same process again for the other intervention	18	Emotional response & social interaction QOL-AD RAID (anxiety in dem) AES (apathy evaluation scale). GDS (geriatric depression scale)	Due to missing data- clinical significance was sought rather than statistical using standardised difference in means. PARO seal had moderate-large effect on QOL-AD, small-moderate effect on anxiety.	The PARO intervention group had higher pleasure scores when compared to the reading group. Findings suggest PARO may be useful as a treatment option for people with dementia. Did not consider the time or cost implications of this however, or how staff could incorporate in to their day. Little data on how much staff input dolls required.	No use of theory was detected	+/-

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Soler et al (2015)	Social Robots in Advanced Dementia	To test the effect of introducing a humanoid robot (NAO), a pet robot (PARO) and a real trained animal (DOG) in the therapeutic sessions for patients with dementia in relation to behavior changes, apathy and quality of life.	Intervention cross over study	Type: individual by a therapist Length: 30/40 minutes Frequency: 2 days per week Duration: 3 weeks Facilitated by: external researcher Assessment: validated observational scales	110	Emotional and behavioural response. The global deterioration scale, MMSE, Neuropsychiatric inventory, Quality of life in late stage dementia	A significant decrease was in NPI apathy and irritability in phase 1. There were no significant changes were observed at follow up.	Humanoid robots and paroseals may be an effective way to connect with residents with AD. The study did not consider the staffs perspectives on this nor time or cost implications of this however, or how staff could incorporate in to their day. Little data on how much staff input dolls required	No use of theory was detected	+/+

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Braden et al (2014)	Implementation of a baby doll therapy protocol for people with dementia: Innovative practice	To evaluate the implementation of the non-invasive evidence-based intervention of baby doll therapy on individuals with dementia	Intervention study	Type: not given Length: not given Frequency: not given Duration: one week Facilitated by: staff working in the care home Assessment: interaction was observed for the first ten minutes, then one week after introduction of the doll..	16	Behaviour, activity, liveliness, interaction, agitation, happiness Baby doll therapy evaluation tool, Engagement Observation rating tool	Significant increase in happiness P=0.01 Qualitative data was positive increased happiness, less anxiety	Baby doll therapy is an effective nonpharmacological approach for improving the well-being of some residents. Staff perspectives not sought, even though they completed the measures. Little data on how much staff input dolls required	No use of theory was detected	+/-

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Pezzati et al (2014)	Can Doll therapy preserve or promote attachment in people with cognitive, behavioural, and emotional problems? A pilot study in institutionalized patients with dementia	Can Doll therapy preserve or promote attachment in people with cognitive, behavioural, and emotional problems?	Intervention – pre-post test	Type: individual Length: not given Frequency: ten non consecutive sessions Duration: 30 days Facilitated by: staff working in the care home Assessment: video analysis following intervention	10	Behaviour and emotion	Participants who received doll therapy were significantly more connected than the control group, characterised by eye gaze. Participants in the experimental group also appeared to explore areas of the doll, moving it around. No other significant findings were reported.	The use of Doll therapy promotes clinically significant improvements in the ability to relate with the surrounding world. This may be important for managing and caring for patients with dementia in institutionalized context.	Reference to Bowlby's theory of attachment	+/-

The use of massage to connect with residents with advanced dementia										
Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Moyle et al (2014)	Foot massage versus quiet presence on agitation and mood in people with dementia: An RCT	To compare the effect of foot massage and quiet presence on agitation and mood in people with dementia	RCT	Type: individual Length: five minute massage on each foot Frequency: five times a week Duration: six weeks Facilitated by: trained massage therapist Assessment: baseline and after the intervention	55	Mood and agitation. Cohen-Mansfield Agitation Inventory Observed emotional rating scale	Agitation significantly increased in both groups P=0.03. No significant changes to mood	Foot massage did not improve mood, only agitation. The person giving massages was a professional therapist, rather than staff, they acknowledged this may have been the problem, also the set times of the massage rather than in response to individual needs. They did not ask staff perspectives or the feasibility of them giving massages in practice.	No use of theory was detected	+/+

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Skovdahl et al, 2007	Tactile stimulation associated with nursing care to individuals with dementia showing aggressive or restless tendencies: an intervention study in dementia care.	To describe from documentation both the caregivers' experiences of giving tactile stimulation with moderate-to-severe dementia and who showed aggressive or restless tendencies, and the changes seen in them.	Qualitative	Type: individual, in residents own room Length: once per day, 20-60 minutes per session Duration: 28 weeks Facilitated by: staff working in the care home Assessment: care givers documentation and field notes	5	Behaviour (but the qualitative nature of the study, made findings relevant to this review)	Tactile massage was positive with residents showing signs of relaxation. Caregivers stated that in general they could interact with the residents in a more positive way, and felt that they had a warmer relationship with them. Some of the caregivers described that they felt a 'closer closeness' to the residents during the tactile stimulation sessions	Tactile massage could be a value way of connecting with residents who are unable to verbally communicate, the non-verbal communication may give a warmer relationship. Staff enjoyed it. However, little emphasis on how feasible it would be to incorporate in to day t day work	No use of theory was detected	+/-

Connecting with people with dementia through the senses										
Sanchez et al (2015)	Multisensory Stimulation for Elderly Patients With Severe Dementia: A Pilot RCT		Pilot RCT	<p>Type: group 1 - snoezelen room group 2 - 1:1 activity sessions looking at photos, playing games according to hobbies using a directive approach Group 3 -control</p> <p>Length: 30 minutes (both groups) Frequency: twice per week Duration: 16 weeks Facilitated by: external researcher Assessment: behaviour, mood assessed at baseline (week 0), mid trial (week 8) and post trial (week 16), follow up (week 24).</p>	27	Behaviour, Mood Cohen-Mansfield Agitation Inventory (CMAI), Neuro-psychiatric inventory (NPI), Cornell scale for depression (CSDD) to assess mood.	Multi-sensory group showed a significant improvement in NPI scores $P < .005$, Agitation at weeks 8 & 16 $P = .003$ compared with the activity group. Agitation worsened by week 24 (8 weeks after the intervention) $P = .002$. No significant effect on mood was found in any of the groups.	Both MSSE and activity groups showed an improvement during the intervention. The focus was on cause and effect of intervention however. They did not involve care home staff or consider their perspective of use in practice.	Alluded to the Model of Imbalance in Sensor stasis (MIS) but did not say if or how it underpinned the intervention	+/+

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Sposito et al (2017)	Effects of multisensory and motor stimulation on the behavior of people with dementia	To examine the effects of a PCC–MSS and MS program on residents' behavior during morning care	Quasi-experimental study using a pre–posttest design	<p>Type: Motor and Multi sensory stimulation individually during morning care</p> <p>Length: not given</p> <p>Frequency: every morning</p> <p>Duration: 2-3 weeks</p> <p>Facilitated by: staff working in the care home</p> <p>Assessment: video recordings of morning care routine. Frequency of behaviours.</p>	45	Behaviour – motor interaction (eye contact) mood, expression (laughter, anger) & verbal communication	The frequency of engagement in task decreased significantly (p 002). Duration increased (p=.039). Duration of gaze directed at direct care workers improved significantly (p=.014) and the frequency of closed eyes decreased (p=.046)	PCC–MSS and MS programs as they may stimulate connections. Care staff were PCC trained to do this during morning care. They found it useful, reduced levels of burnout, improved knowledge about dementia, enhanced feelings of being worthwhile, improved group cohesion, emotional management, and self-awareness. No consideration of how to implement it.	They indicate they used PCC to underpin their MSS intervention i.e. MSS is based on residents preferences , rather than random.	+/+

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Hutson et al (2014)	Sonas: a pilot study investigating the effectiveness of an intervention for people with moderate to severe dementia	To investigate the feasibility and effectiveness of Sonas, a group intervention involving multisensory stimulation, reminiscence, and light physical activity	Pilot RCT	Type: Sonas (group) VS usual care Length: 45mins to an hour Frequency: twice per week Duration: seven weeks Facilitated by: staff working in the care home Assessment: pre and post testing - 1 week before and 1 week after intervention	39	Depression, Anxiety, Behavioural disturbances, communication and quality of life. Rating anxiety in dementia (RAID), Cornell scale for dementia (CSDD), Neuro psychiatric inventory (NPI), Quality of life alzheimer's disease (QOL-AD), the holden scale	No significant results were found in any of the outcome measures.	The results of this study do not suggest that Sonas has any therapeutic benefit. The focus was on cause and effect of intervention however. They did not involve care home staff or consider their perspective of use in practice. Did not address contextual considerations.	No explicit use of theory	+/-

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Matern e et al (2014)	Increasing constructive engagement and positive affect for residents with severe and very severe dementia through group-based activities	A group-based multisensory activity program (Sensory Day) for residents with dementia was developed, to address the challenge of providing personalised activities.	Intervention study	Type: group sessions Length: 45 minutes Frequency: monthly Duration: four months Facilitated by: staff working in the care home Assessment: pre and post intervention	14	Levels of mood and engagement. Philadelphia geriatric affect rating scale for mood and Menorah Park Rating scale for levels of engagement	Significant increase in levels of constructive engagement P=<0.001 large effect r=0.62 Significant positive mood P=<0.001 large effect r=0.62.	The findings demonstrate that it is possible to engage residents with (very) severe dementia in group-based activities. They acknowledged it would be valuable to have input from staff on their views of this approach about feasibility in practice.	No use of theory detected	+/-

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Cruz et al (2013)	Making sense(s) in dementia: a multi sensory and motor based group activity program	To develop a MSS and motor-based group activity program for residents with dementia and assess its impact on residents' behaviour.	Intervention – pre and post test	Type: individual Length: 45 minute session Frequency: weekly Duration: 16 weeks Facilitated by: physical therapist and a gerontologist Assessment: pre and post intervention	4	Behaviour – engagement, interaction, communication , expression. Behaviour categories of Ethogram Video recordings	No statistically significant results $P > 0.5$	The study was not able to demonstrate effectiveness of the intervention. Care home staff were not involved in any part of the intervention. Its implementation in practice was not considered. No staff views were sought	No use of theory detected	+/+

The use of the NAMASTE program for connecting with residents with advanced dementia										
Stacpol e et al (2015)	The Namaste Care programme can reduce behavioural symptoms in care home residents with advanced dementia	To evaluate the effects of Namaste care programme on the behavioural symptoms of residents with advanced dementia in care homes	Action Research	Type: individual Length: 2 x 2hr sessions Frequency: every day, morning and afternoon Duration: two months Facilitated by: staff working in the care home Assessment: baseline and at three 1-2 monthly intervals after Namaste care started	37	Doloplus-2 behavioural pain assessment scale for the elderly	After the introduction of the intervention both neuropsychiatric symptom severity and occupational disruptiveness significantly decreased P=.001 in 4 homes, but increased in 1	Where there is strong leadership, adequate staffing and good nursing and medical care, Namaste can improve QOL for people by decreasing behavioural symptoms. Namaste is not a substitute for good clinical care	The Namaste programme is underpinne d by the theory of PCC	+/-

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Stacpol e et al (2017)	Implementing the Namaste care programme for residents with advanced dementia exploring the perceptions of families and staff in UK homes	To report the effect of the programme on the families of people with advanced dementia and care home staff, and presenting their perceptions of change in care	Qualitative interviews from an action research study Focus groups, interviews	Type: individual Length: 2 x 2hr sessions Frequency: every day, morning and afternoon Duration: 2 months Facilitated by: staff working in the care home Assessment: baseline and at three 1-2 monthly intervals after Namaste care started	5 CH	Experiences of Namaste	The program was welcomed by care home staff and families, and was achieved with only modest expenditure and no change in staffing levels. The positive impact on quality of life influenced the well-being of family carers. Care staff found the changes in care enjoyable and rewarding	Namaste was a way for staff and residents 'to reach out to each other'. The theme of connection, re-connection and shared humanity was considered the foundation of the relationship- Many care staff talked about the emotional significance and power of touch. Namaste gave people permission to touch residents that seemed to be a catalyst for change	Person Centred Dementia Care	+/-

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Magee et al (2017)	Feasibility to the Namaste care programme to enhance care for those with advanced dementia	To apply NAMASTE and to an Irish setting	Service evaluation – focus groups had interesting insights	N/A	9	Care staff experiences of providing NAMASTE care	Staff learned more about the residents as people, more aware of the needs of residents as they changed.	NAMASTE seemed feasible for staff, residents and family. Staff struggled with 2 sessions per day to reduced it to 1. Support is needed by facilitators to support staff. Leadership is important, manager must cascade important information. Whilst committed staff felt they had other duties.	The NAMASTE program is underpinned by the theory of PCC	-/-

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
McNeil and Westphal et al (2016)	Namaste Care™: A Person-Centered Care Approach for Alzheimer's and Advanced Dementia	To explore the experiences of residents, staff, and family involved in the Namaste Care™ program at a long-term care facility in the United States	Qualitative	N/A	14	Care staff experiences of providing NAMASTE care	6 themes emerged including NAMASTE as providing: a peaceful sanctuary, allowing staff to relate to residents, transforming experiences, increasing connections and community, creating positive moments and awakening staff to possibilities.	Results suggest that Namaste Care™ may be useful for individuals no longer able to participate in traditional long-term care setting activities. Staff responded well, said they felt like part of a team, that there was a culture change in the organisation. Little emphasis on how NAMASTE can be implemented however.	The NAMASTE program is underpinned by the theory of PCC	+/+

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Nicholls et al (2013)	Touch, the essence of caring for people with end stage dementia: a mental health perspective in NAMASTE care.	To improve the delivery of palliative care for people with advanced dementia, to increase the knowledge and skills of care staff and enhance communication between staff and residents	Qualitative	N/A	31	Care staff experiences of providing NAMASTE care. Focus groups, semi structured interviews Thematic analysis	NAMASTE program evoked the act of touch. 2 broad themes were revealed: touch by others and touch by the person. The outcome is reciprocal connectedness & awareness	Touch for people at the end stage of dementia is important, NAMASTE can provide a vehicle for this. Staff found this rewarding. The focus was on cause and effect of intervention however. Did not address contextual considerations of implementation	The NAMASTE program is underpinned by the theory of PCC	+/-

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Simard et al (2010)	Effects of Namaste Care on Residents Who Do Not Benefit From Usual Activities	Examine the effects of Namaste Care on Residents Who Do Not Benefit From Usual Activities	Intervention	Type: individual Length: 5 hours per day Frequency: everyday Duration: 30 days Facilitated by: staff working in the care home Assessment: baseline and 30 days	86	Mood, Behaviour MDS cognitive performance scale, MDS depression rating scale, MDS challenging behaviour scale	Decrease in delirium (excluding restlessness & lethargy) $P < 0.02$ Remaining measures not significant	Namaste Care program is beneficial for individuals with advanced dementia. Care home staff are trained. It was suggested NAMASTE helped staff to provide quality care. The focus was on cause and effect of intervention however. They did not ask care home staff their perspective. Did not address contextual considerations of implementation.	The NAMASTE program is underpinned by the theory of PCC	+/-

Connections through day to day care										
Watson et al (2016)	Developing the Senses Framework to support relationship-centred care for people with advanced dementia until the end of life in care homes	To examine the role of embodied and inter-embodied selfhood within care-giving/ care-receiving relationships	Ethnography	Type: individual Length: 207 hours Frequency: twice weekly Duration: 9 months Assessment: interviews and observations	53	Embodied and inter-embodied selfhood within care-giving/ care-receiving relationships	Three overarching themes were identified as important: hands on/body work, recognising and supporting selfhood, witnessing and responding to distress.	Using the body as an analytical lens, this study showed PWD continued to be fully present in interactions until EOL. Care home staff experience is important for helping us learn how to interact	Relationship centred care	++

Author	Title	Aim	Methods	Intervention design	Sample	Primary outcome/ outcome measure	Results	Discussion/ Interpretation	Use of theory to underpin intervention	Quality
Ericsson et al (2011)	Creating relationships with persons with moderate to severe dementia	To describe how relationships are created with persons with moderate to severe dementia.	Grounded Theory – interviews and observation	Type: individual Length: 20-61 minutes Frequency: not specified Duration: 24 sessions Assessment: relational time observations, interviews	9	Relationships	Opening up, assigning time, establishing trust and communicating equality were interrelating factors identified important to establish a relationship with the person with dementia	Both parties had to contribute to create a relationship; the professional caregiver controlled the process, but the person with dementia permitted the caregiver's overtures and opened up, thus making the relationship possible. Interpersonal relationships are significant to enhancing the well-being of persons with dementia	Grounded Theory	++

Appendix 3: Nursing Home Invitation Letter



Miss Kirsty Haunch
PhD Student
The School of Dementia Studies
Faculty of Health Studies
University of Bradford
Richmond Road
Bradford
BD7 1DP

Professor Murna Downs
Head of School
The School of Dementia
Faculty of Health Studies
University of Bradford
Richmond Road
Bradford
BD7 1DP

Dear

My name is Kirsty Haunch; I am a PhD student at the University of Bradford and I would like to invite you to take part in a research project. The aim of the project is to find what helps and what prevents the social inclusion of residents (with advanced dementia) who find it difficult to verbally communicate.

You have been invited to take part in this project as your organisation provides care for residents (with advanced dementia) who have difficulty in verbally communicating. If you would like to be involved I will visit your nursing home and speak with members of staff, relatives of residents (with advanced dementia) and residents living alongside residents (with advanced dementia) about what helps and what prevents social inclusion.

I plan to use the information to share good practice with other nursing homes in the UK to improve practice. I anticipate that it will take approximately three weeks to collect this information. This is flexible and will depend on your availability and the availability of your staff.

If you are interested and would like further information please contact me using the details below

Kirsty Haunch

PhD Student

Tel: *****

khaunch@student.bradford.ac.uk

Appendix 4: Nursing Home Consent Form



Nursing Home Consent Form

Barriers and facilitators of socially inclusive practice for nursing home residents living with advanced dementia.

	Please Initial
We confirm we have read and understood the information sheet provided and any questions we had have been answered.	<input type="checkbox"/>
We understand that taking part is voluntary and that we are free to withdraw at any time, without giving a reason	<input type="checkbox"/>
We agree to identify a lead person who will take an active role in supporting the research.	<input type="checkbox"/>
We agree to provide support in approaching and speaking to residents, relatives and staff	<input type="checkbox"/>
We agree to staff taking part in informal interviews or discussion groups.	<input type="checkbox"/>
We I agree to take part in the project	<input type="checkbox"/>

_____	_____	_____
Name of participant	Date	Signature

_____	_____	_____
Name of researcher	Date	Signature

Appendix 5: Reflexive Diary

Throughout the interviewing process, I was aware that nursing home staff and relatives found it difficult to articulate how they connected with residents with advanced dementia. In the beginning, I thought that this was due to my inexperience and the fact I am early in my research career. While this was, in part true, there were some issues around terminology and the way nursing home staff were able to articulate what they did. Towards the latter end of the interviewing process I found that staff often took their skills for granted. I continually reviewed my terminology, under guidance from nursing home staff in an iterative process to ensure the main and sub categories were valid. I kept a reflective diary throughout the process to keep track of iterations and produced a clear audit trail. This account provides evidence of that.

Initial interviews

Reflecting on the initial interview, I realised I did not feel fully prepared for the task and required further support. Regular supervision, sometimes weekly, enabled me to get advice about how to make the most of interviewing. I learned techniques and sought independent advice on how to maximise responses from participants. One particular challenge was bringing participants back to topic if they drifted off. This was a skill that I developed over time throughout the project. One of the caveats in doing Grounded Theory is to let the participant guide the interview (to an extent), so identifying what was relevant and what was not was unclear at some points. As a result, participants did go off on tangents and I had to keep up. Doing this enabled me to identify issues important to them, a key aim of this study. The following are memos recorded following the initial interview.

MEMO 2.6.16

In the initial interview I struggled somewhat. I had never interviewed before and found it quite challenging having such few questions to ask. While I am aware this is part of the Grounded Theory method, it was a new experience for me and as much as I had tried to plan in advance, I had no idea what the participant was going to say and how I would respond. This made me feel uneasy and I think it showed in my initial interview data.

MEMO 8.6.16

After analysing the first interview and discussing it with my supervisors, we agreed I was going off course somewhat. I was asking leading questions, I was asking many closed questions and often not giving the participants' time to respond. I think this was down to nerves and inexperience. I have read

lots of books about the best way to interview but found it difficult to apply in practice. The data I have collected so far are similar to existing literature. On reflection I can see how my prior knowledge of existing literature has influenced the way I have asked questions in this project. For example, I was asking questions about training, leadership, nursing home culture. These questions are leading questions and will therefore introduce bias to my findings as I am planting ideas in participants' minds, rather than finding out their true experiences from their perspective.

In order to ensure my findings are credible and grounded in the views of participants I need to work on my interview technique. This means asking very open questions and sticking to the interview guide. So far I have tended to panic and talk too much. I have asked very general and broad questions rather than digging deep and asking for specific examples of things that have happened and what the person did and felt about those things. This 'scratching below the surface' is essential for critical realist approach. I was advised to look at the interviews again and focus only on what I was asking. This highlighted a number of pitfalls I was making for example we were talking about residents generally – *THEY* did this and *THEY* did that – rather than asking for specific instances. These specific examples are key to grounding the data.

What have I learned so far that will guide my next questions?

My initial questions included:

How do you include residents with advanced dementia?

What facilitates this inclusion?

What prevents this inclusion?

What advice would you give to a new member of staff?

Maybe it is about asking staff the following.....

When was the last time you included a resident with severe dementia?

What did you do?

What did they do?

Where was it?

How were you able to do it?

How did it make you feel?

What was going on at the time?

What needs to be in place?

What support did you have?

When was the last time you tried to include with a resident with severe dementia?

What happened?

What did you do?

What did they do?

How did they make you feel?

What stopped you?

What do you think needs to happen to help you?

What was going on at the time?

Where were you?

What support do you need?

These questions are more focused and will hopefully elicit grounded responses. After this coaching on interviewing and tips from supervisors I feel ready to do some more interviewing.

Despite honing my interviewing skills at an early stage, I found staff were still unable to articulate things well. In discussion with my supervisors I changed the terminology I was using to try and help. See memo excerpt below:

MEMO 10.7.16

I have just completed three interviews at NH01 and feel they went much better. This time I was more relaxed, I avoided closed questions as much as possible and tried to encourage participants to speak about specific instances rather than general instances.

I feel I still struggled to get specific examples however, particularly with the first two staff. After transcribing the interviews - I feel I could be clearer about what I am trying to find out. Staff did not respond openly to the word 'include' I am not sure if they knew what I meant or what I was trying to find out in the project. Perhaps I need to be clearer and ask 'what happened when you saw Mr X today? What did you do? What did they do? How did that make you feel? It is hard to get staff to talk about what they do. Is that because they don't know what they do or don't think about it or perhaps I need to change the word 'include' to something else?

MEMO 12.8.16

Following on from concerns in the last interview one participant today indicated my questions were too broad - she didn't know whether 'include' meant during personal care or social activities or both. She said she didn't do social activities and only saw residents during personal care, so was unsure whether my questions were applicable to her in her role. She felt that including residents in personal care was not possible as they were unable to do anything.

MEMO 5.9.16

On reflection my terminology might have been confusing to staff. Perhaps it is the language I am using – instead of the words: 'advanced dementia' and 'including' perhaps I should use 'connect with' residents who spend most of their time in bed and who are unresponsive?

From the data I have collected so far, staff have tended to give me examples of interaction/inclusion during personal care rather than any activity. Perhaps this is how it is or maybe the way I am asking the question is confusing? One staff member said to me 'include them in what?' Perhaps it is clear to staff but they are reluctant to talk about this group. It might be uncomfortable terrain for them to be in – if they feel inadequate in their job, if they have no examples of where they have made connections?

I will revise my wording to see if it helps emphasising the group I am interested in.

Discussions in supervision allowed me to reflect further and change the terminology I was using. I looked for clues in the literature and consulted a care home PPI group for ideas.

MEMO 20-9-16

The word 'connect' seems to resonate with staff. However, staff find it difficult to think of examples of where they have connected residents with advanced dementia. They keep suggesting the only time they see the residents in question is during personal care. I have found it difficult to get staff to talk about the resident group that I am interested in (people who spend a lot of time in bed, have trouble verbally communicating and often non-responsive). Instead staff have tended to give me examples of residents they have the most difficulty with i.e. agitated and aggressive residents along with the strategies they use to approach this. These residents are able to move around and verbally interact. Staff therefore often have a lot of interaction with them - whether it is good or bad and much less interaction with residents who spend most of their time in bed.

While the terminology resonated with staff and they understood what I was trying to find out, they generally struggled to articulate or think of examples of where they had connected with residents with advanced dementia. I felt many took for granted the work they did on a daily basis and tried to think of grand gestures or big events rather than subtle connections. It seemed that staff did not really think of subtle connections as significant.

MEMO 6.10.18

I am now being explicit about who it is I am interested in. At the beginning of the interview I am saying 'I am interesting in how you connect with residents who might have trouble verbally communicating and might find it difficult to get around on their own'. However, I am still experiencing the same difficulties. Two particular participants focused on residents with distressed reactions and residents who could communicate. Even when I asked again about the population I was interested in, I got no clear examples of connection. When I probed those participants they closed down and said 'I don't know' or 'I don't deal with those residents' or 'they are mainly in their bedrooms'

Perhaps this is something to do with the nursing home culture or the staff members themselves? S04 was a staff member in the same home. She also focused on mainly residents with distressed reactions residents who could communicate in her interview. When I probed however, she did give an example of a connection which was as a result of personal care and happened as part of a task.

MEMO 8.10.2016

Whilst I suggested staff find it difficult to describe what they do on a daily basis and seem to be struggling to think of examples, on reflection, I have got some great examples of connections, they just don't see them as such. For example eye contact and smiles are some of examples of connections I have received, they are just not grand gestures. It feels like staff take for granted the advanced skills they use on a daily basis. I am trying to make staff feel at ease and not on put them on the spot and highlight some of the more subtle ways connections can occur.

MEMO 10.11.2016

After doing some open coding coding and discussing my initial codes with supervisors, we agreed that while I have coded a number of interesting codes, they might not all be relevant. We thought about changing the terms we used again. I suggested I was looking for examples of meaningful connections

How staff meaningfully connect?

What facilitates these meaningful connections?

What prevents these meaningful connections?

I feel adding the word meaningful is important at this point and it is something that I will use in the next stage of my interviews. There was some confusion in the initial interviews about the words I was using i.e. how do you 'interact' and 'include' 'engage' with residents with AD. One member of staff said to me 'include in what' and the term interact often was met with examples of standard encounters i.e. I went in to her room and fed her. However, this is not a meaningful encounter – it could be but staff are not describing what if anything prevented it. I think by adding the word meaningfully, it might allow staff to think a little bit differently about what I am asking.

By asking myself this question - it has allowed me to look at the data from a different perspective.

With this new perspective I will revisit the data and look for examples of meaningful connections – I will then pick out what facilitated this and what prevented it. I will look for potentially meaningful connections and find out what prevented them.

The change in terminology appeared to help. Continuous regular discussion with supervisors really helped me hone down what I was trying to get out of the interviews.

MEMO 16/1/2017

I have just done two interviews. The first with two carers who work on a dementia unit. I found it tricky at first, but tried to probe and ask for specific examples of meaningful connection. I focused on personal care this time and asked what they did and how the residents responded.

I felt they understood what I was trying to find out and gave a few examples of meaningful connections. There were a lot of general statements about what they did with people with advanced dementia with fewer descriptive examples. A clear theme coming out is that 'knowing the person' is key to drawing them out. Connections are spontaneous, in the moment and cannot happen in any uniform or structured way. Sometimes it will work, sometimes it won't – it often depends on the residents and how they feel at the time. Having a vehicle (i.e. music, food etc) is useful for connection but they didn't use it routinely – one participant said that residents liked chocolate. When asked for an example she went through the steps –i.e. 'I went in, I did put music on, she got a glint in her eye and moved her head, I fed her chocolate, she ate it, I left'

I again got the impression most connections occurred during personal care, so in agreement with my supervisors I focused on asking what they did and what residents did during personal care. While I had to really probe to get examples, when they opened up staff were able to think of many more examples in this context. This guided the remainder of the interviewing process.

Appendix 6: Nursing Home Staff Participant Information Sheet



Staff Information Sheet

My name is Kirsty Haunch; I am a PhD student at the University of Bradford and I would like to invite you to take part in a research project. Before you decide whether to take part it is important that you understand why the research is being done and what the project will involve. Please take the time to read the following information and discuss it with colleagues if you wish. Please ask if there is anything that is not clear or if you would like more information.

Part 1 tells you the purpose of the project and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of this study.

Part 1

Social isolation is a common problem for people in nursing homes, especially those living with advanced dementia who find it difficult to verbally communicate. It is important we find out what helps staff to socially include those residents to ensure they do not become isolated.

Purpose

The purpose of this project is to find out what helps and what prevents nursing home staff from socially including residents (with advanced dementia) who find it difficult to verbally communicate.

Why have I been invited?

You have been invited to take part because you work in nursing home that provides care for people who find it difficult to verbally communicate.

Do I have to take part?

No, it is up to you whether you would like to take part. If you decide not to take part your employment rights will not be affected in any way. If you do, you will be given this information sheet to keep. You are free to withdraw at any time without giving a reason. You can ask for your contribution to be taken out anytime for up to 2 weeks after.

What will happen to me if I take part?

I will meet with you privately at the nursing home at a time that suits you. I will ask you for your verbal and written consent to take part; I will then ask what helps and what prevents you from socially including people (with advanced dementia) who find it difficult to verbally communicate.

What do I have to do?

If you decide to take part you will be asked to take part in an informal discussion, either individually or group. This should take no longer than 30 minutes.

What are the possible disadvantages and risk of taking part?

We do not expect the interviews to be upsetting, but if taking part brings up any issues and you would like to talk about them, you can speak to myself or one of my supervisors: Professor Murna Downs (Head of the School of Dementia Studies) 01274 233991 or Professor Jan Oyebode (School of Dementia Studies) 01274 236330. You may also find it helpful to ring the Alzheimer's Society National Dementia Helpline on 0300 222 1122. The helpline is usually open from 9am – 5pm Monday – Saturday and Sunday 10am – 4pm.

What are the possible benefits of taking part?

There are no direct benefits for you. The aim of the project is to improve the quality of care for people living in nursing homes.

Will my taking part in the study be kept confidential?

All the information you give will remain confidential and you will not be identified in any report or publication.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Professor Murna Downs (Head of the School of Dementia Studies, and Principal Supervisor) 01274 233991 who will answer your questions. If you remain unhappy and wish to formally complain we will be happy to provide you with written contact details.

What will happen to the data gathered in the research study?

The data will be submitted as part of my PhD thesis. It will also be included in presentations to academic audiences and submitted for publication. If you would like a copy of the results please contact me on: 01723 342384 or by email khaunch@student.bradford.ac.uk.

Who is organising and funding the research?

The research is part of a PhD organised by the University of Bradford and funded by Bupa Care Homes.

Who has reviewed the study?

All research projects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by the University of Bradford Ethics Committee.

Appendix 7: Nursing Home Staff Consent Form



Barriers and facilitators of socially inclusive practice for nursing home residents living with advanced dementia.

Please Initial

I confirm I have read and understood the information sheet provided and any questions I had have been answered

I understand that taking part is voluntary and that I am free to withdraw at any time, without giving a reason, and my employment status will not be affected

I agree to take part in informal interviews or a discussion Group.

I agree for the interview or discussion to be audio recorded

I agree to take part in the study

Name of participant

Date

Signature

Name of researcher

Date

Signature

Appendix 8: Relative Information Sheet



Relatives Information Sheet

My name is Kirsty Haunch; I am a PhD student at the University of Bradford and I would like to invite you to take part in a research project. Before you decide whether to take part it is important that you understand why the research is being done and what the project will involve. Please take the time to read the following information carefully and discuss it with colleagues if you wish. Please ask if there is anything that is not clear or if you would like more information.

Part 1 tells you the purpose of the project and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of this study.

Part 1

Social isolation is a common problem for people in nursing homes, especially those living with advanced dementia who find it difficult to verbally communicate. It is important we find out what helps staff to socially include those residents to ensure they do not become isolated.

Purpose

The purpose of this project is to find out what helps and what prevents the social inclusion of residents (with advanced dementia) who find it difficult to verbally communicate.

Why have I been invited?

You have been invited to take part because you have a relative that lives in a nursing home.

Do I have to take part?

No, it is up to you whether you would like to take part. If you decide not to take part the care of your relative will not be affected in any way. If you do, you will be given this information sheet to keep. You are free to withdraw at

any time without giving a reason. You can ask for your contribution to be taken out anytime for up to 2 weeks after.

What will happen to me if I take part?

I will meet with you privately at the nursing home at a time that suits you. I will ask you for your verbal and written consent to take part; I will then ask what helps and what prevents the social inclusion of residents (with advanced dementia), who find it difficult to verbally communicate.

What do I have to do?

If you decide to take part you will be asked to take part in an informal discussion, either individually or group. This should take no longer than 30 minutes.

What are the possible disadvantages and risk of taking part?

We do not expect the interviews to be upsetting, but if taking part brings up any issues and you would like to talk about them, you can speak to myself or one of my supervisors: Professor Murna Downs (Head of the School of Dementia Studies) 01274 233991 or Professor Jan Oyebode (School of Dementia Studies) 01274 236330. You may also find it helpful to ring the Alzheimer's Society National Dementia Helpline on 0300 222 1122. The helpline is usually open from 9am – 5pm Monday – Saturday and Sunday 10am – 4pm.

What are the possible benefits of taking part?

There are no direct benefits for you. The aim of the project is to improve the quality of care for people living in nursing homes.

Will my taking part in the study be kept confidential?

All the information you give will remain confidential and you will not be identified in any report or publication.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Professor Murna Downs (Head of the School of Dementia Studies, and Principal Supervisor) 01274 233991 who will answer your questions. If you remain unhappy and wish to formally complain we will be happy to provide you with written contact details.

What will happen to the data gathered in the research study?

The data will be submitted as part of my PhD thesis. It will also be included in presentations to academic audiences and submitted for publication. If you

would like a copy of the results please contact me on: 01723 342384 or by email khaunch@student.bradford.ac.uk.

Who is organising and funding the research?

The research is part of a PhD organised by the University of Bradford and funded by Bupa Care Homes.

Who has reviewed the study?

All research projects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by the University of Bradford Ethics Committee.

You will be given a copy of the information sheet and a signed copy of the consent form to keep. Thank you for considering taking part, or taking the time to read this sheet.

Appendix 9: Relative Consent Form



Relatives Consent Form

Barriers and facilitators of socially inclusive practice for nursing home residents living with advanced dementia.

Please Initial

I confirm I have read and understood the information sheet provided and any questions I had have been answered.

I understand that taking part is voluntary and that I am free to withdraw at any time, without giving a reason, and the care of my relative will not be affected

I agree to take part in an informal interview or a discussion group

I agree for the interview or discussion to be audio recorded

I agree to take part in the study

Name of participant

Date

Signature

Name of researcher

Date

Signature

Appendix 10: Phase 1 Interview Guide

Introduction

I will:

Introduce myself as the researcher and explain the goal of the interview which is to find out what helps and what prevents nursing home staff from socially including residents (with advanced dementia) who have difficulty in verbally communicating.

Explain I am interested to hear participant's thoughts, views and feelings about what they think are important issues.

Advise that the session will be recorded, but no names will be used in the final report and only people directly involved in the research will listen to the tape.

Ask participant's to introduce themselves for the tape.

Process

For each question I will attempt to probe for specific examples i.e. 'can you give me an example of when...?'

Other probe questions will include:

Are you able to explain further please?

Can you tell me about a time when?

Is there anything else?

Please can you describe what you mean?

What do you think about that?

How does that make you feel?

Topic Guide

In what ways do you socially include residents (with advanced dementia) who find it difficult to verbally communicate? Prompt regarding: the use of music; dancing; massage; touch; aromatherapy; pets, dolls

What helps you to use such approaches?

What prevents you from using these approaches?

Do you have any concerns about using any of the approaches we have discussed?

If you could give one piece of advice about what helps you to socially include people (with advanced dementia) what would it be?

Appendix 11: Phase 2 Interview Guide

Lessons learned:

What I have learned so far that will guide my next questions

Staff find it difficult to think of examples of where they have included residents with severe dementia. On reflection my terminology might have been confusing to staff. From the data I have collected so far, staff have tended to give me examples of interaction/inclusion during personal care rather than any activity. Perhaps the way I am asking the question is confusing, maybe they thought they should be doing something that they aren't. They might be getting confused between personal care and social activities. One staff member said to me 'include them in what'

My initial questions included:

How do you include residents with severe dementia

What facilitates this inclusion

What prevents this inclusion

What advice would you give to a new member of staff

Maybe it is about asking staff the following.....

When was the last time you connected with a resident with advanced dementia?

What did you do?

What did they do?

Where was it?

How were you able to do it?

How did it make you feel?

What was going on at the time?

What needs to be in place

What support did you have?

When was the last time you tried to connect with a resident with advanced dementia?

What happened?

What did you do?

What did they do?

How did they make you feel?

What stopped you?

What do you think needs to happen to help you?

What was going on at the time?

Where were you?

What support do you need?

These questions are more focused and will elicit grounded responses. They include context. Providing questions may be needed i.e..can you tell me a little bit more about that.

Appendix 12: Phase 3 Interview Guide

New things to consider:

Many care staff have told me that most of how they connect is during personal care. Perhaps making the most of time during that time is a key component. Some staff do it and some don't, the ones that make the most of time perhaps connect more. Keep this in mind in the next set of interviews and explore the issue of 'time' going forward pay attention to:

When do connections occur?

What happens during personal care?

How much emphasis is placed on connections?

How they feel about the time they have available to do it?

Do they feel they are allowed to use this time to connect?

For nurses and managers

How do care assistants connect?

How do you support them to connect?

What do you do?

Whose role do you feel it is?

What else can you offer?

Appendix 13: Phase 4 Interview Guide

Theoretically sampling – managers and supervisors

Question 1 - What contextual factors might prevent connections

Question 2 What contextuall factors might facilitate connections

Probing questions

- How do (managers/supervisors) think staff know how to connect?
- How do (managers/supervisors) think staff know what to do?
- What influences the time staff spend during personal care?
- What instructions are staff given about connecting with residents with AD?
- What motivates staff to want to connect?
- Are staff given training?
- Do connections happen regularly?
- What support are staff they provided

Appendix 14 Conditional relationship guide findings

Conditional relationship guide							
No	Category	What (collective definition based on codes using participants words to avoid bias)	When (during what process)	Where (in what setting)	Why (because)	How (by what means)	Consequence (with what result)
1	Caring qualities	<p>Caring qualities such as: empathy, kindness led to connections:</p> <p>“A heart full of kindness”, “Putting yourself in their shoes” “Empathy”, “Passionate”, “I am that type of person”, “I am a big softy”, “it is all about caring”, “if it was me I would want people to be nice”, “I help out where I can”, “the nurse told me how to do it”</p>	<p>During interactions with residents, staff and family i.e. during personal care, formal and informal meetings, at times of pressure, at times of disagreement, at times of distress, at times where residents are not responding .</p>	<p>In all settings i.e.: residents’ bedrooms, bathroom during personal care or social interactions. With staff in team meetings, informal chats, inside and outside of working hours</p>	<p>Because caring is part of you, because it is an expectation from resident, family, co-workers, manager, the organisation and society. It is the right thing to do. Being caring and helping other provides staff with motivation (getting a buzz, feeling good)</p>	<p>Being helpful, caring, going the extra mile, above and beyond what is expected. Staying late, pitching in, being patient, being open to learning to new ideas, listening, putting self in to other people’s shoes.</p>	<p>Enhanced communication, reciprocation from residents and staff in terms of gratitude and thanks. Motivation of staff to make a difference and help each other</p>

2	Using strategies	Thinking about/trying different approaches to connect. For example: using humour, singing, using physical objects, massage, doing the little things	Spending time with residents, brainstorming individually and as a team, collaboration with family, less pressurised environments, high staffing levels, when residents are not responsive.	On the job during interactions and informal chats, also during team meetings, training, supervision	Because it is expected, the staff member believes it is part of their role to connect. To problem solve, because they feel it is important (motivation). To meet CQC regulation.	Making time, staying on top of things, Having skills, knowledge, confidence, being given the opportunity within daily tasks, observing and assessing residents, knowing the persons likes/dislikes, being patience, persevering, trial and error.	Staff member gains new knowledge, expertise of individual resident's needs. Reciprocation, connection, shared moments – motivation to try again.
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3	Understanding advanced dementia	Understanding the impact of advanced dementia: "Knowing everybody is different at different times on different days"	During induction, training, one to ones, mentoring, supervision, reflection, learning from other health care professionals.	In a learning environment, team meetings, courses off site, supervision. Also learning on the job on the nursing home floor, during interactions with residents, informal chats.	Expectation from the organisation, more practical experience, more training, life experience, previous experience, age difference, tacit knowledge.	By being open to learning, having the right attitudes, listening, asking questions, reflecting on own experiences, asking others. Takes time, different approaches	Provides staff with capability (play it by ear), motivation to behave in ways to promote connection, open to new ideas, training, helping others. Respect for people with dementia. Perseverance, awareness, recognition.
4	Accepting, tolerating, understanding dementia	Care staffs thoughts about dementia - "I don't have bad experiences, only good experiences"	During induction, staff meetings, informal chats with other staff and health care professionals, supervision, one-ones, sharing of ideas, collaboration	In a person centred environment which puts the person at the heart. In meetings, supervision where staff are clear about their role, inside and outside of work. On the job when they experience good reactions/reciprocation from residents. Success story from co-workers	Because it is an expectation, more practical and life experience, level of knowledge and education. Because care staff are natural empathisers. They don't make assumptions. Team work is present, shared purpose, values.	Adequate training, adequate knowledge exchange, open communication, collegiality, influence of organisation/ manager, person centred environment	Open to new ideas, not giving up on communicating with residents. Acceptance there is not always a response, tolerating negative or no responses, respect for people living with dementia.

5	Using advanced communication skills	Using non-verbal techniques to connect with residents	During interactions with residents, usually during personal care. Less pressure, more staff, more support from superiors Observing other staff learning on the job.	In residents room Meetings formal, informal, supervision, reflection, mentoring	Because they have level of knowledge, skill and attitude required, it is expected, the staff member believes it is part of their role, to problem solve, they feel it is important, to ensure residents health does not deteriorate, to ensure QOL.	Taking the time, having patience, being efficient, having confidence, knowing the person, knowing your stuff. Practically by moving closer to the person, kind tone, gentle touch, speak slowing, notice subtle reactions,	Build a rapport, create a shared language, receive reciprocation
6	Interpreting reactions	“For me it’s about keeping an eye on facial expressions, their posture & them stiffening up on you – if they are not relaxed and not enjoying what you’re doing, you can tell”	During interactions, usually personal care Learning from other staff, problem solving, resolving issues	In personal care (residents room) social situations, informal chats, formal team meetings	Because they feel a sense of responsibility for resident’s health, they have level of knowledge, skills required, role clarity – is part of their role.	Having knowledge, reading between the lines, making judgements, confidence, competence, empathy.	Problem solving, pre-emptive action

7	Getting to know residents	Knowing residents as people, their likes/dislikes, background, communication repertoire help to facilitate connections	Over time on the job, during personal care, visits with family. Collaboration, sharing ideas, setting goals,	Using time during personal care resident's room, during team meetings, informal interactions, handover visits with family.	Need practical information to meet resident's needs, to problem solve, meet CQC requirements, expectations of, organisation, family and resident, steps to generating outcome, An underlying motivation	Learning from others, reading care plans, who I am booklets, speaking to family, asking other staff, observing and noticing patterns.	Seeing the world from the resident's perspective. Knowing what works, what to say or do, what to
8	Being able to problem solving	"sometimes you have to take a step back and say well this isn't working", "I mean you get negative responses, you have to work round it"	Care planning, Brainstorming, collaboration, team working, sharing ideas	Team meetings, one to ones, supervisions, on the nursing home floor in real time	Make the home more efficient, reducing adverse events, improve resident care, improve resident quality of life and staff working conditions, sense of accomplishment, responsibility.	Contribute, open to ideas, being flexible, a good understanding of dementia.	Respecting each other, trusting in process at times of disagreement, new expertise for staff.

9	Sharing ideas	Process of staff from all levels bringing ideas together	Collaboration Brainstorming Disagreement Care planning	In teams formally an informally, supervision, safe environment	Because need educated opinions, need practical information, problem solving, improves understanding	Share knowledge, Contribute, present ideas, support good ideas, build on ideas, not being self-centred in ideas	Learn what works for who, respect, open to new ideas
10	Taking responsibility	Feeling responsible for the residents well-being can facilitate connections “as long as I leave the room and she is bright eyed and looking happy”	During interactions, usually personal care.	Individually, in teams, formally, informally	To ensure residents do not become socially isolated, better team working	Helping out others, staying late, going above and beyond, sharing ideas, sharing knowledge	Residents experience interaction, teams experience support.

11	Being hands on	Working with residents directly for a sustained length of time facilitated connections	Daily interactions with the resident during personal care. Care planning, disagreement, collaboration, problem solving, sharing information	During interactions with the resident in their room. At team meetings, one to ones, supervisions, on the nursing home floor in real time	Staff have first-hand knowledge, they know the resident well, know signs, their communication repertoire.	Having knowledge, practical experience, acquired skills, confidence	Reciprocation, respect, relationship with resident
12	Fostering relationships	Process of building relationships with residents, family and staff of all levels which leads to connections	During interactions with residents, communication. In a stable workforce, where staff feel valued and supported, helpful when there are low staff levels, busy pressurised times	In and out of nursing home, formally and informally	Because it is expected, needed for efficient working	Knowing resident, Contributing, pitching in, helping out, open to new ideas, dialogue	Reciprocation, respect, Shared purpose, shared goals.

13	Pushing boundaries	Being creative to connect with residents with advanced dementia	During interactions with residents, when there is little communication or reaction, collaboration, care planning, times of feeling helpless.	In teams, formal and informal meetings, direct contact with residents	Staff member is motivated, has the right attitudes, wants to make a difference, wants to raise standards, improve quality, meet expectations	Pester power, trying new things, trying everything	Reciprocation, better time management. Learn new skills, gain more experience, make personal care more pleasant,.
14	Using positive approaches to residents	"They might not understand what you say but it is the tone and the way you approach them. If you are happy and jovial, they will be happy and jovial back"	During personal care	In residents bedroom, bathroom	Practical experience of staff, level of knowledge, life experience, age, caring attitude	Communication, telling resident what you are doing, calm, gentle touch, caring, kindness, observe their reactions	Reciprocation, respect

15	Playing it by ear	Dealing with issues as and when they arose could facilitate connections	On the job in real time, group collaboration, competing priorities, under pressure, to meet deadlines, during disagreements	In teams, formal and informal meetings, direct contact with residents	Clinical knowledge, practical experience, life experience, age, level of education,	Constant adaption, assessing residents room, health, taking it in their stride, juggling, balancing the influences	Flexibility, knowing to come back later, learning to juggle tasks, deficient working, reciprocation, quality care
16	Experiencing reciprocation	Getting a response from a resident/team member - cooperation	During interactions with residents, on the nursing home floor with staff	In personal care (residents room) social situations, informal chats, formal team meetings	Because it motivates staff, gives a sense of accomplishment, is expected	Having knowledge, skills and attitude. Knowing the person, having role clarity, staying on top of tasks, being up to date, pitching in to help others	Shared moments, sense of achievement, quality care.

17	Experiencing outcomes of connections	The product of connecting with a resident during reciprocal interactions facilitated connections with other residents	Reflection, learning from experiences, sharing ideas with team. At busy times, short staffed, uncertainty, care planning	In teams, formal and informal meetings, direct contact with residents, when there is an uneven playing field (less experienced staff)	To raise standards, improve quality, meet regulation (CQC), meet expectations, to progress in role, educate less experienced staff.	Knowing what you're talking about, knowing your stuff, sharing it with others, helping, pitching in.	Role model, knowledge transfer, Job well done, job satisfaction, feeling good, motivated, happy.
18	Working in home for longer/shorter periods of time	Staff became skilled at connecting with residents over time, with experience	During frequent/prolonged encounters with resident over time, continued contact. knowledge exchange	On the job during personal interactions (residents room), Formally at informally and in meetings, chat, one to ones.	Familiarity, more practical and life experience, more opportunity for training. Age difference, more opportunity to learn on the job allowing staff to get to know residents, understand dementia, get role clarity, become efficient.	Getting to know residents, being confident, competent, perseverance, patience, knowing your stuff, working efficiently, role clarity, being up to date with jobs.	Relationships with residents, reciprocation, relationships with staff ability to share knowledge with others, role model.

19	Experienced staff	"I must admit I have become pretty good at reading people with experience"	During problem solving, times of pressure, low staffing levels, high resident acuity.	Uneven playing field (i.e. less experienced staff mix), In formal supervision with newer, less experienced staff. On the job as support for less experienced staff.	Pecking order, expectation from managers and less experienced staff, level of education, more practical and life experience, more opportunity for training. Age difference, tacit knowledge.	Role modelling, Contribute, present ideas, support good ideas, being a source of clinical knowledge, sharing skills, expertise, ability to juggle multiple tasks transferrable skills, knowing stuff, understanding dementia, confidence, reading between the lines, Knowing what to do, what to say	Respect of others, being a role model, instinct, tacit knowledge, familiarity
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20	Being part of a stable workforce	A constant, steady workforce (low staff turnover) can facilitate connections	At times of high work load, short staffed, during problem solving	Throughout the nursing home. A stable environment that creates security. In atmospheres that values and rewards staff.	Staff have clear direction/role clarity, more practical experience, more skills, There is organisational efficiency, there is potential for decrease workload	Familiarity, getting on well, bouncing off each other, knowing each other's limitations and abilities, picking up the slack	Better working relationships Staff know residents well, Reciprocation, respect, Shared purpose, shared goals, motivation, going the extra mile.
21	Having enough staff	Higher levels of staffing facilitated connections	During time of pressure/work load, high resident acuity,	In residents room, nursing home in general, in meetings formal, informal	Regulation, minimum standards, resident safety, more hands on deck, more expertise, more practical experience	Problem solving, support, contributing, staying on top of thing, giving extra time, keeping up to date.	More time to spend with residents with AD, more attention, feelings of support for staff.

22	Effective leadership	Inspiring change in team members can facilitate connections	During supervision, mentoring, reflection, coaching, support, one to one, problem solving, scenario based training, brain storming, during disagreements, busy times, conflict, and lack of confidence.	In meetings, one to one, on the nursing home floor, managers office (open door policy)	Gives role clarity, the right attitudes and behaviour, encourages communication, team spirit, impart knowledge, build a skilful competent team, kerb bad habits, bonding	Role model, clinical knowledge exchange, care coordination, professional oversight, giving permission to connect, giving ideas, extra time, pitching in, providing reassuring	Boost morale, Staff feel supported in role, they know their role, are given confidence, autonomy, time, respect, relationships, going the extra mile
23	Perceiving it is your role to connect	Know what your role is, knowing it is part of your job to connect with residents with advanced dementia can facilitate connections.	During daily interactions with residents (personal care), at induction, supervision, mentoring, one to ones. During times of high workload, collaboration, disagreement	Environments with clear guidance and direction, in meetings formal informal, supervision. A good leader	Expectations, chain of command, resident safety, efficient working, to get the job done	Having confidence, trust in the process, knowing professional self, knowing scope of duties	Better working relationships, staff feel supported, confident, better communication

24	Being able to manage time	“You have little moments with them, it is how you use that time”, “just giving him that extra little bit of time to respond”, “one of the saddest things about this job is that you don’t have the time”	During interactions, daily routines, personal care, paper work, busy times, care planning	In residents rooms, team meetings formal and informal,	Practical experience, staying on top of things, being up to date, life experience, experience in role, expectations, level of education	Adapting, autonomy, juggling tasks, organising own time, having knowledge, confidence, competence, assertiveness, knowing your stuff, time spent	Making the most of time, flexibility, going the extra mile, making decisions, taking responsibility.
25	An appropriate physical environment	“When its noisy she doesn’t respond to me” – a quiet environment facilitates connections	During personal care, intimate times	In residents rooms, bathrooms.	Awareness, flexibility, previous experience, practical experience, level of education, attitude.	Knowledge of dementia, knowledge of the person, confidence in your ability	Reciprocation, shared moments, motivation, job well done

26	Specialised dementia unit	Residents are at the heart of care, regardless of the level of their cognitive impairment	At all times	In the nursing home	Manager setting the tone, organisational culture is one that values people living with dementia.	Clear mission statement, clear about roles and responsibilities	Person Centred Dementia Care
27	Caring culture	The tone of environment in which people work	Stability, security,	In the nursing home	Because the manager sets the tone, the organisation makes employees feel valued.	Open communication, respect	Efficient working, Motivation
28	Having family engagement	Family were able to facilitate connections between staff and residents	During collaboration, care planning, uncertainty, times where there was little response, disagreement, busy periods.	In nursing home visits, formal and informal meetings, chats, correspondence, phone calls	Because of expectations, less familiarity with resident, less practical experience	Shared learning, sharing ideas, drawing on family experiences. Asking for help.	New knowledge and understanding, new insights, new skills, ideas. Reciprocation

29	Learning environment	Staff members who are able to learn on the job are more likely to connect	On the job in real time, group collaboration, under pressure, to meet deadlines, during disagreements	In teams, formal and informal meetings, direct contact with residents, when there is an uneven playing field (less experienced staff	Because it was expected, staff wanted to learn gain practical experience, uncertainty, stop feeling helpless, were motivated.	Trial and error, getting to know residents learning patterns of communication, recognising communication attempts, getting to know staff, asking for help	Instinct, Playing it by ear, Knowing what to do, knowing something is going to happen before it happens, juggling multiple things, Playing it by ear, new knowledge, confidence, staying on top of things
30	Knowing professional self	Dealing with issues as and when they arose could facilitate connections	On the job in real time, group collaboration, competing priorities, under pressure, to meet deadlines, during disagreements	In teams, formal and informal meetings, direct contact with residents	Clinical knowledge, practical experience, life experience, age, level of education,	Constant adaption, assessing residents room, health, taking it in their stride, juggling, balancing the influences	Flexibility, knowing to come back later, learning to juggle tasks, defficient working, reciprocation, quality care

31	Learning on the job	Staff members who are able to learn on the job are more likely to connect	On the job in real time, group collaboration, under pressure, to meet deadlines, during disagreements	In teams, formal and informal meetings, direct contact with residents, when there is an uneven playing field (less experienced staff	Because it was expected, staff wanted to learn gain practical experience, uncertainty, stop feeling helpless, were motivated.	Trial and error, getting to know residents learning patterns of communication, recognising communication attempts, getting to know staff, asking for help	Instinct, Playing it by ear, Knowing what to do, knowing something is going to happen before it happens, juggling multiple things, Playing it by ear, new knowledge, confidence, staying on top of things
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